VIBRATIONS

NEWSLETTER OF COLORADO SERVICES FOR CHILDREN WHO ARE DEAFBLIND
Serving Children with Vision and Hearing Loss, Their Families,
and Service Providers
Winter 2004

Somewhere Under the Rainbow!

Written by
Cherie Teter, James' mom

It was an evening in August 1997 that I found out I was pregnant. It took me three weeks to tell Allan my husband. He was thrilled! On April 1, 1988, my water broke. We went to the hospital to have our first baby. Nobody believed I was in labor, not even my husband's boss. 22 1/2 hours later we had our new son James. I was exhausted; I remember only getting a quick peek at his precious face they needed to get him to the nursery. James' Apgar scores were very low and he needed some oxygen. They also told my husband there might be something wrong with his right eye. As my husband carried our little bundle to the nursery he begged, please fix our baby so my wife does not have to hurt. Upon arrival to the nursery the doctor examined James. Allan was then told that James was born without his right eye. He was instructed not to tell me because of the amount of blood I had lost. Six hours after having James I was told he was born without his right eye and that he had a coloboma (which is a key hole shape and only a horseshoe of color) of the pupil in his left eye. If it were not on his retina he would see out of that eye okay, but unfortunately it was on his retina too.

On April 6th we all came home. Three weeks later on Sunday, James had a grand mal seizure. I called Pam (at the Boulder County Health Department) on Monday and told her that James had stopped breathing. Pam asked me to describe what happened, I told her and she said that was a seizure. She then called HCP back

Table of Contents

On Monday evening I let my parents know what was going on. James and I headed over there so I might get some sleep. My dad stayed up all night with him making sure he was breathing. I went home on Tuesday and waited for the phone call. They finally called around 8:00 am and said I could come today or on Wednesday. I said, "today," as Sunday and Monday were long enough. My dad was going to drive me to The Children's Hospital when I needed to go, I had really never driven to Denver. Boy was that about to change. As my dad arrived he said everything was going to be okay because he had seen a rainbow over my house. After our first trip to The Children's Hospital we learned that this place would be our home away from home. Not only was James born without his right eye, he was missing half of his brain. We were told he would not live to be 1 year old. I said to the doctor, "what do I do to make sure he lives?" He said, "what do you do for you and your husband." I thought, why would I care about *that* when it's my baby's life we are talking about! James also was diagnosed with craniostenosis, and hydrocephalus, which both required numerous surgeries. As we continued our journey, we were thrown into a sea of medical jargon. We looked up every word we didn't understand. We asked them to speak the truth at all times. Sometimes we felt as if we were being repeatedly stabbed, other times we celebrated that the doctors were wrong.

At an early age, we were hooked up with DDC, which now is Imagine. They were of great support and were the ones that said James was visually impaired. I didn't want to believe that. Then came the shock when we went to see an ENT because James was having a lot of ear infections. We were then told he was also hearing impaired. Now they labeled our child multidisabled. WHAT WERE WE TO DO? WHO WOULD HELP US?

At age 2 1/2 years old we would find out about transition, I was to let my baby go to preschool! Were these people nuts? James couldn't even walk or talk or feed himself. I met the people at Tiny Tim Preschool, they seemed nice. The first day was really tough on me, but it gradually got easier. They were fabulous. He really loved music time; they were so supportive and helpful. James began to really roll all over and play with toys. They made sure that the toys were bright and made some sort of noise so that he could find them. I was really comfortable with them. In his second year of preschool James could finger feed himself finger foods. He did this on Mothers' Day! Then came graduation, another transition. Off to public schools we go. I really was spoiled at Tiny Tim. I learned that I was James' voice and if I wanted him to get the best I would have to become quite tough myself.

Later during the elementary years I was told James was on the registry for Deafblind, I really didn't know what that meant but later found it to be a great resource. It was time for middle school boy did we have quite a battle. His home school wanted James to conform to their program. (HA) My first real battle. I thought I could make them change or we could start this new program. I chose the latter because I didn't want James to suffer. It was a very good decision, James really bloomed and I was very spoiled. Anything James needed was done. For three years I was able to focus on my other children especially James' brother Tyler who has significantly learning disabilities.

As I attended Family Learning Retreats year after year I was able to apply what I was learning, to both of my children and their IEP's. James' health has deteriorated quite a bit, but we still advocated very loudly. We decided to move from our home to a new site in Colorado. It was an awesome move. Quite a bit of adjustment but we knew we were home. James was in 8th grade so we decided to finish out the school year for him in our former school district. Now he was moving on to 9th grade and I had to leave behind my safe and secure haven for James. His ninth grade year was about to begin.

This was an opportunity to use all that I had learned. But not just the tools taught to me by the other parents before me and all the retreats I had been to, but to also call in all of my support people. You see, this transition did not go as well as all of the others had. This was a new school district, which did not have that many high needs children. Well, of course, I was not about to let anyone tell me this is the way it is. The school year began and everybody was quite nervous. I had more people at my house from the school district, than you could imagine. They were so concerned about legalities, that they forgot about James' needs. Well, the madder I got, the more I thought he should just stay home. In October we had an IEP meeting. Now let me tell you, I wanted to rip them up one side and down the other, but I maintained. Since that IEP meeting things are starting to look up. The lake is not always a lake sometimes it is just a pond.

No matter what life offers always know there are people who will help you. It is okay to roar when needed. Sometimes educators need to be reminded that the parent does know best. It is now January 2004, 15 years later. I have learned that those lakes are still ponds, and an advocate's voice is never done. I also have learned that to take care of your family you **must** take care of yourself. No matter your battle remember you count too! James has been a blessing in disguise, who knew what would lie under that rainbow in 1988.

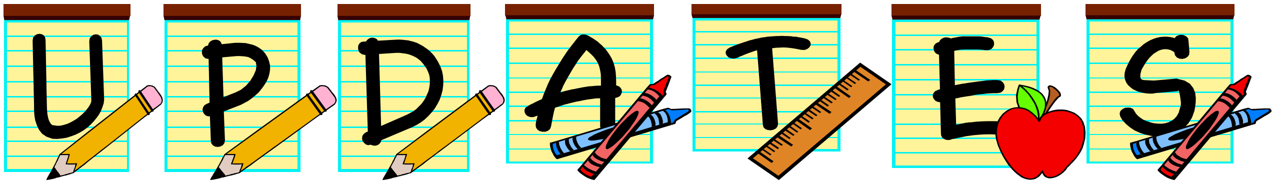
On-Line Courses Offered to Professionals Working with Children who are Deafblind

The Project for New Mexico Children and Youth Who are Deaf-blind will be offering our two online distance education courses this spring semester, 2004. The course *"Overview of Deafblindness With an Emphasis on Communication"* is scheduled to begin very soon (once they have enough students for the class). It will be offered for graduate or undergraduate credit or noncredit. While the course is self-paced, the syllabus/course assignments must be followed in sequence and within the time frame allotted. There is a $100 course fee. Students wishing to get college credit must register through New Mexico State University at an additional fee.

The second course, *"Assessments and Interventions: Case studies in Deaf-blindness"* will be offered mid to late February, 2004 dependent upon enrollment. This course is not offered for credit at this time. There is a course fee of

Participants will receive a certificate of completion. This course utilizes a Problem Based Learning approach, within a "team" format. For additional information and to register, contact:

The Project for New Mexico Children and
Youth Who are Deaf-blind
Karen Tobey, Administrative Assistant
Phone: 877-614-4051
E-mail: nmdb@unm.edu
Web Site: http://cdd.unm.edu or
http://dblink@tr.wou.edu for information on
additional on-line class offerings from the
DB-Link



UPDATES

This Newsletter Edition: The topic of this edition is the importance of communication for learners who are deafblind (have combined vision and hearing loss). Communication is the foundation of a good education program for our children and youth. Please be in touch with the project, if we can assist you with a communication program for your students.

Colorado Census of Children and Youth with Deafblindness: A resounding “thank you” to everyone who turned in their census forms in a timely manner. We are still chasing a few forms here and there, but for the most part the census process is complete. We will report the numbers of identified children and youth in the next newsletter. If you have a new referral to the project, please be in touch with Tanni or Gina.

Colorado Student Assessment Program Alternate (CSAPA): During this school year, the CSAPA will be administered in two different formats, depending on the student’s grade and content area. In Reading and Writing for Grades 3,4,5,6,7, 9 and 10 and in Math for Grades 5 and 6, the assessment will be administered in a typical format (completing a protocol). In Reading and Writing Grade 8 and 11, Science Grade 8, and Math Grades 7, 8, 9, 10, and 11, teachers will receive an activity with indicators and report the results in an online format. Teachers will have from February 2 – March 12, 2004 to administer and complete scoring. If you have any questions around the CSAPA, please call –Gina at (303) 866-6605 or Tanni at (303) 866-6681.

Lending Library: The Lending Library continues to grow with **many** new items. The Lending Library Inventory and Request form are now available on the website.
<http://www.cde.state.co.us/cdesped/SD-Deafblind.htm

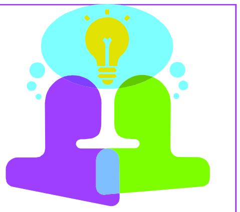
Technical Assistance (TA): Staff are available to provide free consultative assistance to families and school personnel—both in the child’s home and school setting. In addition to actual site visits, information can be provided via email, telephone, and the mail. Please let us know your technical assistance needs.

Family Learning Retreat (FLR): The FLR is scheduled for Friday evening, June 4th through Sunday afternoon, June 6th, 2004. We will be at the Colorado School for the Deaf and the Blind and the topic for the retreat is “Taking Care of Yourself.” We would love to have more participants. If you have any questions, please give Gina Quintana a call at 303-866-6605. If you would like to talk with a family who has attended a previous retreat, Gina can provide you with names and numbers to contact them.

Summer Institute: Hold the dates June 28, 29, and 30 - We’ll focus on self determination and life planning. David Wiley from Texas will be our featured speaker.

Needs Assessment: Be on the look out for the Family Needs Assessment in the mail very soon. We generally have about 20 families, out of the 100 on the census that respond. Your input is very valuable to us, especially as we plan for future trainings and Family Retreats.

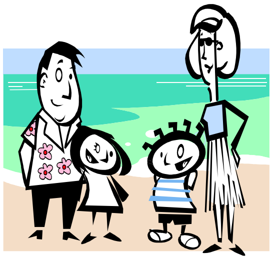
Perceptions of Light - International



Abstract: *An announcement about the development of a new photographic book on deafblindness*

Keywords: *deafblindness, photography*

Perceptions of Light - Canada, is a photographic documentary book portraying the personal realities of Canadians who are deafblind. This book was crated by Natalie Schonfeld over the period of six years. It shares through a series of black and white photographs *"an intimate portrait of the distinct culture of individuals with deafblindness, and is a testament to their strength and the elevation of the human spirit."* Natalie is about to take on a new project on this topic. She wants to create an international body of work to illustrate the differing realities of the deafblind experience around the world, this new work would be titled, Perceptions of Light - International. She would like to achieve Include aspects of people of all ages who are deafblind (either congenitally or adventiously), with different degrees of deafblindness, living under different conditions and in different environments. If you are interested in learning more about this project, visit Natalie's website at http://www.bbhosting.com/documentos/perceptions/index.html. If you want to explore becoming part of the development of *The Perception of Light - International*, contact her by e-mail at Natalie.schonfeld@sympatico.ca, phone (416)889-7761 or mail to 147 Winnett Ave., Toronto, Ontario M6C3L7 Canada.



Family Learning Retreat 2004
"Taking Care of Yourself"

Colorado School for the Deaf and the Blind
33 North Institute Street
Colorado Springs, Colorado 80903
June 4-6, 2004

The Family Learning Retreat will be returning to the Colorado School for the Deaf and the Blind on June 4-6, 2004. The weekend retreat is for any family with a child who is deaf/hard of hearing, blind/visually impaired or deafblind. This is an opportunity for families to meet other families while learning and having fun together. This year's theme is "Taking Care of Yourself."

The cost of the Family Learning Retreat is only $10.00 per adult and $5.00 per child under the age of 18. Spanish and Sign language interpreters will be provided upon request. Call Marybeth Herens at the Colorado School for the Deaf and the Blind at (719) 578-2225 to call in your registration. For Spanish speaking participants, contact Gina Quintana at CDE at (303) 866-6605. **For a reservation to be confirmed, a registration form must be filled out and payment received by Friday, April 30, 2004.** Any registration not confirmed with a payment by that date will be released to allow others on the waiting list to take advantage of the opportunity. Please contact Marybeth Herens in Colorado Springs at (719-578-2225) or Gina Quintana in Denver at (303-866-6605) if you have any questions.

Communication Systems to Last a Lifetime: Implications and Strategies for Adolescents and Young Adults

By Maurice Belote, Project Coordinator, California Deaf-Blind Services

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Abstract: *This article is about preparing individuals who are deafblind to have a seamless transition from special education to adult services. It discusses the importance of leaving the school system with an "effective, functional, dynamic, and accessible communication system."*

Key Words: *deafblind, transition, communication*

Meeting the needs of individuals who are preparing to leave educational systems and enter adult services and adult life is a challenge. Among the many considerations that are unique to this population, it is vital that students leave school with communication systems that are effective, functional, dynamic, and accessible. Access to a formal communication system is not just an IEP goal or a task to consider once the appropriate funding sources have been identified. It is, rather, a basic human right, and allows individuals to lead fulfilling, enriching lives that include the sharing of feelings, emotions, deep desires, concerns about the future, and the delights of the past.

It is first necessary to define two terms so the intent of the following strategies is clear. The term "formal communication system" refers to a system that is documented, used consistently among various people and locations, and follows the individual wherever he or she goes - from program to program and into adult life. It is a system that is, in most cases, unique to one person only, and designed to effectively address a specific individual's expressive and receptive communication needs. The term transition age refers not only to an individual's chronological age - typically 14 to 21 - but also to the nature of that individual's school program, which probably by this age includes community based instruction, life skills, work experience, and job training.

The following are strategies or suggestions that might assist educational teams and families as they consider how best to meet the needs of their students, clients, sons and daughters.

Create the best communication system possible while the individual who is deafblind is still receiving special education services.

In many cases, the level of support that individuals who are deafblind receive while in school far exceeds the level of support they will receive once they leave school and enter the adult services system. Chances are the adult service system will not provide communication specialists at the same frequency level and with the same skill level as provided by the school system.

The result is that, for most individuals, the communication system they have when they leave school, is the system they will use for many, many years. The communication system will probably not be significantly expanded or improved after the individual is graduated from school.

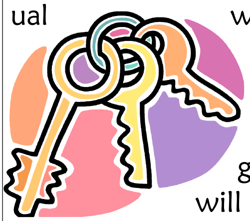
Admitting this, however, is not the same as acceptance; we can and must strive to build adult services that are as individualized as possible. We also know of exceptions, e.g., supported employment programs that have access to augmentative and alternative communication specialists who will adapt communication systems to match specific interpersonal and environmental needs. Family members may also be in the position to assist in expanding and making improvements to the communication system. In addition, the individual who is deafblind will always be expanding or changing the system - adding new signs, new photos, new drawings, etc. But this does not guarantee that these changes or additions will be documented or formalized into the system without the assistance of a knowledgeable service provider.

The goal is to create dynamic systems that allow for growth and change, while at the same time be aware that the systems may remain static for long periods of time.

Document the individual's communication system

It is critical that an individual's communication system be documented. Too often, students who are deafblind are forced to learn new communication methods every time staff and/or program changes occur because their communication system doesn't follow them from program to program, or because new staff isn't adequately trained in using the existing system.

There are many components to an individualized communication system that need to be documented. For example, if an individual uses sign language - expressively and/or receptively - it is important for the people who serve that individual to know exactly which signs are used. For most individuals, the sign systems that develop throughout a person's school career are a mix of American Sign Language (ASL) signs, Signing Exact English (SEE) signs, and home signs. Home signs are signs created specifically for that person. Sometimes home signs are needed because a sign for something the individual wants to communicate about doesn't exist. In other instances, home signs are used because at the exact moment a particular sign was needed, the teacher or family member didn't know the correct sign, so one was invented "on the spot" and the individual who is deafblind never forgot the made up sign.



If an individual's system includes objects, the exact objects will need to be documented so that if objects are lost in transition from one program to another, replacement objects can be gathered quickly. Documentation of objects will need to include either photographs or very clear drawings of each object so that someone unfamiliar with the system will have a clear idea of each object.

Even spoken language should be documented if the individual has enough hearing to take advantage of spoken language, especially in cases where the individual may only recognize or respond to a limited number of spoken words. For example, a person who is deafblind may understand the question "Do you need the bathroom?" because the question has been asked the same way - with those same words - for many years. If the person then enters an adult work program and the question is posed "Who needs the lavatory?" or a staff member shouts "This is your chance for a restroom break," these phrases may not have the same level of meaning to the individual who is deafblind. Some service providers may consider their clients as falling into two distinct groups - clients who are deaf and therefore unable to respond to speech -or clients who are hearing and therefore able to respond to all speech. It's not that service providers are uncaring or unwilling to understand, it is just that they are probably not experts in sensory loss and need to be oriented to the person's specific hearing loss, i.e. frequencies they can and cannot hear, environmental considerations, and specific words and phrases the person is most likely to hear and understand.

There are many ways to document communication systems. A personal communication dictionary can be created that describes through text and drawings the various components of a specific individual's system. Videotape is also an effective method, especially when documenting home signs or modified signs. For instance, if the individual who is deaf-blind signs bathroom, not with the shaking "T." but with a closed fist at ear level, it may be very helpful for future service providers to be able to see this on video in case a written description alone isn't clear enough to fully prepare the service provider to recognize and respond to this modified sign.

Remember that an effective communication system often includes many modes, and a person's expressive modes and receptive modes may not be the same.

When children are young, their communication systems are not usually too complex. The team decides, for instance, that the child will use an object system, later to be paired with sign language, and then Mayer-Johnson symbols, and so on. As the child ages, the communication system often becomes more complex and more complicated to use.

By the time the individual who is deafblind has reached transition age, their communication system may utilize many components. For some individuals who are deaf-blind and have other disabilities including cognitive impairments, a typical communication system might include signs, objects, photographs, line drawings, touch cues, speech, and print or Braille. It is all of these components, when documented and formalized, that make up a person's unique communication *system*.

In addition, an individual's expressive communication mode(s) may not be the same as their receptive mode(s). For example, after many years of exposure to sign language, signs may be an effective receptive system for an individual who is deafblind, i.e., the individual understands when others sign to her or him, but that same individual may have little success in forming signs to use expressively. She or he may, however, be a competent user of a voice output system that will meet expressive communication needs. In this case, it probably doesn't provide much information to simply describe the person who is deafblind as "a signer" or a as "a voice output board user," as these descriptions cannot fully describe the complexities of the person's receptive and expressive abilities.

Develop a communication system that meets everyone's needs.

When developing or modifying a specific communication system, it is important to remember that the system has to meet *everyone's* needs, and not just the needs of the service providers and family members. The system needs to include components that allow the individual who is deafblind to communicate what she or he wants to communicate about. The system should also consider what same age peers are interested in, and include language on subjects that will interest peers so that peers can use it effectively as an "ice breaker" to start conversations.

The only way to be certain that a communication system meets everyone's needs is to develop the system using a team approach, and employ this same approach when significant modifications and adaptations are made to the system. The team would include the individual who is deafblind, family members, service providers and peers. The inclusion of peers on the team will ensure that current topics, interests, slang and colloquial expressions are included.

Remember that the system must be accessible to its user at all times.

The communication system for an individual who is deafblind must always be accessible. This is true regardless of the individual's age but becomes a greater challenge for a student of transition age. Meeting this challenge is intensified because students at the transition level are frequently off-campus for much of their school day. They may be grocery shopping at a local supermarket, participating in job training programs at community work sites, and/or accessing community recreational resources such as libraries, health clubs, and teen centers. In addition, each of these activities may require public transportation, which means time spent waiting at bus stops and time on buses and subways, locations that do not necessarily facilitate ease of communicative interactions.

The communication system designed for a specific individual must take into account the issue of accessibility in all locations in which it will be used; it would be unfair to the system's user to deny the availability of the system in one or more locations. This doesn't' mean the entire system must be portable. For instance, if the individual uses a picture schedule, he or she may have a master calendar at home and/or school, and may have a smaller accordion-style schedule to take off -campus that covers shorter periods of time. If an individual uses sign language effectively at school and home but doesn't live in an area where community members are likely to also know sign language, a back-up system could be developed, e.g., communication cards with printed words and line drawings, that allow the individual to be as successful a communicator in public places as she or he is at home and school.

Don't let yourself be overwhelmed if your time with the individual is limited.

For teachers of transition age students, it can be overwhelming to welcome a new student into the program who is 18 or 19 years old and who may have had little or no prior access to a formal communication system. It may seem like an insurmountable task to undertake, to compress into tow to three years what other students receive throughout their entire school careers. The same scenario may also be true for foster care providers, or anyone else who serves teenagers and young adults.

It is important to remember, however, that *anything* and *everything* that is accomplished in the area of communication will be tremendously valuable to the individual who is deafblind throughout their adulthood. For example:

- Teaching a student to give a physical location to the sign "hurt" in order to differentiate between ailments may help that person not have to sit through a day of work when he or she has a terrible headache.
- Teaching calendar skills may allow an individual to make sense of the activities over the course of a day or week, and lessen or eliminate the frustration and anger that can develop when life is a constant surprise.
- Teaching reading may save the individual the embarrassment (and danger) of walking into the wrong restroom in public places.
- Teaching an individual to make and use experience books may give that individual the opportunity to experience the joy of reliving special occasions in a way that would otherwise be nearly impossible.
- Teaching the use of a sequence board may help an individual follow a complex job routine that would otherwise require a full-time job coach using invasive physical prompts.
- Documenting a communication system may help ensure that new service providers understand adapted signs or systems that an individual who is deaf-blind has used, successfully, for years, such as a unique sign for bathroom or a symbol/word card that means "If someone doesn't help me soon, I'm going to lose it!"
- Considering peers when designing systems may allow the individual who is deafblind to make a new friend at a party or gathering by discovering a common interest or life experience.

Transitioning from school to adult life is a scary time for students and families. Families report that they are asked to be at the highest levels of involvement and energy, and at the same time, they are exhausted after years of navigating systems and meeting their child's needs. For students, they are asked to be at their absolute best - this is the time they are probably being evaluated and considered for inclusion into work and supported living programs - at the same time they are upset and nervous over the significant changes occurring in their lives. The more we can all do to prepare individuals who are deafblind to have a seamless transition from special education to adult services has value beyond measure.

A Communication Idea!

Think about doing a home-school book where the activities that occur at school can be sent home for review and the activities that occur at home can be sent to school for review. The book can be designed with objects, pictures (e.g. from board maker) and/or scanned photos that are familiar to the child. School personnel and family members can use the book to reinforce vocabulary, expressive language, and literacy skills. The book can be very simple - two to three items to represent an activity that can be kept in a 3-ring binder.

MAKE IT ROUTINE

By Robbie Blaha, Teacher Trainer, and Kate Moss, Family Training Coordinator, Texas School for the Blind and Visually Impaired. Reprinted with permission from P.S. News, Vol. 4 No. 3, (1991)

There are few events in our day to day lives that do not become routines. Whether it is brushing our teeth, putting gas in our cars, or going bowling, there exists in our minds a series of predictable steps and specific objects associated with those steps. Often, we move through these familiar activities with little notice. However, there are aspects of these routine activities that deserve a second look. A well organized routine can have a powerful effect on a child with severe disabilities. Children with severe disabilities have been shown to benefit from learning through routines.

If you consider your child's day, you probably have already established a variety of routines. Think about changing a diaper, eating a meal, bath time, etc. These events happen daily and generally in a predictable or routine way. Here are some things that these routines are providing your child.

AN OPPORTUNITY TO COMMUNICATE

You may notice during these activities, your child seems to communicate a great deal with you. His subtle or sometimes not so subtle responses during these events might "tell" you, "I'm not hungry", "I'm ready to get out of the tub", etc. You understand and respond to these communications by skipping to dessert or pulling the plug on the tub and wrapping the child in a towel.

EMOTIONAL SUPPORT IN LEARNING

Routines feel comfortable and the child uses his energy and attention more efficiently. When a person who is not familiar with your routine way of doing an activity, attempts to feed or bathe your child, the child might become anxious or uncooperative. Yet if you direct that person to do it your way, the child will often calm and respond better. He's familiar with the routine. That helps him to better anticipate and participate in the activity.

A FRAMEWORK FOR LEARNING

Routines develop a sense of beginning, middle and an end to an activity. They also help weave a cluster of people, actions, objects and locations into a meaningful whole. Routines make use of natural cues, i.e. one step acts as a cue for the next step. This type of cueing does not require another person to always prompt the child because the objects used in the activity serve as the prompts. In addition, routines can help a child anticipate an end to an undesired activity or recognize the beginning of a desired activity.

A WAY TO BUILD PROCEDURAL MEMORY

Routines build a memory foundation for other learning. Paul Carreiro and Sue Townsend (*Routines: Understanding Their Power*) note that the development of a sophisticated memory is dependent on a core memory system referred to as "procedural memory." Procedural memory is defined as "the ability to retain a simple everyday 'low attentional' understanding of how things work." If a child does not have an organized experience, he cannot understand. If he cannot understand an experience, he will not learn from it.

A WAY TO HIGHLIGHT NEW INFORMATION

When a child has an internal picture of an activity, he can recognize when something changes. He Is alerted to attend and learn the new part. He can become aware of specific bits of information that impact him and is more likely to tune in to that particular concept. For example, if a child has a routine for making pudding, you can introduce a new flavor. The child will tune in to the flavor being different because everything else in the activity has stayed the same. The difference in flavor can be "spotlighted."

Using routines at home can reinforce learning, improve communication between the child and family, and reduce frustration for everyone. The information that follows will help you formalize your existing home routines. If you do not use routines, you might want to consider developing some. As you develop routines, share them with school personnel. If your school is not using routines currently with your child, you might encourage them to become familiar with the concept of using routines in learning.

Figure 1 *- Mapping out a typical week day and weekend schedule helps to identify existing routines which can be formalized. It can also help to identify times when routines might be helpful to the child and family.*

Week Day Schedule	**Weekend Schedule**
6:30 a.m. wake up	7:30 a.m. wake Up
6:40 a.m. bathroom	7:40 a.m. bathroom
6:50 a.m. Breakfast & Medications	7:45 a.m. Help Dad cook pancakes
7:15 a.m. Brush teeth	8:30 a.m. Breakfast & Medications
7:30 a.m. dress	9:00 a.m. Brush teeth
8:00 a.m. Catch bus	9:15 a.m. dress
AT SCHOOL	9:45 a.m. Free time
	10:45 a.m. Family activity
3:30 p.m. Return home	1:00 p.m. Lunch time
3:50 p.m. Snack	4:00 p.m. snack
4:15 p.m. Free time	4:15 p.m. Free time
6:00 p.m. dinner	6:00 p.m. dinner
7:00 p.m. Plays with dad	7:00 p.m. Plays with dad
8:00 p.m. bath	8:00 p.m. bath
8:30 p.m. bedtime	8:30 p.m. bedtime

CHOOSING THE ACTIVITIES

Before you set up your routines, it is important to decide which of you child's daily activities you want to formalize into routines. The following tips will help you in this process:

1. Map out a typical week day and weekend day for your child.
2. Begin by picking obvious activities where routines are likely to exist already such as eating, toileting. Give special consideration to those activities that will be most beneficial to the child's mental and physical health. Next look at those activities that adults must do for the child. Would these activities be made easier if your child could participate partially? For example, it would be helpful if the older child could anticipate when you need to slide a diaper him and participate by raising his bottom rather than requiring you to have to lift him. Finally, look at those activities that could be done as vocational activities.

DEVELOPING THE ROUTINE

After you have identified activities for routines, it will be helpful to write these routines out. List all the steps in the activity in the order in which they occur. The amount of detail in each step will depend on the expectations you have for your child. You might have the staff at your child's school review these routines and decide which specific IEP objectives could be worked on during the routine. These objectives could be written into your routine script. One objective might be included in several different routines.

Figure 2 *- A mealtime routine might include steps in which IEP objectives can be imbedded. The objectives appear in ital-*

MEAL TIME ROUTINE

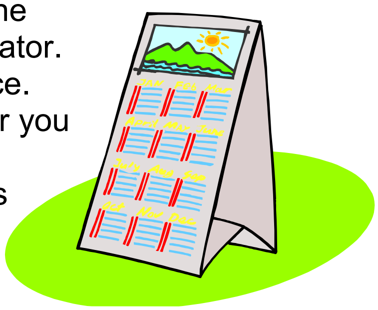
1. Walk to dining table *-Trail wall from hall to dining room*
2. Find chair and sit down
3. Wait for mom/dad to put on bib
4. Look for spoon when tapped on table and pick it up - *Use visions to explore space and locate objects. Grasp object*
5. Allow mom/dad to help scoop and carry spoon to mouth - hand over hand
6. Set down spoon and reach for cup when drink is offered, or set down cup and reach for dessert - *indicate choice by reaching for preferred item*
7. Help move plate away when meal is finished
8. Allow mom/dad to wipe off hands and face
9. Drink medication from medicine cup
10. Remove bib - *remove clothing independently*
11. Get down from chair

You might enjoy tracking your child's success in carrying out the routine. A nice way to do that is by making periodic video tapes of the activity or keeping a log that you share with school. You may even come up with some other method to note the changes. It is important to remember that this type of information can and should be shared with the IEP committee when assessment data is being reviewed.

SETTING UP A SCHEDULE

Family life is subject to unexpected events and unplanned for crises. Given that, set up a schedule that is reasonable for you. Don't plan to take on too many new routines until you feel comfortable with the existing routines. When a routine becomes formalized, it may take longer to do especially if you expect your child to participate more in the activity. Allow for more time to complete the activity, or if that is not possible, opt to reduce the level of the child's expected participation. For example, family meal times may prove to be too hectic for encouraging the child to try emerging self feeding skills; however, snack time might be more relaxed. Instead of writing out a meal routine that includes using new self feeding skills, you might focus on these during the snack activity.

Once you have identified some routines that exist in your day, write out a schedule. You may not be able to follow it exactly every day, but if you have a schedule and everyone knows it, you will be more likely to follow it. Post the schedule on the refrigerator. Tape up the individual routines near the area where the activity will take place. Share this schedule and the routines with those individuals who may fill in for you such as grandparents, baby sitters, and siblings. It is especially important to share these routines with the educational staff who work with your child. This will help the staff to design their routines to be consistent with the routines that take place at home.



Sibling Support Project of the ARC of the United States

The Sibling Support Project is a national project dedicated to the concerns of the brothers and sisters of people with special health, developmental, and mental health concerns. The project specializes in providing workshops on family issues. It also sponsors email discussion groups for and about brothers and sisters of people with special health, developmental, and emotional needs. Both SibKids (for younger brothers and sisters) and SibNet (for older siblings) allow brothers and sisters an opportunity to connect with their peers from around the world. For more information visit the website at: www.thearc.org/siblingsupport or contact:

Don Meyer, Director
6512 23rd Ave. NW #213
Seattle, WA 98117
206-297-6368
donmeyer@siblingsupport.org

Coffee, Crud and Karma

By Karen Roberts,
Family Specialist

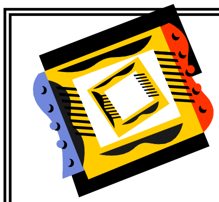
Ok, the title is out of the ordinary. I was going to title this spiel, "It's Up to Us," which would also fit because it's true. It just doesn't have quite the same ring…Gina Quintana asked me if I would consider the position of Family Specialist with the State Combined Hearing and Vision Loss grant. It must have been an energetic and bright day last spring because I said yes. I was honored (and still am.) Do you have those days? Ones where you feel like you can take on the world, maybe even change the world? Do you have those days where you feel like life is crud and it will never change? And you have no power or control over it? I know I'm not alone because I have met other parents since our son Benjamin was born and we've shared many of these feelings. And I've done a little reading, too, and it bears out what I think many of us already know in our guts:

So that's why it's up to us. There are great supports out there and it's all because families have insisted on it. Some of us can make a difference just by living our lives well. For others, we need to cut the nonsense and get what we need for our child. Most of the time it is legally required, but that still doesn't mean it will happen. And karma—well, that can be tricky because good karma, I believe, depends on good days and there is no way every day is a good day. Some days can be really, really tough and we need the support of one another to get through those days to the other side. That can come with talking to other parents that have been there, talking with professionals that take more than a "professional" interest, and faith in whatever it is you believe in. That may be in yourself, in religion or simply, in the future. With our kids and their challenges, it had better be something—but when Benjamin was born, it turned my beliefs upside down and part of the healing process has been finding new things to believe in that fit my new world.

I know the state Deafblind Project—or as it is now called, Combined Vision and Hearing Loss Project, has helped me in many ways. From this newsletter to resources from the library to technical assistance both at home and at school, I feel fortunate to have such a wonderful resource within the Colorado Department of Education. But other parents—that's the weak spot we need to all work on because we can help each other—us "veteran" parents and brand new parents. We need to share more of ourselves and our experiences. Because we are truly our own best resources.

Shannon Cannizzaro has been with the project for awhile and she and I will be calling parents throughout the year. You can hang up on us or become our best friends. Or in-between. I think we understand both reactions. And if you are like me, it will depend on the day you are having. If it's a bad one but you'd like to talk at some point, tell us to call back and we will try you at a better time. If you are interested in coffee and conversation about how we might better connect and a little support concerning our kids and crazy lives—join us on Thursday, February 26, at 9:30 a.m. at the I-Hop at Sixth and Simms in Lakewood. That can be a real juggling act for me and many of you may live too far—let us know if there are other connecting points that might be easier. Is a parent website of interest? An evening or weekend time? Topics and speakers? Better locations? A newsletter that is geared only to parents? A family directory?

My job is still evolving and I'll be researching what families do in other states. But most importantly, I want to hear from you and find out what you think will work for us in Colorado. E-mail is great and my address is kdot62@comcast.net. My phone number is 303 329-8950. Please call and introduce yourself, and Shannon and I will also be contacting you. I hope this new year brings all of us new friendships that will enrich our lives and the lives of our kids!



Adaptation of Radio Shack Talking Photo Frame

Linda J. Burkhart

Description:

Talking Photo frames may be adapted to provide a small "talking switch" that can be used as a beginning augmentative communication device. The lid of the photo frame is used as a switch to activate the voice. This eliminates the need for a separate switch and there are no wires from the switch to the voice-output device. A picture and/or texture symbol can be attached to the top with Velcro to represent a simple message. A number of these "talking switches" may be placed around the environment or in an array within reach of the individual who is unable to communicate verbally.

Materials:

Radio Shack Voice Recording Photo Frame cat. # 63-942 hot glue stick (regular size: just under 1/2" diameter) stick-tac (or other putty used for holding posters on a wall) adhesive backed loop Velcro (about 6 inches) adhesive backed hook Velcro (about 3 inches)

Directions:

1. Cut a slice of the hot glue stick about 1/4 inch thick with a pair of scissors.

2. Fasten the slice of hot glue to the lid of the photo frame with stick-tac so that when the frame is closed, the glue stick pushes on the play button and activates the recorded message. See diagram 1. Note: Move the slice of hot glue when you do not want the switch to activate accidentally. For example, in a book bag.

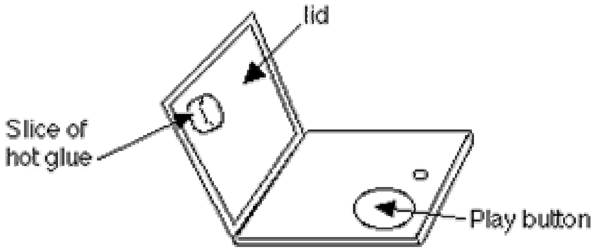


Diagram 1: Inside of talking photo frame.

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3. Place a 4 inch piece of loop Velcro beginning on the top of the lid, folding back on itself and ending on the bottom of the lid. This makes a flap about 1 1/4 inch long that will fold under the frame and attach to a small piece of hook velcro on the bottom. The purpose of this flap is to fasten the lid loosely shut, leaving enough space so that the lid can move up and down to activate the play button. See diagram 2 and 3.

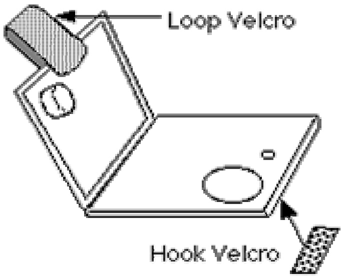


Diagram 2: Make a flap of loop Velcro.

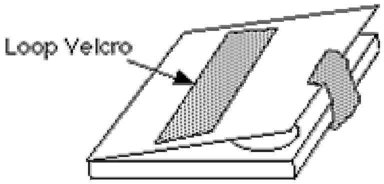


Diagram 3: Shows finished talking switch.

© Linda J. Burkhart

4. Use a piece of loop Velcro on the top of the switch to fasten pictures and/or texture symbols. Use hook Velcro on the bottom of the switch so that several switches may be attached to a piece of indoor/outdoor carpet mounted to the wall, table or wheelchair tray.

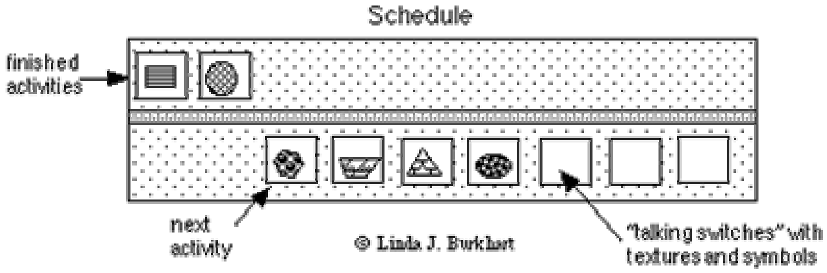
Activity Sample: Balloon play

Place five "talking switches" on a piece of indoor/outdoor carpet with space between each switch, but close enough for the child to reach each one individually. Use picture symbols and words to represent the messages: "Blow up the balloon", "Yeah!", "Make it squeak", "Let it go!" and "I'm finished with this." Allow the child to direct the actions of an adult or peer to blow up the balloon, let it go, make it squeak, etc. The speaking partner can model the use of the switches by pressing "Yeah!" when the balloon flies across the room.

Picture Communication Symbols ©Mayer-Johnson Co. 619 550-0084, fax: 619 550-0449

Additional Application:
Talking Schedule:

A daily schedule can be made with a set of "talking switches." The sequence and specific activities can be changed according to changes in the daily schedule. Place the switches in a single row from left to right on a board or carpet scrap with some space between each switch. Use picture symbols with written words and/or texture symbols to represent each daily activity. Help the individual go from left to right to see, hear and feel the day's schedule. After each activity, re-record the message indicating that that one is finished and move the switch up to another row on the board. A message indicating how the activity went would be appropriate also. For example: "lunch is finished, I had a really good turkey sandwich." This schedule would be presented at the end of each activity as a transition to the next activity so that the individual can see, hear and feel what will be happening next. Consider sending the schedule home for the individual to use to "talk" about his day with his family.



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Calendar of Events

2004 2004 2004 2004 2004 2004

April 14-17	**CEC Annual Convention** - New Orleans, LA Contact: CEC Office - 1-888-CEC-SPED
June 4-6	**Family Learning Retreat** – Colorado Springs Contact: Gina Quintana – (303) 866-6605
June 10-12	**State Assistive Technology Conference** – Westminster Contact: AT Office – (303) 315-1280 or www.uchsc.edu/atp
June 28, 29, 30	**Summer Institute on Deafblindness** - Breckenridge Contact: Tanni Anthony - (303) 866-6681 or Anthony_t@cde.state.co.us
July 13-18	**Biennial International AER Conference**—Disney World Contact: AER website at www.aerbvi.org
July 26 & 27	**The Early Childhood Summer Symposium** - Breckenridge Contact: TBA

Touch: A Magical Means of Communication

Presented by Sheela Sinha (India)

Reported by Marianne Riggio

Reprinted with permission - Article from *Deafblind Perspectives*, Volume 11, Issue 2 - Winter 2004

Sheela Sinha, coordinator of the Helen Keller Institute for the Deaf and Deafblind in India, gave a very insightful presentation on the importance of touch as the primary means of creating a link between a deafblind person and everyone and everything in his or her environment. She emphasized the importance of using strategies to promote joint exploration through mutual touch by offering our hands as co-explorers to children who are deafblind. This is a way to stimulate children's interest in the world around them. Through jointly exploring the world, natural conversations occur, trust is built, and a desire to communicate blossoms.

She presented a case study of a 16-year-old woman who is totally deafblind and attends the vocational program at the Helen Keller Institute. Yogita has excellent orientation and mobility skills and is very independent in many daily living and vocational tasks. Staff members at the school, however, were very concerned that she had no interest in people and in building relationships. Whenever someone approached her, even gently, she would pull away and cry and bite herself. The staff tried various strategies that were considered educationally sound, such as:

- creating activities with objects that Yogita liked;
- removing her from group activities and limiting the number of people who interacted with her to those whom she found most tolerable;
- teaching in a quiet, low stimulation environment;
- beginning each day with activities that she expressed some interest in.

There was some limited success with these strategies, but Yogita remained quite withdrawn.

After the educational team from the Helen Keller Institute met with staff at the school and the hostel where Yogita lives, a new strategy was devised. A schedule was developed that included many interactive and group sessions. A major difference between this strategy and previous strategies, however, was that this time no one initiated interactions with her. Instead, staff members sat close to her, making their hands available whenever she chose to participate. The outcome for Yogita is that she is now much happier. She initiates interactions and indicates when she would like hand games or other interactions to continue. She has also become a more willing participant in her vocational program.

Sheela stressed that the following points should be considered when using this type of strategy:

- The hands that are jointly exploring the world should be those of someone familiar and trusted.
- Topics of natural discussion must come from the child's own environment.
- The pace of co-exploration must be comfortable for the child.

Sheela also talked about the use of massage at the Helen Keller Institute, where it has become an integral part of their program. She reported that through gentle massage, restless children become calm and asocial children become more interested in building relationships with others. She presented several case studies of how massage helped make dramatic changes in several children at the school. She also highlighted the importance of infant massage in the bonding process and in helping families tune into the body language of their child.

Sheela concluded her presentation by saying that touch becomes the eyes and ears of a deafblind person and, more than that, the seat of all their perceptions, emotions, and feelings. She emphasized that sighted hearing people should be mindful of their use of touch. They should not poke or prod or constantly, tap, pat, pull, hold, or guide in a constraining manner. We should be gentle and respectful of how we use touch. We should show personal regard for the type and frequency of touch preferred by the person who is deafblind. She ended with a poem:

Touch

There is no need to speak: I understand
Each quick impulsive movement of your hand,
By some strange magic of the heart I guess
The meaning of each gesture, each caress.

Your fingers can be gentle, firm, or kind;
Or fierce when anger surges through your mind
Or they can trace, with such exquisite grace,
The tenderness love mirrors in your face.

Oh, when I reach to take you by the hand,
It is because I need to understand
That I am not alone in this broad land.

Robert Smithdas

—

New Items in the Lending Library

New Books

G40 My Word Book: Words and Tools for Writing and Spelling, by Marilyn Dale, M.S., Woodbine Publishers, 2003.

V94 Braille is Beautiful, A Braille Awareness Project of the National Federation of the Blind (Video Options 1&2) NFB. (Kit includes 2 video tapes, slate and stylus, book, alphabet card, and card stock.)

V95 The Little Eye Book: A pupil's guide to understanding ophthalmology, by Janice Ledford and Roberto Pineada II, SLACK Incorporated, 2002.

V96 Visual Impairment, Understanding the Needs of Young Children, by J. H. vad der Poel, Sikon, 1997.

G50 Cooperative Services Handbook for Youth in Transition, CDE and CDVR, Summer 2002.

G51 Cooperative Planning Handbook for Youth with Developmental Disabilities, CDE, December 2003.

G52 Colorado Options: A Handbook of Post-Secondary Education Services for Students with Disabilities, CDE, 2003

V97 Early Development in Children with Severe Visual Impairment: Needs Assessment for Kindergarten and Strategies for Remediation, by Susan Timmins, Vision Associates, 1997.

V98 My Friend Jodi is Blind, by Lighthouse International.

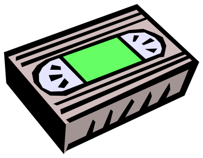
V99 The Lighthouse Handbook on Vision Impairment and Vision Rehabilitation, Vol. 1 & 2, Oxford University Press, 2000.

V100 Understanding and Living with Glaucoma, from the Foundation for Glaucoma Research, American Foundation for the Blind, 1984.

V101 Classroom Collaboration, by Laurel J. Hudson, PhD, Perkins School for the Blind, 1997.

V102 Equals in Partnership: Basic Rights for Families of children with Blindness or Visual Impairment, by Pamela Crane, Diana Cuthbertson, Kay Alicyn Ferrell, PhD, Hazel Scherb, Hilton Foundations, 1997.

New Videos



106. Actions Speak Louder than Works: Understanding the Communication of Young-Deafblind Children , Washington Sensory Disabilities Services
107. Serving Low-Incidence Children in a High Standards Environment" NASDE, 2003.
108. The Early Communication Process: Using Microswitch Technology, OIDD Design to Learn Projects.
109. Pediatric Vision Testing: Examining Normal and Visually Impaired Children, Western Virginia University Department of Ophthalmology, Vision Associates.
110. Testing of Vision in Preschool Years, Precision Vision.
111. Cerebral Visual Impairment in Pre-School Age, Lea Hyvarinen, Ulla Hirvonen, Susan Laine, Mikko Kemppinen, University of Helsinki, Finland, Vision Associates.
112. Connecting to the World: Early Intervention for Young Children Who are Blind and Visually Impaired, The Canadian Institute for the Blind.
113. Michigan Institute on Deafblindness, (Part 1 & 2), July 30, 2003.
114. Look How far We've Come, Can Do! Kids and their Can Do! Teachers, Visually Impaired Preschool Services, 1996.
115. What You should Know About the CSAPA, Colorado Department of Education, 2001.
116. Communicating and connecting with Learners Who are Deafblind, Massachusetts Matchmaker Project, 2000-2003.
117. Serving Low-Incidence Children in a High Standards Environment, NASDE, September, 2003.

New DVDs

CD3 LH Materials: Vision Assessment of Children, by Lea Hyvarinen, Vision Associates.

CD4 Use of Assistive Technology with Deaf-Blind Series, Department of Special Education, San Francisco State

1. No tech/Low Tech? Beginning at the Beginning
2. Newborn hearing Screening and Follow Up
3. Computer Usage Update
4. Assistive Technology for Access in the School