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Building Relationships: “Friends of…Club”

By Tracy Jess, Consultant, Washington State Services for Children with Deaf-Blindness
Director, National Family Association for Deaf-Blind, Region 10

Abstract: This article gives an approach to utilize informal activities and supports within a formal structure to increase social and recreational networks.

Key Words: Family, deafblind, socialization, friends, recreation, supports.

We talk on the phone to a friend, order a latte, read the newspaper, go to a movie with a family member, hike, dance, go to church, sing in a choir, host a Tupperware party. Socializing and recreating are an essential part of our lives. These activities renew our energy, relax us, decrease stress, and give our lives balance.

For a person who is deafblind — with or without other disabilities — the focus too often is limited to academics, health issues, communication, orientation and mobility, transition, and daily living skills such as feeding, grooming, and bathing. Those of us who live with or teach these individuals often run out of time and energy to help support their needs for socialization and recreation, or we simply may not realize the importance of these activities. As a result, many people who are deaf-blind have too few opportunities to enjoy life.

The “Friends of…Club” (fill in the person’s name) is one strategy to address this need.

WHAT IS THE FRIENDS OF…CLUB?

• People known to a deafblind individual come together to plan and support a regular schedule of social and recreational activities for him or her.

• These activities should be ones already occurring in the life of the individual, or ones that the “friend” believes might be enjoyable for him.

• Activities might range from a 5-minute phone call to an all-day outing.

• The activity should be based on the interests of the “friend” as well as of the person who is deafblind.

• A meeting of the “Friends of… Club” can serve as a brainstorming activity to assist the
individual in making transitions or increasing social opportunities.

**WHAT YOU NEED TO BEGIN:**

- A facilitator: Someone, preferably not a family member, who is willing to take responsibility for working with the family to prepare for and conduct the meeting. Options include: a state deafblind family specialist, a school counselor, a teacher, or a minister or priest.

**BEFORE THE FIRST MEETING:**

- The facilitator, family and deafblind individual meet to discuss the Friends of…Club.
- Prepare a list of the person’s needs, interests, likes and dislikes, abilities and current daily schedule to share with participants.
- List people who show a genuine interest in the individual who is deafblind. The facilitator invites them to the meeting. (This relieves the family of feeling like they are intruding on peoples’ lives.)
- Think in broad terms of whom to invite, for example, the grocery store clerk you see every weekend, hairdresser, neighbors, youth leader at church, extended family, lunch worker at school, bank teller, or friends of both the family and the individual.
- Agree on a date and meeting place. The location should be comfortable, informal, and allow you to share a snack (e.g., school, home, church, or local restaurant).

**DURING THE FIRST MEETING:**

1. Introduce everyone present and his or her relationship to the individual.
2. Present a brief history of the person and the reason for the meeting.

   Sample: “Linda is graduating from school and enjoys doing the things on this list. We want to see her continue to grow and be involved with others. We have asked everyone here to help her by sharing some activities on a regular basis that may already be occurring in your lives or that you are interested in doing with her.”

*Activity Examples:*

- Five-minute phone call weekly
- Invite her to dinner once a month
- Mail a letter or post card to her every two weeks
- Shopping excursion one Sunday a month
- Go to a movie every other month
- Walk around the block
- Haircut expedition
- Take to church choir weekly
- Swim every other week
- Go for a 20-minute car ride
- Walk to Starbucks for cocoa
3. Brainstorm to generate other ideas from friends and neighbors.
4. Ask for a formal commitment and write down planned activities on a large calendar.
5. Be accepting if people do not wish to commit to a specific activity or schedule, and permit the option of spontaneous or occasional activities.
6. Get contact information (phone numbers, e-mail, and addresses) for “club” members.
7. Allow time for questions, comments, and eating.
8. The individual who is deaf-blind, or a friend or family member, commits to sending out a monthly schedule to all “Friend of . . .Club” members.
9. Organize follow-up meetings as needed.

**SAMPLE SCHEDULE**

**Friends of Tony Club Calendar – February 1998**

<table>
<thead>
<tr>
<th>Sunday</th>
<th>Monday</th>
<th>Tuesday</th>
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<th>Thursday</th>
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<th>Saturday</th>
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<tr>
<td></td>
<td></td>
<td></td>
<td>7:00 p.m. Choir with Sam</td>
<td>10:00 a.m. Grandparents for the day</td>
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<tr>
<td></td>
<td></td>
<td>Letter from Susie</td>
<td></td>
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<td></td>
<td>1:30 p.m. Movie with Larry</td>
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<tr>
<td>15</td>
<td>16</td>
<td>17</td>
<td>18</td>
<td>19</td>
<td>20</td>
<td>21</td>
</tr>
<tr>
<td>4:30 p.m. Walk with Jimmy</td>
<td>6:30 p.m. Dinner with Pyles</td>
<td>7:00 p.m. Choir with Sam</td>
<td></td>
<td>9:00 a.m. Swimming with Nina</td>
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<td>22</td>
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<td>25</td>
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<td>27</td>
<td>28</td>
</tr>
<tr>
<td></td>
<td>Letter from Susie</td>
<td></td>
<td>7:00 p.m. Phone call Lisa</td>
<td></td>
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</tbody>
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Utilizing this tool not only frees up some time for the caretaker, but also provides the deaf-blind individual with important opportunities to socialize and access recreational activities and live a healthy life-style.
Jacob’s Circle of Friends

By Nancy Hartshorne, Parent of Jacob and former Director of the Michigan Deafblind Project

Key Words: Family, blind, visually impaired, deafblind, building relationships

Abstract: One parent shares how her son’s Circle of Friends has worked for them in creating community that not only supports Jacob, who is deafblind in having a rich and fulfilling life but has had reciprocal impact on those within his circle.

Editor’s Note: Nancy Hartshorne, PhD, is a school psychologist and consultant. Nancy previously directed a federally funded grant to serve children and youth who are deafblind in the state of Michigan. She has chaired the Professional Advisory Board for the CHARGE Syndrome Foundation, Inc. She is coauthor of numerous book chapters and journal articles pertaining to development in children with CHARGE syndrome and inclusion strategies and tools. She is an advocate for quality education in the least restrictive environment for her son as well as for all children.

A Circle of Friends is a circle of support, which forms around a person with a disability. It is meant to be a support to the person’s inclusion into the school, community, and workplace, and thus, is considered an “inclusion tool”. The person with the disability invites who he or she wishes to be involved in the circle, based upon who they feel supports them in their lives. For a person with limited communication skills, those closest to the person (parents, for example) would decide who would be invited. Circles of Friends often start by using a person-centered-planning process, MAPS, Personal Futures Planning, or PATH. Then the action plan is carried out by the members of the circle.

Circles of friends may or may not involve professionals, depending upon whether the person feels these folks are part of her/his support network. This person included her developmental disabilities caseworkers in her circle. Community Mental Health, the agency responsible for services to the DD population in Michigan, also supplied the circle facilitators. The MAPS process is facilitated by two people: a verbal facilitator and a graphic facilitator who records the ideas of the others through the use of words and imaginative graphics depicting the ideas so that everyone can access them.

Jacob’s (my son’s) circle of friends includes his school friends, for the most part, although the deafblind consultant attends and helps facilitate (she has provided deafblind simulations, helped the kids come up with name signs for Jacob, etc.) and the general education teacher has been attending this year.

Jacob’s circle has about 18 student members, about half boys/half girls. They have identified themselves over the years as the kids who really seem to connect with and care about Jacob in his inclusive setting (he is in sixth grade, this year). Although Jacob doesn’t give these kids much social feedback, they really care about him, and have hung in there for a while. Most of them are charter members, since first grade. Each meeting we spend some time planning, snacking, interacting, and having fun. Until now, the circle has focused on social interaction with Jacob. This year we are focusing more on transition to the middle school than anything (there is only one middle school in town.) The kids have decided to go to all of the sixth grades in the city (six schools) to speak about Jacob and his circle of friends. Then when Jacob starts middle school inclusion, there will be (hopefully) much less “pointing at the freak” than there would be otherwise, because of understanding having been facilitated. Activities we have undertaken in the past couple of years have included the following:
• **Halloween party:** the kids each bring a snack, decoration, and game that Jacob can access (usually they make something really neat), and something for the haunted house. (I don’t have to bring anything!) They come in costume and have a great time. This year, after the deafblind simulation, they decided to do the haunted house in the dark, to see what it would be like for a person who is blind. : )

• **Birthday Party:** each year in the same place, the local pool. They tried the gymnastic center one year, but Jacob hated it, and they learned that because swimming is his favorite activity, and because it is his birthday, the pool is a better place. Last year for his birthday they made him a quilt with all of their pictures (faces) scanned onto it. They decorated it with tactile paint, etc. We keep it on his bed, so he can see all of them. It is really beautiful. I will be bringing it to Indianapolis for my presentation on Circles, and all can see it.

• **Canoeing in the summer**—Jacob loves this; he sits in the middle at the bottom with another student sitting behind him, and trails his fingers in the water. I didn’t even have to be in his canoe, which made it much more fun for me!

• **School talent show.** One year the circle did a “men in black” number, really cute, all dressed up in ties and sunglasses, and Jacob was “the alien”, because he was still using a wheelchair. They made him (with him) a papier mache alien head to fit over his wheelchair, and we rigged up a jellybean switch for him to operate the lights in the eyes. It was a cool dance. Last year they did a number from Tarzan, Trashing the Camp. They dressed up as gorillas, and danced. Jacob and a few others stood in the back and were percussion, hitting pie plates with wooden spoons during the number.

The circle is facilitated each year by a volunteer special education student teacher from our university. This has worked out great, as I still have input, but much less work. She brings the snacks, supplies, etc., and I just reimburse her. Ideally, the circle would be facilitated during school by a teacher, and could include the whole class that Jacob is in. This is a different model, but would lend itself to more ideas being generated for inclusion in school lessons.

The circle evolves in membership, and will continue to. Some drop out, but most stay the same. As they move away to college, etc., we hope more people will identify themselves as they get to know Jacob. We hope the circle continues throughout his life span, although this is difficult, as kids get busier with sports, adults get busy with studies, jobs, families. It will change, but hopefully, will always be there to fall back on in a time of crisis, even if through an email listserv!! My ultimate goal is that Jacob will have a circle of support in place to take over decision making for him in case something happens to Tim and me. He would have a guardian, of course, but also a “steering committee”, with his best interests, dreams, and wishes at heart! One little girl was running for student council president, and on her poster, she wrote: “Activities I am involved in: 1. Jacob’s Circle of Friends, 2. Junior Choir, 3. Girl Scouts” (In that order --- I was thrilled by this!!!)

This year, our focus is fund-raising. The kids (hopefully about 8 of them) are going to try to raise enough money to support their attending the CHARGE conference. I have invited them to help me present on Circles of Friends. I have had them do this in several forums before, and they do a GREAT job! I hope they can raise enough funds, because I really want all of you to meet these great kids. And their parents always extol the virtues of the circle, how valuable it has been to their character building, sensitivities to differences, compassion, and ability to think and plan for things. It also becomes a general circle of social support to all of them, less and less for Jacob, and more and more for the group as a
An Effective Complement: Advocacy and Forgiveness

By Joan Guthrie Medlen, R.D., L.D.
Program Director and Editor
Reprinted with permission from Disability Solutions, a publication for families and others interested in Down Syndrome and developmental disabilities.

To learn more, please go to their website at <http://www.disabilitysolutions.org/>

Abstract: One parent shares her perspective on maintaining a healthy balance between being an effective advocate for your child with disabilities and practicing the fine art of forgiveness. The author provides a wonderful guide for parents to use in making forgiveness part of their advocacy tool kit.

Key Words: family, parent perspective, parent advocacy strategies

Author’s Note: This October 12, 2005 blog is admittedly written from the slant of the parent. However, all the concepts are true from the perspective of a teacher or support person.

Living the life of a disability advocate can make the world seem like a very adversarial place. Of course, a lot of it depends on your experience. Most of the time, parents of children in early intervention services feel nurtured by their early childhood specialists. Everyone is concerned about the development and health of your baby and looks for the typical milestones along with you. Parents feel supported as specialists suggest strategies to keep the baby from sliding out of the high chair, to finally get up on all fours to crawl, or to sign their first word, “more,” which everyone regrets later. I hear many parents describe Early Intervention services as a type of cocoon, protecting them from what lies just around the corner: school-aged services.

Over the years, I’ve had to advocate staunchly for my son. I remember walking into a “brainstorming meeting” to find it was a full-blown IEP review with no notice. Seventeen (17) people sat around a table smiling pleasantly at me, reassuring me there was nothing to worry about. He was only five at the time. In those early years I was devastated after every meeting. I felt exhausted—like one of the whole—they ALL support each other!

In a recent video interview, one charter circle member was asked why she thought the circle was important. I kind of held my breath, wondering what she would say. She blew me away. She said, “The circle is important because we help make sure that Jacob participates and is included in everything. That’s important, because if he wasn’t included in everything, he’d just be with teachers all day, and who would want to just be with teachers all day? That’s no fun!” I loved that response, because it shows that she sees Jacob as a KID, first!

Lastly, these kids are the kids who will grow up to be leaders, workers, legislators, educators, etc. in our and other communities. They will use this experience to further the lives of people with disabilities in whatever career they pursue. They will grow up to be Jacob’s employers, support persons, and friends to others with disabilities.

And Jacob will have a group of people committed to ensuring he has a rich life. Not just an integrated life, not just a life free of pain, abuse, neglect, segregation, but an “enviable” life.
“Dementors” from Harry Potter had sucked all but a last breath from me. In just a short time, “advocacy” became synonymous with anger and frustration.

Since then, I’ve learned that being an effective advocate for my son, who has significant disabilities, means having impenetrable skin. It also means not thinking of him as my son, or me as his mother, during the meetings or at school. Rather, it becomes a business deal from my perspective. I force myself to sit back and watch the interaction of the team, listen to their comments, and then ask for the time I need to process the information. All must be done with as little emotion as possible. Sometimes I am more successful than others.

There are times when my feelings get the best of me and I am overwrought with anger, hurt, resentment --- every negative feeling we have words to describe and some we do not. It is easy, perhaps too easy, for parents to fall into a constant pattern of righteous indignation. One of the best things about the years Andy was included in elementary school was being able to spend time with other parents who were constructively involved with the school community rather than being surrounded by anger and frustration all the time. This is because the school did not have a “special education room.” When he moved on to middle school, I cried when I met some parents in his homeroom, a visually-based classroom. The first meeting I attended was filled with anger, bitterness, and blame. I felt like I was being poisoned.

How did this happen? I agree that more often than not parents have a lot to be frustrated and angry about. Constantly maneuvering to find someone who sees your child as a great kid (rather than being told all the things he can’t do) is not easy. Living under the microscope of special education without feeling judged at some point is impossible. The “evaluation” is not limited to academics, school situations, or your child’s strengths. Folks tend to want to know just what it is we’re doing at home to teach our children.

I’ve been doing some reading on forgiveness over the past year. I am increasingly convinced it is the missing link in advocacy efforts. Not being able to forgive eats away at us and breeds bitterness. The injustice takes on a life of its own; it is all consuming. It becomes a part of daily life. That means your adversary wins.

My first introduction to this concept came from the book, How Good Do We Have to Be? By Harold Kushner. He tells the story of asking a woman whose husband had an affair, left her, and fell chronically behind in child support payments to forgive her husband. When asked how he could suggest such a thing, he replied, “I’m not asking you to forgive him because what he did wasn’t so terrible; it was terrible. I’m suggesting that you forgive him because he doesn’t deserve to have this power to turn you into a bitter, resentful woman.” For me, that was a new spin on forgiving someone.

The last thing my children need is a bitter, resentful, angry mother, nor do I want to be that person. I enjoy life and like to revel in the good things, large and small. I love watching my children learn and grow, each at their own pace. I enjoy being helpful and looking for constructive solutions or steps to overwhelming situations. I like to laugh. I want to be a nice, warmhearted person, not a sour, negative, cross one. I want to be able to walk into my son’s school community and be the person I was before special education entered my life.

Like many people, I wondered if I forgive people who have hurt me—whether it was intentional or not—I also agree that nothing wrong happened. What I have learned is I do not. I had to learn what forgiveness is, and what it is not. Here is some of what I have learned.
Forgiveness is:
- Letting go of the anger and resentment you feel.
- Looking for the good in a situation.
- Restraint from seeking revenge and harboring resentment.
- A freely chosen gift.
- A personal decision. It only takes one person to forgive.
- A way of healing your wounds from the injustices and hurts you have incurred.
- Healthy. Research suggests forgiving those who offend you may ease depression, high blood pressure, backaches, muscle tension, and even heart disease.
- Brave. It takes a brave person to forgive someone who has hurt them without asking for anything in return.

Forgiveness is not:
- Forgetting what happened. In fact, it is better to forgive without forgetting. “You can forgive the bully and still watch your back.” (Bob Enright, International Forgiveness Institute) We can learn from every experience and make corrections. This strategy seems the best for advocacy work. Learning (and remembering who you can trust) without hanging on to the bitterness.
- Letting the other person or people off the hook. You can forgive someone and still hold them accountable for their actions. This is especially true in legal situations, including IEP meetings. Rules are rules.
- A guarantee there will be reconciliation. Forgiveness is a gift we choose to offer to another person. They may not reciprocate. It takes two people to reconcile.
- Overlooking what happened. In fact, in order to forgive, a person must truly understand the offending event.
- Condemning someone. Backhanded forgiveness doesn’t do anyone any good. In other words, offering forgiveness to show how hurt you are defeats the purpose.
- A means to justice. Forgiveness does not demand compensation first. You choose to give it or not, no strings attached.

I believe forgiveness strengthens my ability to advocate effectively. By letting go of resentment and anger, people are more willing to talk and problem-solve. They are less likely to worry that the discussion will become a battle with an angry parent. Remember, forgiving someone does not mean they are not accountable for their actions. No one loses their rights by forgiving an injustice.

Learning about forgiveness has given me a lot to think about. Have I truly forgiven every situation I am resentful over? No. But I am working on it. I am learning that it is harder to forgive those things that I have held onto for a long time—such as the IEP I mentioned earlier—than events that are recent. Perhaps our response to situations becomes so ingrained that changing how we feel about it takes time and work. After all, forgiveness is not meant to be easy, if done correctly.
These days I am not as easily upset in meetings about my son, though I have my moments. I am working on remembering to truly examine the situation, tease out the lessons, and then work on forgiveness. It feels much healthier. And I am much happier for the work.

Take care of each other.

Sports Extravaganza 2005

By Alexie Rendon, Student, Ennis, TX

Abstract: An enthusiastic seven-year-old student from Ennis ISD shares her experiences in participating in the Sports Extravaganza 2005, held in the Dallas area.

Key Words: family, blind, visually impaired, deafblind, personal experience, recreation, sporting event

Editor’s Note: Sports Extravaganza is an annual event open to any student with visual impairments across Texas. It is sponsored by Region 10 Education Service Center. To get more information about Sports Extravaganza contact Kitra Gray at <Kitra.Gray@region10.org>.

Sports Extravaganza was a weekend of fun, laughter, and play. It was this past October. You can bring your family and friends. There are many types of events you can participate in. There is running and many more events you can try. You should get in touch with Region 10 if you have trouble seeing or cannot see at all. There are many teachers there that can come to your school and help you with your work. My teacher is Sandra Greenman. The people at the Sports Extravaganza are very nice and caring. They can come to your aid if you are having problems. It will build up your strength and running, you will love it. One of the best things is making new friends. I made a new friend; her name is Anna. We met at our first event, the softball throw.

My name is Alexie. I was there. That is why I am writing this story. It was fantastic and I had lots of fun. I was running, jumping and laughing. You might be nervous and excited at the same time. I was when I was on the way to it. When we first got there, we registered and I saw Petra Hubbard. I have not seen her in a long time. She gave me a T-shirt and meal tickets for my family. We then went up in the stands. Christy spoke to us and gave us instructions. She said that the events were starting now.

My favorite event was the 25- and 50-meter run. You should try to do running; it will build up your health and you will love it. Beep ball is an event where you have a ball that beeps. If you are blind, you can hear the ball. One beep ball event is hitting the ball off of a tee. Goal ball is a ball that has a bell in it. You might have to roll it to a goal. I was blindfolded and I had to roll it fast. Or, another event they roll it to you. Sometimes the ball may be close to you or it might be further away. You get more points for the far balls. You will love all the events, I know.

You can win a medal. First place gets you a gold medal. For second and third place and they give you a silver and bronze medal. For fourth and fifth place, you will get a ribbon. After the event, they take you to the medal stand. There you sit until it is your turn to get your medal.

Fun and more fun is what I thought about it. I hope you will participate in it. Look on the Internet for more information.
Keeping It All Together: Lessons Learned from the 2005 NTAC and NFADB Annual Conference

By Lisa Wick, proud wife to Jay and mother to Jason 9 and Julie 3, Texas Deafblind Family Leadership Graduate, Burkburnett, TX

Abstract: One parent shares what she learned at the Annual NTAC/NFADB Family Conference so that other families can benefit from knowing strategies for managing life when you have a child with deafblindness. While this training was specifically designed for family members of people with deafblindness, the information is helpful to any family when they have a loved one with a disability.

Key Words: family, blind, visually impaired, deafblind, strategies for managing family life, self-help

Editor’s Note: Lisa wrote this article shortly after her husband, Jay, was deployed to Iraq. On behalf of the deafblind community, the See/Hear team would like to extend our thanks to Jay for proudly serving our country. We eagerly await his safe return to his beloved family.

I had the privilege of attending the 2005 NTAC and NFADB Annual Family Conference, which was held in Salt Lake City, Utah, August 25-27, 2005. For those of you who are not familiar with NTAC and NFADB, they are the National Technical Assistance Consortium for Children and Young Adults who are Deafblind and the National Family Association for Deaf-Blind. The conference theme was Keeping It All Together: Strategies for managing family life when a member is deafblind. Now there is a title I could immediately relate to! From the onset of our daughter’s medical problems, my husband and I have searched for the solution of how to “keep it all together.”

So I was thrilled to get the opportunity to attend this conference with 150 other parents of deafblind children from across the United States (even three families from Puerto Rico). The hardest part, as most any parent can relate to, was leaving the house. Weeks of preparation and list-making went into actually getting out the door. I spent my two-hour layover at the airport calling the durable medical equipment (DME) company ordering supplies to be sure we didn’t run out of anything. I also filled my time running through Julie’s schedule with my mother and husband half a dozen times, even though I know that they know her schedule just as well as I do. I even contemplated not sending her to school or therapies while I was out of town. I felt so guilty having anyone else try to juggle her schedule; it’s just second nature to me. No surprise Dad and Nana managed it all like professionals. Everything ran perfectly well without me the four days I was gone.

The keynote speaker was Marlyn Minkin, a professional counselor in Seattle, Washington who works with several families with deafblind children. She was wonderfully in tune to this group of parents. Our first session, which was titled “We Are Not Alone”, described how much parents of a deafblind child have in common. We share many of the same concerns, hopes, fears, battles and celebrations for our children and our families. Marlyn then showed us how birth order (oldest child, middle child, and youngest child) affects how we, as adults, deal with situations and also how birth order affects how our children interact and view their siblings.

The most insightful activity was when Marlyn had each of us fill out the Myers-Briggs Personality Type Indicator (short version), a personality profile that sorts everyone into temperament types. As we saw where we fell into each of the four categories, we were able to see our strengths and how we function best. Being aware of this allows us to take control of a situation. For example, based on my profile I don’t like confrontation, and need to be able to think a situation out before I take action. That sure hit the
nail on the head! What I learned is that if I am presented with a challenging situation, I should take some
time to think it over before coming to a decision. Marlyn stressed that there are no right or wrong
personality types, but that it is important to know your own strengths and weaknesses so that you can
make them work for you and your child.

One topic that parents find hardest to hear is that it is important to take care of themselves. Most
parents find that topic low on their priority list, and then when you add a special needs child into the mix,
self-care usually doesn’t make the list. When Marlyn polled the audience of parents, the number one
reason we don’t do more for ourselves was guilt. We feel guilty doing for ourselves when there are so
many other things we believe we could be doing. As she stressed over and over to us, you aren’t going to
be any good to your family if you are not good to yourself.

The second most popular reason was “there just isn’t enough time.” One solution was “learn to
delegate.” Another solution was “letting go.” Even though your husband or family member can’t do for
your child as well as you can, like you do, or as timely as you can yourself, you have to “let go” and let
them do the best that they can do. Marlyn showed many of us how we add to our own stress levels by
thinking we are the “only ones” who can or will do the care for our children. Others can be taught, with
a little bit of love and patience.

One of the hardest things for us, as parents of special needs children, is asking for help. An analogy
she used was that most of us really mean it when we offer to help a friend or family member and that we
sincerely hope the person accepts our offer. Why is it any different when the situation is reversed? Most
people offer to help because they truly want to help. So let them pick your kids up from school, mow
your lawn, or cook you a meal and then use that generous gift of time to take care of yourself!

Marlyn held strong that there is always time for you. Skip doing the dishes late at night and read that
book or take that bath instead. The dishes will be there tomorrow and you’ll have to wash dishes tomor-
row anyway. One mother said she splurged on herself by hiring a maid to come into her home once a
week. It was interesting to hear what things we think are selfish: reading a book, watching a movie,
sewing, going to the grocery store alone, going out to eat, time alone with our spouses. These are not
unreasonable requests, yet we deny ourselves day in and day out.

Several parents stepped forward to say that they feel like they are always angry, or feel like they have
to be in “attack mode” all of the time. They feel all alone or overwhelmed. These feelings really wear on
your mind, body, and spirit. Our children can usually pick up on these feelings, and these are not feelings
we want to give to them.

Marlyn talked to us about not being afraid or ashamed to seek counseling for ourselves, our spouses
or our children (those with and without the special needs). Several couples stepped forward to say that
counseling saved their marriages, because they were not “keeping it together”; while several others wished
they had sought counseling before their marriages ended in divorce. Many mothers stood to say that
prescription medications helped them “keep it together”. It doesn’t matter where your family gets their
help from, just that you get the help that you need.

Marlyn also showed us how easy it is to form a parent group. She organized a parent panel by asking
six parents from the audience to come up on stage. She threw a couple of questions at us from time to
time and it went from there. I think the six of us could have gone on for days. It was so natural for us to
just talk about our families. It was a great success. Marlyn challenged parents who said that they “have no one to talk to” to find someone, even if it means starting your own parent group. I’ve stayed in touch with a parent from Indiana who went home and did just that.

One thing I am always reminded of when I meet other parents is that “I am really lucky; we don’t have it bad, because things could be so much worse.” There was a mother from South Dakota who was a hero to all of the other parents in attendance. She was the mother of eight children, and her special needs children were her four-year-old quadruplets. Wow, can you imagine having four toddlers at one time. Even without the special needs figured in, that is quite a handful.

I urge every parent to find a support system. There is NFADB, DBMAT (Deaf-Blind Multihandicapped Association of Texas), TAPVI (Texas Association of Parent for Children with Visual Impairments), and numerous other groups that you can link up to. It is a good feeling to know that you are not alone in your journey, and a great opportunity to share information. The best ideas and tips I get come from other parents. I am a firm believer in the old adage “there’s no need to reinvent the wheel.” If you are looking to form your own group, look to local churches, hospitals, schools, or other nonprofit organizations for help. You can look for a counselor under the yellow pages, or your family doctor can refer you to one. Most churches also offer counseling.

The most important thing I brought home from this conference is that I need help in “Keeping It All Together” and the only shame in needing help, is not asking for it.

Creating STARS Through Friendship

By Sarah Hinds, Sibling, LaPorte, Texas and Elizabeth Madden, Sibling, Alice, Texas

Abstract: Two siblings share what each other’s friendship has meant to them and invite other siblings to email them at their newly formed sibling email support group.

Key Words: family, blind, visually impaired, deafblind, sibling support

MOM’S INTRODUCTION:

STARS, which stands for Siblings Talking, Answering, Reassuring and Supporting, is a sibling email support group created because of a friendship forged between two girls. The purpose is to encourage siblings to connect and share their feelings, frustrations and joys. Just knowing they are not alone can be a tremendous support. The girls have a big dream of starting a sibling support group in Texas and have taken their first step by creating STARS. They are exploring setting up a website so that any sibling in Texas can connect with someone who knows what they are going through. STARS has great potential and with these creative and dedicated young ladies working on it together, they are sure to take their dream far beyond our expectations. If you are interested in joining or want to help Sarah and Elizabeth, you can email them at <txsibstars@yahoo.com>.

SARAH’S DREAM COMES TRUE

Hi, I’m Sarah Hinds and I created STARS: Siblings Talking, Answering, Reassuring and Supporting. I’m the oldest in my family. I have a brother who is two and a sister who is five. I love being their big
sister! My sister is deafblind and multiply disabled. I love my sister, but sometimes I feel left out because everyone is always coming over for “playtime” with my sister (really therapy), and she takes up a lot of my parents’ time. There are some good things about being a sibling, like we get to go to fun events like the beeping Easter Egg Hunt and Sibshop. STARS is different than Sibshops because you can be a pen pal with another sibling who doesn’t live near you, but you still have a lot in common because of our brothers or sisters. My mother met a girl who had a brother with disabilities too. She was just three days older than me and wrote me a note. I was so excited – finally someone who understands my position. We immediately began emailing and calling each other and have become very good friends. We finally met at the Deaf-Blind Multihandicapped Association of Texas (DBMAT) Family Retreat. We were roommates and did everything together. Every year, I look forward to going to DBMAT so that I can spend time with Elizabeth and other kids who are also siblings. I was very excited to return again this year to DBMAT and see my friend Elizabeth. This summer we went to Rangerette Camp together and learned to do some dances. We also did fun things like swimming. Elizabeth spent a week at my house. When we are not together, we email each other to keep each other up on what is happening. It is fun having a good friend that’s just like you. We always have a lot to talk about.

Just like my mom found Elizabeth for me, we want to find siblings that are feeling left out and help them to find a friend forever. Who knows, they might end up helping us.

ELIZABETH JOINS THE STARS TEAM

Hello, my name is Elizabeth Marie Madden. My brother, John Terry Madden, has many disabilities. He is 12 years old, deafblind, can’t talk or walk, has seizures, eats through a G-tube and has developmental delay at a three month old level. We don’t get to play together like other brothers and sisters. Every since my parents found out about all those problems, my mom has been going to meetings, family education and state conferences and taking me with her while my dad takes care of John Terry. One of the meetings my mother and I went to was in Austin, Texas. There, we met a lady named Alaine Hinds. She had told us that she had a 9-year-old daughter named Sarah. We are just two days apart! Ms. Hinds suggested I write Sarah and I did. The next thing you know we were writing and calling each other a lot. We kept begging our moms to meet each other so we all set it up to meet at the DBMAT Family Retreat. Since then, every time we had a chance to see each other, we have taken it. So if my mother hadn’t taken me to that meeting, Sarah and I wouldn’t be friends. This summer, we went to Rangerette Camp in Kilgore, Texas. Sarah and I were roommates in the college girls’ dorm. We ate in the cafeteria, learned dances and made new friends, all in four days. On the way back home, Sarah asked if I wanted to stay at her house for a week. I decided to stay, and we had a great time together.

October 2005 was my third trip to Camp John Marc and Sarah’s second time. We got to be roommates again, climb a rock wall, slide down a zip line, go fishing and have lots of fun together. We are excited about our new sibling support group. Through email, Sarah and I will be able to stay in touch better and make friends with more brothers and sisters of children with special needs around Texas.

My older brother and sister are 23 and 25 years old. They did not have a chance to make friends with other siblings. Even adult siblings need someone that understands and to talk to. So send us an email to <txsibstars@yahoo.com>.
Staying Connected
Holly L. Cooper, Ph.D., TSBVI Outreach Assistive Technology Consultant

Author’s Note: This article contains time-sensitive content written in November, 2005. Technology is a rapidly changing area, and some information contained in this article may not be accurate even several months from now.

Abstract: A discussion of current cellular telephone technology that has voice output capability for users who are blind and visually impaired. Specific phone models, software add-ons, and wireless service providers are cited.

Key Words: programming, accessibility, blind, visually impaired, deafblind, cellular phones

What could be more important to the social life of our visually impaired students or children than access to the telephone? How many teenagers do you know who have their own cellular phone? Staying connected to friends and family is highly desired by young people today. Isn’t it important that our visually impaired youth be able to participate in as many of the same activities and friendship groups as their peers? For many years cell phone users had to make do with phones with which they could only dial to place calls and answer calls. Now virtually all cell phone features are accessible with special voice output software.

A cell phone may be a luxury, but it can also save time, and worry. Not only is it an instrument of popular culture for teenagers and others, it’s an important safety tool for people who may be stranded alone in an unfamiliar place. Usually parents buy cell phones for their teenagers to keep track of their location, and to provide help if needed. Safety is even more of a concern for our students. People with disabilities are more likely to be victims of crime than the population at large. According to Joan Petersilia, Professor of Criminology at the University of California, Irvine “Children with any kind of disability are more than twice as likely as non-disabled children to be physically abused and almost twice as likely to be sexually abused.” Isn’t it important that they have access to emergency services and assistance when they need it?

As recently as a few years ago, strategies for making cellular phones accessible to blind users consisted of braille overlays for the keys and little else. Why is it that we can make computers talk, but not cellular phones? Well, now they can, and if it’s been a while since you looked at cell phones for blind users, it’s time to look again, because there has been a windfall of accessibility options made available at ever more reasonable prices.

You don’t have to be an engineer or able to understand all there is to know about the differences in cell phone technology, and the technology of the carriers. However, it helps to have a general understanding of some basic information about cell phones and the software that runs them when making choices. There are three major types of cell phone technology in use today: GSM, CDMA and iDEN. For our purposes here, it doesn’t matter what these are, but it’s important to know that these systems are not compatible with each other. GSM is used by Cingular, AT&T, and SunCom. CDMA is used by Sprint and Verizon. iDEN is used by Nextel. Currently the accessibility software for blind and visually impaired users all use the Symbian Operating System, which is found only on GSM phones.

Computer users may be fans of Windows, Mac and Linux, but cell phones have their own special operating systems. The Symbian Operating System (OS) was designed especially for cell phones, and it allows third party software to be installed on them. Symbian OS phones are typically made by Nokia and
are GSM, so the major carriers are Cingular, AT&T, and T-Mobile. Making the cell phone accessible for
blind users requires special software. Currently, software packages most useful for users with visual
impairments are Mobile Accessibility, Mobile Speak and Mobile Magnifier from Code factory; and TALKS
from Cingular. These software packages are compatible with the Nokia 3650, 3660, 6600, 6670, 7610,
and N-Gage QD.

Accessibility software makes speech output available for almost all of the cell phones features, in-
cluding caller ID, battery meter, text messages, email, call list and the like. But remember, you must have
the right cell phone with the right operating system, and you must also purchase the software. While
paying full price for the phone and software can run as high as $300 or more, some carriers give rebates
on the phones with a one or two year service agreement, and some give a rebate for signing a service
agreement and providing proof of disability.

**GSM TECHNOLOGY**

TALKS is accessible speech output software available through Cingular Wireless for the Nokia 6620
model phone. The software is stored on a Multi Media Card (MMC) that is inserted into the phone
similar to a SIM card. TALKS software provides speech output for screen displays, keystrokes, menu
selection and other features. It also allows the user to hear incoming caller ID; monitor the signal and
battery strength; write and read notes, text messages and email; add, edit and dial entries in the contacts
list; use the appointment calendar and alarm clock; and edit the phone profile and settings.

Additional software solutions for phones with the Symbian Operating System are available from
Code Factory and include Mobil Accessibility, Mobil Speak, and Mobil Magnifier. Mobile Accessibility
is the most full featured software, allowing users to read and send text messages; access, add and remove
contacts list entries; use caller ID; access calls-received lists, including calling back the numbers; access
call logs such as calls missed and numbers dialed; read battery levels and signal strength; and associate
ring tones with specific callers. In addition, the voice output is available in English, Spanish, French,
German, Italian, Dutch and Norwegian. Mobile Speak includes all of the features of Mobile Accessibil-
ity and an accessible calculator, an accessible sound recorder, a game, an MP3 player, and FExplorer, a
file-system browser. Mobil Magnify enlarges all items of the cell phone display, and automatically
detects and magnifies the area of interest as the user navigates through the cell phone’s menus and func-
tions. The user can zoom in to different areas of the phones display to magnify desired items.

**iDEN TECHNOLOGY**

For iDEN technology used by Nextel, Text-to-Speech (TTS) software is available as an upgrade to
the Motorola i355 phone. TTS uses voice output to guide the user through menus, and placing and
receiving calls. It allows the user to hear the numbers pressed; hear the name, numbers and contact types
of each entry in the contacts list; hear the status information such as signal strength, battery level, date
and time, and hear menu options as you scroll through the main menu.

**CMDA TECHNOLOGY**

Another accessibility approach is a cell phone with built-in voice recognition and voice output soft-
ware. CMDA phones used by such carriers as Sprint and Verizon include these options and are available
on LG VX4650 and LG VX4700 and others. They allow users to access voice dialing, caller ID, phone
status and other features. Contact names and phone numbers can also be entered. These phones are
usually less expensive than those with the Symbian OS with purchased third party software, but they do not allow access to email or text messages. Some models do not allow access to other cell phone features for visually impaired users. In addition, speech recognition software can be difficult to use in noisy environments.

DEAF BLIND ACCESSIBLE COMMUNICATION

A new product from Alva, makers of braille displays for computers, is the Alva MPO. The Alva MPO is a portable personal organizer and note-taking device with a refreshable braille display that runs the Windows CE operating system. The MPO includes an accessible cellular phone that uses voice output and a braille display. It also has text messaging capability. The phone itself is a typical cellular phone, not a TTY, so the user must have adequate hearing to listen to phone calls, or must use text messaging. Unlike some other braille note takers, the Alva MPO does not feature internet access or email, although it can use Active Sync to send files to and from a computer so the user can read stored web pages, or compose email and send from a computer. The Alva MPO is available from Nanopac, and is comparable in price to other braille note takers on the market.

Another accessible communication option for users with deafblindness are braille note takers with refreshable braille displays. The BrailleNote and PAC Mate are braille note takers with optional refreshable braille displays have internet and email capability. The PAC Mate features MSN instant messenger pre-loaded, and the BrailleNote has the capability of running instant messaging software loaded by the user.

GENERAL INFORMATION

The organization American Foundation for the Blind (AFB) has taken a substantial interest in the accessibility of technology for people with visual impairments. AFB’s technology division is the Technology and Employment Center in Huntington (TECH), West Virginia. AFB TECH conducted a survey of blind and visually impaired people to determine which features of cellular telephones users considered the most important. They developed the list they call the “Sweet 16,” of the sixteen most desired features. As you can read in the list below, the first three features: keys that are easily identifiable, voice output, and accessible documentation are all tied for first place. As cell phones become smaller and sleeker, it’s important for consumers to try the keypad and be sure that the keys are arranged in a standard order and can easily be distinguished from one another. All accessibility options included in this article (except Mobil Magnify) include voice output, but the phones and software vary in how many of the features in the list are accessible by voice output.

1. *Keys that are easily identifiable by touch
2. *Voice output
3. *Accessible documentation
4. Battery level indicator
5. Roaming indicator
6. Message indicator
7. Phonebook
8. Phone lock mode
9. Keypad lock mode
10. Power indicator
11. Ringing or vibrating mode indicator
12. GPS feature
13. Signal strength indicator
14. Ringer volume control
15. Caller identification
16. Speed dialing
See the resources list below for further information about accessible cellular telephone technology for people with visual impairments. Read the product reviews on the APH TECH website and newsletter, read the features offered by each wireless phone company, and talk to or email people who actually use the phones, if you know any. Bear in mind that products and software are constantly changing, so information on which someone based their selection on six months ago may no longer be valid. For the most current information, talk to your local dealers, and read their websites.

RESOURCES

ABC Channel 7, Chicago.
*Cell Phones Help Blind and Visually Impaired Communicate*
This feature article about an attorney who is blind who discusses cell phone features was written in May 2005.

Access World Newsletter from American Foundation for the Blind
*We think they hear us now: Cell phones with speech*
Discusses the Sweet 16 most desired accessible features and which phones and software are currently the best. May 2004.

American Foundation for the Blind
*TECH evaluates cell phones*
AFB rates desired features in this article and finds accessible phones lacking. They like Cingular which offers TALKS along with the Nokia 6620 for a total price of $299 after rebates. Undated.
<http://www.afb.org/Section.asp?SectionID=57&DocumentID=2419>

This article includes a spread sheet of models and features with ratings for accessibility. A blind user posted this site, which has few visual features, but much good information
<http://itaf.home.att.net/>

American Council for the Blind in Nebraska website includes this article written by Ray Gonzales, a sighted cell phone user and engineer who sold phones and wanted to help users with visual impairments find cell phones that worked for them.
<http://www.acb.org/nebraska/accessiblecellphones.htm>

Cingular Wireless
TALKS software with Nokia phone. Read about the software and phone and features, as well as a special rebate offer that is available as of November, 2005.
<http://www.cingular.com/about/talks_program>
Taking Up Makeup
by Cyral Miller, Director of Outreach, TSBVI

Abstract: Collected tips and resources to help parents and teachers provide instruction in how to use cosmetics for young girls with visual impairments.

Key Words: programming, blind, visual impairments, deafblind, makeup, cosmetics, self-esteem

Social acceptance and self-esteem are often related to how young people perceive others, or think their peers observe them. Physical appearance and types of grooming will factor enormously into those perceptions. It is no surprise that magazines aimed at this age group heavily feature advertisements for beauty products. In junior high or high school, many young girls are wearing makeup to class, to social events and even for sports. Young girls with visual impairments clearly need to be aware of this dimension of the peer scene and be offered enough information to make informed choices on how they approach cosmetics.

Learning the proper use of makeup is an aspect of independent living skills, part of the Expanded Core Curriculum for students who are blind or visually impaired. Many moms or older sisters teach makeup skills to their daughters and siblings, designing adaptations as needed. In that case, these skills will not need to be addressed at school. Other parents are not sure how to teach their child who either cannot see at all or who has impaired vision. In those situations, it would be appropriate to consider adding goals related to these skills to an IEP.

There are a variety of primarily informal sources for learning how to adapt the art of makeup to accommodate blindness or visual impairment. In the Independent Living Skills Curriculum published by the Texas School for the Blind and Visually Impaired, Volume 2, there is only this short paragraph specifically about makeup: “Allow students to experiment with applying different types of cosmetics. Discuss colors and shades appropriate for their skin type, hair, and clothing. Discuss the importance of not using too much makeup. Help students choose people to give them advice and assistance when selecting makeup (e.g., friends, sales people at cosmetics counters).”
There are several important related skills in the personal hygiene and grooming section of that curriculum, such as exploring hairstyles, shaving, purchasing grooming supplies, and tweezing eyebrows.

A practical strategy is to seek out the expertise of cosmetic professionals. Many department stores have cosmetic sections with salespeople who are skilled in selection and application of a range of types of makeup. These individuals can give valuable tips and help to find the proper colors and tints for specific complexions. Teachers (or family members) may want to accompany a student with a visual impairment and provide verbal explanations of what the professional is doing.

An older written resource is *The Art of Makeup for the Visually Handicapped* by Dorothy Pirozzi. This booklet was published by The Lighthouse, from The New York Association for the Blind in the 1970s and may no longer be available. Ms. Pirozzi, a former fashion model, asserts “I have discovered various methods of applying my own makeup that demonstrate that a blind person can makeup as well as any sighted person.” The booklet is comparable to other written materials available on this topic, which are primarily suggestions written by blind adults with tips based upon their experiences.

Two other references of a similar nature are found on websites: The American Foundation for the Blind has an article with tips for makeup application. Look on the AFB website at <http://www.afb.org/Section.asp?SectionID=40&TopicID=215&DocumentID=2773>. Another written source based upon personal experience is the American Printing House for the Blind’s Fred’s Head. This is an excellent resource for a wide variety of tips and suggestions about both typical and unusual aspects of living with blindness. Go to <http://sun1.aph.org/cgi-bin/starfinder/18399/fred.txt> or go to <www.aph.org>, click on Fred’s Head Database and search for “How to Apply Makeup”. There is also some information on a British website, Action for Blind People at <http://www.afbp.org/information/advice/beautysense.asp>.

Nancy Hefner and Jeri Cleveland, teachers at the Texas School for the Blind and Visually Impaired, also shared their suggestions. Nancy even took a free period to put on her makeup and shared tips as she went along! The consensus from these women, and others, is that the face is such a sensitive part of the body that it is relatively easy to be able to monitor putting on makeup.

The following are tips found in many of these sources:

- First, have the student practice each new makeup technique using fingers or brush without makeup so that she can feel exactly where to apply the product.
- Put on moisturizer before applying foundation, as that helps stabilize the rest of the makeup and has a slightly sticky feeling that makes it easier to feel where the foundation or other products have been spread.
- When applying foundation, use a finger rather than a brush so you can feel your progress. The key to even application is to use fingers to feather and smooth up and out so that you can barely feel the makeup. Blend and blend some more!
- Several women suggested mineral powders that apply with a brush without fear of lines yet feel more like a cream.
- Use a predictable sequence; start at the same place each time so that you can keep track of
what has already been applied. It is helpful to start at the cheeks, then the chin, then the nose and finally the forehead.

- For powder – start on one cheek and go across, being careful around the nose. Makeup tends to pool on either side of the nose so feather carefully with your fingers.
- Blush is easy to apply once you find the cheekbones and follow that line up to the hairline. To apply blusher, smile and brush the blusher onto the apples of your cheeks away from your nose towards your ear. Less is better with blush.
- Count the number of strokes needed to apply each kind of product when you are learning how to apply, so that you can put on the right amount.
- Cream-based makeup is less prone to going in the wrong places.
- Start with a clear gloss or chapstick until the student is comfortable with the motion, and then proceed to deeper lipstick colors. You only have to apply lipstick to your bottom lip. It will naturally cover the top. Pinch the sides of your mouth and the centre of the top lip to get rid of any excess.
- Some people prefer a brush and some a sponge for applying eye shadow. With the eyes closed, it can be applied and then smoothed with the fingers. Use the fingers to wipe away any excess that may have accumulated under the eyes as well as in the inner and outer corners.
- Eyeliner and mascara can be harder to apply and some consider them optional. For special occasions, many spas offer eyebrow and eyelash tinting that lasts for about three weeks. Some women have had eyeliner or mascara permanently applied by a beautician.
- Place the mascara brush at the lash roots and slowly pull it away as you close and open your eye to avoid letting it touch the area around the eye.
- Keep your eyebrows tidy by brushing them through regularly with a toothbrush or stroking through a dab of Vaseline.
- If you want to use nail polish, consider a clear coat or simply buff them. You may also put a little vaseline around the finger, next to the nail so that any mistakes can be wiped off easier. Keep your nail polish in the refrigerator so that it will be easier to feel where the polish is going. Or, simply save your money and get a manicure and/or a pedicure.

Many, if not most, people with visual impairments have some level of residual vision. A strong magnifier mirror and proper lighting can help take some of the guesswork out of applying makeup. There are also products such as the Eye-To-Eye cosmetic lens (<http://www.see-eye-to-eye.com>) that offer magnifying powers with a single lens designed to only cover one eye at a time. This allows application of makeup to one eye while getting the best possible vision from the other. A visit to a cosmetics department will yield many other products designed for any user that can help make the task easier for a person with visual impairment, too.

Looking good can be as important to a young girl with a visual impairment as it is to her sighted peers. Not all girls will want to wear makeup, but knowing what it is, and how to apply it for the best effect, is another way to provide a girl with opportunities for self-expression and self-determination on how to present herself to the world. Have fun exploring the world of cosmetics!
Incorporating Active Learning Theory into Activity Routines
By Kate Moss and Stacy Shafer, Education Specialists, TSBVI Outreach

Abstract: This article focuses on Phase IV and V of Lilli Nielsen’s five educational phases of educational treatment outlined in her book, Are You Blind?, and how the Active Learning principles can be incorporated into activity routines.

Key Words: programming, blind, deafblind, visually impaired, Active Learning, Lilli Nielsen, activity routines

In Dr. Lilli Nielsen’s book, Are You Blind?, she outlines the five phases of educational treatment we can use to help the child with blindness or deafblindness grow emotionally and develop cognitively. The purpose of using the techniques of the first three phases is to establish “an exchange and balance between periods of interaction and sound self-activity, between dependence and independence.” In Phase IV, which Dr. Nielsen calls “sharing the work”, she describes a child who is at a place where he is ready to learn that taking action and interacting with others is within his capabilities.

If we think about the child at each of these educational phases we can see the progression:

Phase I – The child is very inwardly focused, engaging in self-stimulation, with very limited experiences with objects in the environment, and who is very reluctant to engage with others except the most trusted adult (usually a caregiver).

Phase II – The child is somewhat more interested in his environment and others and can be engaged in brief interactions around high-interest objects or actions or “start-stop-start” games such as patting, swinging, bouncing, rocking, etc. He is still somewhat withdrawn, has limited interests, has limited ways to make contact with others, and has limited things he can do with objects. He can “play” along side the adult and show some interest in what the adult is doing, but does not try to imitate the adult.

Phase III – The child is interested in more interactive types of games (sometimes referred to as “you to me and me to you”) where he can take a turn, although he may not be able to initiate these games. Many of these games have imitative elements. The child may take time out from the game to process the experience or explore independently, but will come back to the adult to continue the game. He is interested in his environment and other adults and may fuss when the activity comes to an end.

Phase IV – The child is ready to learn that taking action and interacting with others does not mean he has to do everything or do it perfectly. He has confidence in some of his actions or activities. He is beginning to understand time and a sequence of events and will often become upset or act threatened when familiar activities are changed.

Phase V – The child is ready to learn that his own actions have consequences. He generally feels secure interacting with others and though he still may have difficulty initially handling change, he is showing more coping skills. He should have an emotional age of two years before attempting to work with him at this phase. (Nielsen, 1990)

Dr. Jan van Dijk, in his approach to working with deafblind multiply disabled children, also emphasizes the importance of establishing a relationship and learning to read the child’s subtle communication
as a first step. Similarly he uses co-active movement following the child’s lead to engage the child in interaction. He develops anticipation through building structured activities and routines; then slightly changes something in the routine to introduce novelty and learning. All along his goal is to build the child’s self-esteem and confidence in his abilities to do for himself and to interact with others. Specific communication skills are tied to these experiences as concepts are developed through experiential learning. (van Dijk, 2001)

Best practices teach us that throughout the child’s development in these early stages, routines and turn-taking interactions play a critical role. For example, all children participate in basic care-giving activities such as bathing, diapering, and feeding. Through these care-giving activities that occur daily, the child begins to establish a memory and can anticipate events. Later on, through participation in simple turn-taking games that are done in a routine way, the child is able to cause the adult do something pleasurable by taking an action of his own. Still later in his development, the child is able to take part in a simple series of actions that result in some desired outcome through more structured routines. Finally the child develops independence in completing the steps of the routine he has spent time “helping” the adult to complete.

PHASE IV – SHARING THE WORK OR LEVEL I ROUTINES

In her book, *Communication: A guide for teaching students with visual and multiple disabilities*, Linda Hagood describes three levels of routines, and the child at Phase IV is just at Level I. In the Level I routine she describes an activity that:

- Uses short, easy, predictable steps.
- Has a consistent beginning and end.
- Occurs at a consistent place and time with consistent objects and person.
- Is based upon the interests of the child.
- Is done with the adult in close proximity.
- Focuses on relationship building.
- Does not have the expectation of the child completing the activity on his or her own.
- Uses non-language forms such as objects, vocalizations, touch cues, etc.
- Views non-communicative behaviors as having communicative intent.

When a child is engaged in an Active Learning approach, it is at Phase IV when we begin using activity routines to supplement his independent exploration activities and simple interaction times with an adult.

At this phase the child should exhibit confidence in performing some actions or activities and have some beginning understanding of time and a sequence of events. When the child is demonstrating these traits, you can begin to include some routines where you expect the child to play an active part into a portion of each day. For example, he might show some anticipation of a familiar set of steps used in making his breakfast by trying to help pour the milk in his cup when the milk carton is opened. He may also become upset when he discovers that the carton contains orange juice and not milk.
Select a Motivating Activity

So how do you begin? As a first step, try to select activities that are motivating to the child. Think about the things (the objects) the child most enjoys playing with in independent exploration or in times when you are interacting with him. Are there activities you can design that will incorporate these materials? For example, if the child is interested in wire whisks, could you use a whisk to make instant pudding? Also consider the kinds of actions the child finds interesting. Can some of these actions be included in the routine you design? If the child likes to bang the whisk on another object can you have him bang the whisk from the finished pudding on the side of the bowl?

Pick an activity that is simple, one without a lot of complicated steps. Some of the payoff for participating in the routine needs to be apparent to the child from the beginning — “I get to play with the object I like.” Additional perks for hanging in there until the end of the activity should also be included along the way — “I really like chocolate. I like banging the whisk on the side of a bowl with my teacher. I like to tear open cartons.”

Organize the Materials

Participating in a routine with a child requires your undivided attention so you can respond to him emotionally and not miss any of his comments or reactions. Make sure you have all the materials you will need collected before you begin the activity. Think about the space where you will do the routine. Is this a space where the child feels comfortable and is not distracted by events or people? Is the area set up so that you can be at the child’s level, even if that means sitting on the floor? If the child can’t or won’t sit, can he physically access all the materials and complete an action? This might mean covering the floor with a protective cloth if the activity is likely to get messy. Will the child help you collect some of the materials or is that too much to ask of him at this point? Get everything ready before you ask the child to come “play”.

Provide Time to Explore

Give the child time to explore the space and the materials you will be using during the routine. Be sure to let him explore it in his own way and not the way you think he should explore it. If possible, let the child experience his own exploration of the objects outside the routine before introducing it into a structured routine.

Share in his exploration by having a duplicate set of materials for you to use or by giving joint attention to the object. For the visually impaired child this is often demonstrated through a shared tactile experience using a hand-under-hand approach (Barbara Miles, 1999). For example, if he bangs the wire whisk on the table, have one you can bang along side him. If he puts his hand in the water, put your hand in there with his so that he knows you are aware of what he is doing. Don’t hurry him in his exploration — this means you need to allow plenty of time for the routine.

Set up the Sequence

It is necessary to the child to provide a clear sequence of steps in the activity. Using a slotted box like the ones typically used for a daily object calendar works well. Place an object you will use in each step in sequential slots of the box. Organize them from left to right so the child can find his way to the next step easily as each step is completed. Provide a finish basket or box to discard the object after you have completed the step. After he becomes more familiar with the routine the child may be able to help
you load the objects into the slots after he has thoroughly explored each one. If not you may quickly review each one that you have pre-loaded into the slotted box so he knows where each object and action occurs in the sequence.

**Complete the Steps**

As you introduce each step, give the child a little time to re-explore the object before asking him to “help” complete the step. Then you can give him the word or sign for the object and model what you are going to do such as pour, stir, throw, tear open, etc. In the beginning the tasks you are asking him to complete can be completed in a few seconds up to a few minutes without any consideration for how perfectly the child can complete them. Be sure he understands which parts you are asking him to complete and which parts you will do. Most importantly, give him plenty of time to attempt to do the step before helping him complete it.

Modeling using a hand-under-hand approach during the routine, allows him to access what you are doing without making demands upon his hands to do all the work. If the child wants to explore the object a bit more after you use it, let him, but finish each step by helping to place the object in the finished box. Going back to the left-most slot and feeling for the next object can be beneficial in encouraging the child to look for the next “step” in the routine. (This is the perfect time to begin to introduce the concept and language of “next”. ) Eventually (after many times helping you do the action) the object should prompt the child to take the action independently. Wait silently and patiently!

**Be Mindful of Pacing**

Though you don’t want to rush the child through the activity, you also don’t want to lose him by dragging things out too long. This is where your teaching becomes an art; you have to be a keen observer of the child’s emotional state. You know the child and can read his signs of boredom, anxiety, or pleasure. Allow more time for his “fun” parts and move more quickly through steps that are less pleasurable.

**Clean Up and Put Away**

To whatever degree the child is capable have him help you collect materials and clean up the space. At first this might simply mean helping you get a key item from its place or put the object representing the activity in the finished basket. If he can carry dirty materials to a sink or throw a water toy into the bucket, get him to do that much. Over time, he should be able to take on greater responsibility for collecting and putting away the materials.

**After the Activity is Completed**

Take a few moments after the activity is done to “talk” about how the child helped. Don’t overly praise him, just comment on his successes and what you did together. If the child is using a calendar system at an anticipation level (at least), you may be able to reflect on the activity before you place the representing symbol in the finished box or basket.

**Throw a Curve Once the Routine is Well-Established**

When the routine has been completed a number of times and the child is definitely familiar with both the materials and the steps, it may be time to throw him a curve. For example, change the container that holds the milk, put bubble bath into the water, get a very large wire whisk or a very small one. Don’t change too much too quickly. You will likely see some surprise or even anxiety when he encounters the
change. This surprise will provide a great topic for conversation. It also will expand the child’s knowledge of objects and/or actions based on a very familiar, understood event. This is the way we all learn the best, not too much new to take in at one time.

CONCLUSION

Using routines is an invaluable tool when working with children who are developmentally delayed. A well-designed routine provides a great structure for learning. Incorporating Active Learning principles into the routine is also helpful. Just remember some of the points Dr. Nielsen mentions:

- Help the child learn that to be the one who does something does not necessarily mean that one has to do everything or do it perfectly.
- The abilities the child has been successful with in previous educational phases form the basis for deciding which activities can be used for the technique of sharing work.
- Keep tasks short (few seconds or minutes) initially, accept whatever the child does as correct.
- Explain each time which parts of the activity the adult will perform and what the child will do.
- Give plenty of time for the child to initiate the task and wait silently and calmly — be neutral.
- Let the child know how long the activity is supposed to last.
- Try to keep the environment the same or only make gradual changes.
- Before going to more complicated and longer lasting activities the choice of technique for every part of the activity should be given careful consideration.

REFERENCES


Building a Foundation of Confidence
By Barbara J. Madrigal, Assistant Commissioner, Division for Blind Services

Abstract: This article reviews services available through DBS and how to access those services.
Key Words: News & Views, blind, visually impaired, deafblind, Division for Blind Services, DARS, disability, confidence, self-esteem, services

As I have crisscrossed the state speaking to consumers and parents about developing confidence and self-esteem in their children who are blind and visually impaired, I have been encouraged and inspired by the welcoming and enthusiastic response to this message. Parents across the state have told me, and then told me again, how much they desire for their children to be challenged to meet their potential, to become confident and independent, and to contribute to the community. And, inevitably, I have encountered the question, “But what does DBS do, and how can it help me and my child?”

Well, to quote Elizabeth Barrett Browning, “Let me count the ways…."

DBS has two programs that serve youth and children, the Blind Children’s Vocational Discovery and Development Program (BCVDDP) – or the Children’s Program – and the Transition Program.

As you can tell by the name of our Children’s Program, we believe in encouraging and preparing for the future and for the world of work from an early age. Preschool children understand that their parents go to work and they begin talking about what they will do when they grow up. So our Children’s Program works with families to cultivate a positive adjustment to blindness and good communication and independent living skills that will foster confidence and independence as well as contribute to the child’s vocational potential.

The Blind Children’s Specialist works with each child and family to create a plan of services that is tailored to the child’s unique needs and circumstances. The Specialist works in partnership with the family and extended family, school personnel, doctors, therapists, and others in the community who provide assistance, services, and/or supports to the child.

The Transition Program focuses on preparing for the youth’s future transition from school to adult life. Transition planning is student-centered and involves collaboration between the student, the family, the school system, and any other support systems available to the youth and family. Transition services bring together resources and supports that promote the achievement of independence and vocational success; the earlier planning can be initiated, the sooner supports and services can be coordinated to achieve the goals of the student.

The Division for Blind Services starts early transition planning for students beginning at age ten. Although age ten is the targeted age for referral to the Transition Program, children who are developmentally delayed or more severely impaired may remain in the Children’s Program until they have attained the developmental milestones necessary to benefit from the Transition Program.

Both the Children’s Program and the Transition Program offer a wide range of services associated with six major skill areas. We think of them as stepping stones to an independent, productive, and satisfying life.
SERVICES ASSOCIATED WITH SIX MAJOR SKILLS AREAS

Adjustment to Blindness

Blind Children’s Specialists and Transition Counselors familiarize families with diagnostic procedures, medical treatments, and other things they need to know to support their child. Other services are designed to equip the youth with coping and self-advocacy skills to boost their confidence and self-esteem as they adjust to living with a visual impairment.

Independent Living (IL) Skills

IL services promote independence and self-sufficiency as the youth grows and matures. DBS and the family identify services that support the child in being as independent as possible in everyday life.

Communication

With strong communication skills, youth who are blind or have a visual impairment can thrive at home, in school, and in the community. DBS promotes development of a variety of skills including reading, writing, and using Braille; using assistive technology; accessing information; and other communication techniques.

Travel

Youth who are blind or have a visual impairment must develop orientation and mobility skills to safely navigate and explore the world around them.

Support Systems

DBS helps youth and families connect with a wide range of community support systems such as peer, parent, and sibling support groups; advocacy organizations; and educational support groups.

VOCATIONAL DISCOVERY AND DEVELOPMENT

For a child with a vision disability, vocational discovery begins at an early age and involves the whole family. In order to grow into independent, confident, and productive adults, the children learn problem-solving and organizational skills. DBS assists youth in career exploration and vocational development.

But what does this mean in terms of services? Again, let me count the ways. DBS staff provides ongoing evaluations to determine changes in vision and/or service needs. They provide individual and group skills training in a variety of areas such as social skills development, technology, advocacy, and independent living skills. They share knowledge and expertise by developing workshops and conferences, often in collaboration with the local ESC or other community resources. They can provide information and training to support the family in understanding their rights and responsibilities throughout the educational process, including attendance at ARD meetings or on-site educational observation and consultation with teachers and other education professionals. They assist in developing connections to support groups for youth, parents, and siblings and to mentoring relationships with peers and adults. They develop summer work activities and programs for older youth, including individual or group training for students and families (e.g., Braille, social/behavioral skills for vocational success, using technology,
accessing information, advocacy skills, career exploration, job readiness workshops, etc.). They provide literature and training materials, information about assistive technology and developmental equipment, and referrals to other resources. The family’s economic resources, the responsibilities of the child’s educational program, and the availability of comparable benefits and resources are considered during the purchase of services.

The Division for Blind Services would like to work with you and your family. If you are currently working with a Blind Children’s Specialist or Transition Counselor but were not aware these services are available, please contact your provider to schedule a meeting. If you would like to work with us and are not yet enrolled in services, please contact DARS Inquiries at 1-800-628-5115 (V/TTY) — let them know you would like to apply for DBS services and they will give you contact information for your local DBS office.

**The Gift of Time**

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

*Abstract:* Dr. Phil Hatlen discusses the importance of making time to teach the expanded core curriculum to students with visual impairments, blindness and deafblindness.

*Key Words:* News & Views, blind, visually impaired, deafblind, expanded core curriculum, role of the TVI

When my youngest son was five years old, a summer birthday kid, my wife and I became entangled in a very distressing situation. Two groups of “experts” began to talk with us. One was the Association for Early Childhood Education who strongly promoted the position that the “barely five” child should start kindergarten. The other group, founded, I think, by Gessel, bombarded us with their favorite phrase: “Give your child the gift of time”. There is no hurry in starting school. Your child could gain so much information, confidence, and maturity by waiting another year.

Lucas began kindergarten that year, and six years later repeated sixth grade. In his case, the “gift of time” would have been so important. He spent six years in school being the youngest and most immature child in his class. Now he is the oldest and most mature, and it’s made an amazing difference in his self-esteem and performance.

The gift of time. It sounds so politically incorrect at a time in our evolvement when preschool children are supposed to be reading fluently by the time they get to kindergarten, at a time when high-stakes testing begins at third grade, and pity the poor eight-year-old who doesn’t pass, at a time when the expectations we place on children become higher every year. Do our children suffer anxiety and frustration as expectations of their achievement grow higher and higher?

Does time and instruction in the Expanded Core Curriculum (ECC) have any relationship? You would probably answer, “Of course they do. My ability, as a TVI, to deliver the ECC is totally a time issue”. And for years I’ve been telling TVIs that the time issue is theirs, and if they would get their priorities straight, they would find the time to teach the ECC. In recent years, I’ve offered several potential solutions to having the time to teach the ECC. They went up the flagpole, but I don’t think many colleagues saluted.
One suggestion about delivering the instruction needed in the ECC was (is) to involve others in this effort. Why not have the local rehabilitation agency teach social skills and independent living skills? Why not have some other agency take over in the area of career education? Please know that this has never been my suggestion, because I have a major problem with this proposal. I believe that you TVIs and I have very, very special skills—skills that provide us with the knowledge of how to adapt a visual concept so that it provides similar information either tactiley or auditorily. Skills that enable blind and visually impaired students to learn. I question the skill level in creative adaptation and development of our colleagues in other disciplines.

So let’s take another look at the time issue. How about giving the gift of time to the blind or visually impaired student? I believe that it is unrealistic and a disservice to many of our students to expect them to complete their education in 12 years. Most blind and visually impaired students should have at least 14 years of education. It should consist of a balance between academic needs and ECC needs. Even for those students whose academic needs are overshadowed by their functional needs, these additional years are critical.

This concept requires a recognition that blind and visually impaired students have more to learn than their sighted classmates. Their loss of vision adds significantly to the concepts and skills they need to learn for adult life. This does not mean that they are being “held back” because of academic failure, and this may be the most difficult concept for parents and to students.

I propose that we study ways in which we can extend the educational life of blind and visually impaired students from 12 years to 14 years. This will take some doing. First, we will have to convince parents that the blind or visually impaired child has so much more to learn that it will take this additional time. Second, we will have to convince students that this does not mean we are retaining them for academic reasons. No student wants to be “held back”, and thus not graduate with her peers. Yes, it will be a significant task to convince students that blindness and visual impairment require additional learning opportunities to the extent that they will graduate from high school at age 20, rather than age 18.

Many have recognized the need for this “gift of time”, and have tried various approaches to meeting the ECC needs of blind and visually impaired young people. In 1972, the Living Skills Center for the Visually Impaired was opened in Richmond, California, because it was recognized that RLF graduates from regular high schools in Northern California were not ready to live and work in the community. In 2002, TSBVI, in collaboration with the DARS - Division of Blind Services, opened a post-secondary program for the same reason. These attempts at solving the issue of teaching the ECC meant that most or all learning of ECC curriculum took place after high school graduation. I suppose this is better than nothing, but it’s the equivalent of teaching an 18-year-old to read because there wasn’t time to do it in school.

If we infuse in our blind and visually impaired children the concept of equality, including the equality of education, then how do we convince them and their parents that equality really means providing the time to learn all aspects of academic education and the ECC in order to be prepared for adult life?

What’s the big hurry in life? Why not give our students the gift of time?
In an Emergency
By Beth Dennis, BCP/Transition Consultant, Division for Blind Services

Abstract: This article reviews and consolidates articles and emails circulated following Hurricanes Katrina and Rita that provided specialized advice regarding emergency preparation for parents with children who are disabled.

Key Words: News & Views, blind, visually impaired, deafblind, disability, emergency preparation, disaster

In the aftermath of Hurricanes Katrina and Rita, many articles were published and emails circulated providing advice for parents and caregivers of children with special health care needs. The panic and distress of dealing with an emergency can be alleviated to some extent with thoughtful preparation.

BEFORE A DISASTER

Not surprisingly, the number one tip for emergency management was to prepare for your family’s needs before a disaster. Remember that telephones and cell phones may not be available after a disaster strikes, so advance preparation is a necessity. Discuss your specific needs with your support network. Give a key to family, friend or neighbor who may be able to assist you, or inform your support network where you hide the extra key.

Local emergency management offices often maintain registers of people with disabilities. Contact your local emergency management office now to register. Obtain and use a medical alert tag to identify your child’s disability.

If you have pets, include the pet’s needs in your planning.

Prepare an emergency kit that includes:

1. Flashlight with extra batteries
2. Portable, battery-operated radio and extra batteries
3. First aid kit and manual
4. Emergency food (including special foods or formulas) and water for at least two days per person
5. Manual can opener
6. Essential medication for 3-7 days
7. Cash and credit cards (be sure to withdraw cash in advance)
8. Sturdy shoes

Also, maintain a list of important items and store it with the emergency supplies:

1. Special equipment and supplies
2. Current prescriptions (names and dosages)
3. Names, addresses, and telephone numbers of your medical providers
4. Summary sheet of your child’s medical conditions with details about medications (including dosages), assessment results and specific medical needs. The American Academy of Pediatrics (AAP) and the American College of Emergency Physicians (ACEP) have developed an Emergency Information Form used to record health data for children with special health care needs. Store this in the home in a place where emergency medical personnel can easily find it, and take it with you when you are traveling. The form can be located at <www.aap.org/advocacy/blankform.pdf>

5. IEP documents, including assessments and IEP goals/objectives and adaptation sheet

6. Summary of your child’s communication style/needs

In addition, prepare an overnight kit that includes:

1. Comfortable clothing for 2-3 days
2. Personal hygiene items
3. Identification and valuable documents (see next paragraph)
4. Blankets and pillows
5. Sleeping bags
6. Portable (folding) chair
7. Ear plugs and eye shades
8. Comfort items, such as CD players and CDs (with extra batteries), DVD player and DVDs, books, favorite toys

Lastly, place an envelope in the glove box, purse or carry bag that is marked “In Case of Accident,” that provides emergency information should the caretaker be unable to respond. Information should include the child’s name and medical/disabling condition as well as the name and phone number of an emergency contact. Be sure to include information about the child’s communication system if they are nonverbal. The doctor’s name, blood type, known allergies, medication needs should also be included.

DURING A DISASTER

Most important: Be Calm! Even if you do not feel calm, it is important to project a demeanor of calm. Children will sense your emotional state and imitate it.

Secondly, check for hazards in the home. During and immediately after a disaster, ordinary items in the home can cause injury or damage — anything that can move, fall, break or cause a fire, such as bookcases, hanging pictures, overhead lights, etc. Look for displaced electrical lines. Beware of carbon monoxide poisoning: per Centers for disease Control, do not use generators, grills, camp stoves or other gasoline, propane, natural gas or charcoal-burning devices inside the home or other contained area.

This information has been consolidated from several sources, including Partners Resource Network web article, “Disaster Preparedness Tips for Our Families,” FEMA report, “Disaster Preparedness for People with Disabilities,” as well as several emails (author not identified) that circulated after Hurricanes Katrina and Rita.
NASA Helps Visually Impaired Students Touch the Sun

Excerpted from <www.nasa.gov> website (Release: 04-389)

Abstract: This article reviews the book “Touch the Sun”, an accessible book featuring raised and texturized images of space.

Key Words: News & Views, blind, visually impaired, deafblind, NASA, space, sun, Touch the Sun

A new book, “Touch the Sun,” allows blind and visually impaired students to experience images of the sun and solar activity by feeling transparent raised textures bonded to the pictures.

The book features arresting images from the Solar and Heliospheric Observatory (SOHO) and the Transition Region and Coronal Explorer (TRACE) spacecraft, as well as a close-up of a sunspot from the National Solar Observatory at Sacramento Peak in the Lincoln National Forest, N.M.

“Invisible magnetic fields rule the violent solar activity that generates space weather,” said Dr. Joseph Gurman, the U.S. project scientist for SOHO at NASA’s Goddard Space Flight Center, Greenbelt, MD. “We are all blind to magnetic fields, so the visually impaired can be just as successful as the sighted in solar science,” he explained. Gurman collaborated with Steele Hill, the SOHO imaging specialist at Goddard, to select the images and edit the scientific content.

The book was written by Noreen Grice, author of two other books featuring textured celestial images for the visually impaired: Touch the Universe” and Touch the Stars. Touch the Sun was funded by a partnership among NASA, the Lockheed Martin Corporation’s Advanced Technology Center in Palo Alto, CA, and the Stanford Solar Center, Stanford University, Stanford, CA.

“Touch the Sun brings exciting new discoveries in solar science to those who otherwise might not have a chance to participate,” said Deputy Director of Earth-Sun Systems, Dick Fisher at NASA Headquarters, Washington. “This is an integral part of what NASA hopes to accomplish with the new Vision for Space Exploration---to share the thrill of exploring space with everyone,” he explained.

“Our bright yellow star appears unchanging but in fact is an active, violent place that directly affects our home planet,” Grice said. “Touch the Sun is a universally designed book for readers of all visual abilities. You can explore the sun with embossed color pictures of swirling gas currents, dark sunspots, curving magnetic fields and explosive eruptions,” she said.

Raised patterns embossed over the images in Touch the Sun translate colors, shapes and other intricate details of the sun and space weather, allowing visually impaired people to feel what they cannot see. It incorporates Braille and large-print descriptions for each of the book’s 16 photographs, so it is accessible to readers of all visual abilities. Students at the Colorado School for the Deaf and Blind in Colorado Springs, CO, evaluated each image for clarity and provided suggestions for improvement.

Gurman initiated Touch the Sun after he saw Touch the Universe presented at the June 2002 meeting of the American Astronomical Society in Albuquerque, N.M. “I realized solar science was a natural fit for a book like this, and our partners did as well. This was one of those rare projects where there was no resistance to the idea. Everyone who heard about it was enthusiastic,” Gurman said.
**Touch the Sun** will be published by the Joseph Henry Press, trade imprint of the National Academies Press (publisher for the National Academy of Sciences). Approximately 2,500 copies will be printed. The majority will be distributed free to blind and visually impaired students, with the assistance of the National Organization of Parents of Blind Children, a division of the National Federation of the Blind. The remainder will be available for public purchase.

To view related images on the Internet, visit: <http://www.nasa.gov/vision/universe/solarsystem/touch_sun.html>.

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**Traveling Exhibit from American Printing House for the Blind to Visit TSBVI**

*Abstract: Information on the upcoming visit by the APH Callahan Traveling Museum to Texas School Blind and Visually Impaired in August and September of 2006.*

*Key Words: News & Views, lind, visually impaired, deafblind, TSBVI sesquicentennial, APH Callahan Traveling Museum*

Callahan Traveling Museum Exhibit, on loan from the American Printing House for the Blind of Louisville, Kentucky, presents “In Touch with Knowledge: The Educational History of Blind People.” This traveling museum is coming to Texas School for the Blind and Visually Impaired in August and September, 2006. This exhibit draws on the Callahan Museum’s unique collection and extensive research on the history of the education of blind people. It is the only museum in the country devoted to this history.

IN TOUCH WITH KNOWLEDGE includes original artifacts, reproductions, graphics, tactile exhibits, and hands-on activities. Braille labels and audio text and descriptions provide accessibility.

The four components that make up the exhibit are:

- **Hands-On Reading and Writing** – the evolution of tactile writing for blind people from the first experiments in the eighteenth century to the development of braille and the invention of the braille writer.

- **Hands-On Geography** – from the first hand-stitched and molded paper maps to a contemporary tactile, talking globe.

- **Hands-On Mathematics** – the quest for a practical way to make math calculations accessible to blind people, beginning with peg and board devices in the 18th century and ending with the Nemeth braille code and talking calculators.

- **Hands-On Science** – learning science using natural history specimens, philosophical apparatus, and anatomical models and highlighting the contributions of blind scientists, past and present.

Each of the four components of IN TOUCH WITH KNOWLEDGE includes original artifacts, reproductions, graphics, tactile exhibits, and hands-on activities. Braille labels and audio text and descriptions provide accessibility.

For more information about this special event and other events marking the sesquicentennial celebration of TSBVI, visit the TSBVI website at <http://www.tsbvi.edu/school/sesq/index.htm>.
“It’s a New IDEA”

Announcement from the Advocacy, Inc. and Arc of Texas websites

Key Words: News & Views, blind, visually impaired, deafblind, disability, “It’s a New IDEA,” Advocacy, Inc, The Arc of Texas, special education

The September 2005 updated version of the Parent Manual, now called “It’s a New IDEA”, The Manual for Parents and Students about special Education Services in Texas, is now available online on The Arc of Texas website <www.thearcoftexas.org/Inclusion_works/ideaman.htm> and Advocacy, Inc.’s website <www.advocacyinc.org/handoutEducation.htm>. This version can be downloaded and used by anyone. However, at this point there will be no hard copies produced by a printer.

Advocacy, Inc. and The Arc of Texas know that they will have to make changes again when the final IDEA regulations are adopted (probably December 2005) and they didn’t want to print manuals that would need to be changed in just a few months. They are working on a Spanish translation that will be finished once they have final regulations. At that point, they will make any changes necessitated by the final regulations and then have the updated manuals available online and in a printed format. The new version does reflect current law, which is what districts are expected to follow until different regulations are adopted.

On the APH Website <www.aph.org>

Key Words: News & Views, blind, visually impaired, deafblind, CVI, Braille, webcast

CVI PERSPECTIVES VIDEO

This video developed by APH explores cortical visual impairment (CVI) from three perspectives: medical, educational, and personal. Neonatologist Dr. Alan Lantzy presents a medical perspective on the causes of CVI. APH CVI Project Leader Dr. Christine Roman presents an educational perspective focusing on characteristics and recommended approaches. In the final segment, seven families talk about their personal experiences from the difficulty of the diagnosis to finding help and hope.

BRAILLE TRANSCRIBER’S KIT: COUNTRIES AND CONTINENTS

The Braille Transcriber’s Kit: Countries and Continents is a collection of embossed and printed outlines of maps commonly found in history, geography, and social studies textbooks developed by APH. The embossed sheets may be used as templates when you create tactile maps. Add to these sheets with spur wheel lines, craft ink, glued-on textures, etc. Add braille labels as needed. The printed maps may be used as masters for “swell paper” tactile graphics. Photocopy the images onto your capsule paper, add labels, lines, and symbols as needed, and produce the raised image by running the graphic through the heating machine.

APH WEBCAST OPPORTUNITIES

A Webcast is a multimedia presentation that uses the Internet to broadcast live or delayed audio and video transmissions, much like traditional television and radio broadcasts. The Summer Book Port™ Webcast Series will Begin July 12 (previously scheduled to begin July 5th). These webcast presentations will take place once a week during the months of July and August. Each webcast will cover a different Book Port-related topic, and will run from 30 to 45 minutes, depending on the number of questions each topic generates. For more information about this series go to <http://www.aph.org/advisory/webcast.html>
Texas School for the Blind & Visually Impaired
Sesquicentennial Events Scheduled for the Spring and Summer

March
- March 31st - April 1st - American Foundation for the Blind meets at TSBVI.

April
- April 27th - 29th – South Central Association of Schools for the Blind (SCASB) Track Meet – Schools from six states (Texas, New Mexico, Oklahoma, Alabama, Mississippi & Louisiana) will compete in track and field, cheerleading and arts performance. The public is invited to attend the on-campus event.

May
- May 4th-6th and 10-11th - Student Performance of the annual spring play - the public is welcome.
- May 10-13th - TSBVI hosts the International Seminar on Preschool Blind.
- May 25th - TSBVI Graduation - winner will be announced for Round 2 of the Poetry Competition.

August
- All Month - Callahan Traveling Museum Exhibit - On loan from the American Printing House for the Blind of Louisville, Kentucky, presents “In Touch with Knowledge: The Educational History of Blind People.” TSBVI’s will also create it’s own museum of Texas artifacts. The public is encouraged to come see this wonderful exhibit and learn more about education of the blind. See <http://sun1.aph.org/museum/intouch.html> for more information about this traveling museum coming to Texas in August and September, 2006.
- August 16th - A special commemorative stamp cancellation honoring TSBVI at Austin post offices. Envelopes cancelled with this special postmark will be on sale at the School.
- August 18th - 20th - Memory weekend! — Reunion for former students of the School - musicians, speakers, sight-seeing tours of TSBVI’s humble beginnings.
TSBVI Special Programs
Calendar for Spring

SHORT PROGRAMS
February 16-19 - Low Vision Weekend (secondary)
February 26-March 3 - Technology Week #2 (secondary)
March 23-26 - Elementary Independence Weekend
March 30-April 2 - High School Independence Weekend
April 23-28 Elementary:
· Elementary IEP #2
· Elementary Technology

Annual Introduction to the Intervener Model Workshop set for June 12-13, 2006 in Austin

This introductory-level statewide training for Interveners and team members who have not attended previous general intervener training. If you are interested in learning more about the use of the Intervener Model with students who are deafblind, please contact Beth Bible at Texas Deafblind Outreach (512-206-9103) or email to bethbible@tsbvi.edu.

Additional information and a registration brochure will be made available in the early spring.

Mark your calendar for Texas Focus dates! June 8 & 9, 2006

watch for information on the Statewide Calendar at <http://www.tsbvi.edu/Outreach/vi.htm>

The Cornelia DeLange Syndrome Foundation’s 23rd National Conference June 22-25, 2006

The historic setting of the Philadelphia area will be the backdrop for a celebration of OUR history -

For more information visit the CdLS Foundation website at http://www.cdlsusa.org or call (860)675-8166 or (800)223-8355.

Joubert Syndrome Foundation & Related Cerebellar Disorders 8th Biennial Conference July 5 – July 9, 2006 Sheraton Grand Hotel Irving, Texas

For information email to joubertduquette@comcast.net or visit the Joubert Syndrome Foundation website <http://www.joubertfoundation.com/>

The Arc of Texas’ Inclusion Works Conference February 22-25, 2006 Renaissance Austin Hotel

For information contact The ARC of Texas website <http://www.thearcoftexas.org> or call (800) 252-9729 or (512) 454-6694.
Texas Chapter of the Association for Education and Rehabilitation of the Blind and Visually Impaired (TAER) Annual Conference
Date(s): April 7-8, 2006
Location: Corpus Christi, TX

For more information contact:
Debbie Louder, Texas AER Conference Chair
E-Mail: debbie.louder@netxv.net

2006 AER Biennial International Conference
Date(s): July 13-18, 2006
Location: Snowbird, UT

For more information, contact:
Barbara C. Sherr, Conference Manager
Phone: (703) 671-4500 ext. 201
E-Mail: bsherr@aerbvi.org
<http://www.aerbvi.org>

American Association of the Deaf-Blind Conference Towson University Baltimore, Maryland June 17-23, 2006

Contact Jamie Pope, Executive Director
(301) 495-4403 TTY: (301) 495-4402
Email: AADB-info@aadb.org
Website: <http://www.aadb.org>

Other Training Events

February 17, 2006
Spotlight on Technology: What’s New for Students with Visual Impairments
Presenters: Vendors
Location: ESC Region 4, Houston, TX
Contact: Cecilia Robinson at (713) 744-6379 or crobinson@esc4.net

February 23, 2006
Social Skills and Independent Leisure Skills
Location: ESC Region 1, Edinburg, TX
Contact: Marguerite Horney at (956) 984-6264

February 24, 2006
Teaching Students with Visual and Multiple Disabilities
Presenter: Dr. Jane Erin
Location: ESC Region 4, Houston, TX
Contact: Suzy Scannell at (713) 744-6315 or sscannell@esc4.net

February 24-25, 2006
Deafblind - Multihandicapped Academy: Infants and Toddlers (birth-6) with Deafblindness
Presenter: Gigi Newton
Location: Four Points Sheraton - McAllen
Contact: Peter Graves at (956) 984-6165 or pgraves@esconett.org

February 28, 2006
Emerging Low Tech AAC for Students with Significant Multiple Impairments
Presenter: Jim Durkel
Location: ESC Region 10, Richardson, TX
Contact: susan.lawrence@region10.org

February 28, 2006
District Innovations: CTWI and COMS
Presenters: Susan Lawrence and Christy Householter
Location: ESC Region 10, Richardson, TX
Contact: susan.lawrence@region10.org
March 1-3, 2006  
**Balanced Language and Literacy Instruction for Students with Complex Communication Needs**  
Presenter: Marguerite Horney  
Location: ESC Region 1, Edinburg, TX  
Contact: Marguerite Horney at (956) 984-6264  

March 3-5, 2006  
**2006 Josephine L. Taylor Leadership Institute (JLTILI)**  
Location: Atlanta, GA  
Contact: AFB Communications Group  
<http://www.afb.org/jltli.asp>  

March 6, 2006  
**Write to Talk (TETN# 11624.1)**  
Contact your Regional Education Service Center or local assistive technology team for more information.  

March 24-25, 2006  
**Deafblind - Multihandicapped Academy: The Academic Deafblind Student**  
**What You Should Know**  
Presenter: Kate Moss  
Location: Four Points Sheraton - McAllen  
Contact: Peter Graves at (956) 984-6165 or pgraves@esconett.org  

March 29, 2006  
**O&M Evaluations - The Full Spectrum**  
Presenter: Tanni Anthony  
Location: ESC Region 10, Richardson, TX  
Contact: susan.lawrence@region10.org  

April 13, 2006  
**Effective Strategies for Facilitating Oral Options**  
Presenter: Gus McHam  
Location: ESC Region 4, Houston, TX  
Contact: Theresa Johnson at (713) 462-7708  

April 19, 2006 from 1:30-3:30 PM  
**Speech-Language Assessment Issues for Students with Visual Impairments (TETN # 12415)**  
Presenters: Valerie Bradshaw, Kim Conlin, and Tish Smith, TSBVI  
Contact your Regional Education Service Center for more information.  

May 3, 2006  
**O&M and Post-High School**  
Presenter: Diane Barnes  
Location: ESC Region 13, Austin, TX  
Contact: Diane Barnes at (512) 919-5331  

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**Deafblind Spousal Support Group**  
A new support group is starting up for spouses and partners of persons who are deaf-blind (DB) or hearing-and-visually-impaired (HVI).  

To subscribe to this group by sending a blank e-mail request to:  
<DB-Spousal-Support-subscribe@yahoogroups.com>  
(mailto:DB-Spousal-Support-subscribe@yahoogroups.com) .
**SEE/HEAR**

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

**Deadlines for Submitting Articles**
December 1st for the Winter edition
March 1st for the Spring edition
June 1st for the Summer edition
September 1st for the Fall edition

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