



reSources

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Communication: The Basic Tool for Independence

by Gloria Rodriguez-Gil, CDBS Educational Specialist

A student who is deaf-blind could go through life without a formal communication system. She will wake up in the morning and more or less follow her daily routine by following people and environmental cues. If she is lucky, she will grow up in a predictable environment and very few things will take her by surprise. When she experiences uncomfortable situations, she will do things like pull away from the hand of the adult who accompanies her as though saying “I want to leave now”, or start fussing or crying because she is feeling pain (or for no clear reason). She may start moving her body in a repetitive way as though to say “I am bored” or “I need to take a break”. When she does not like someone or something, she may push the person or the object away. When she is happy, she will smile and allow physical contact, and stay with the activity for a longer period of time. When she is hungry she will go to the kitchen, look for a specific pan, and bring it to her mother to tell her that she wants to eat. I am thinking of a student I served many years ago who was about fifteen years old at that time. I’ll be calling her Isabel although this is not her real name. She was my first student with deaf-blindness.

Isabel and I were able to establish a bond and most of the time we had fun together. The first day that her mother left her with me, the only thing Isabel wanted to do was walk. (I think she was trying to find her mother.) Eventually, I discovered that she liked to do a number of things, including going places, preparing and eating meals, and exercising on a mat. She also liked to be tickled. She would take my hands and bring them close to her ribs as though to say “I want you to tickle me”.

Months later, a teacher from a well-known school for the blind who had years of experience working with people who are deaf-blind observed me working with Isabel. Following the observation, he provided feedback by saying something like “I think you have a great relationship with Isabel but I don’t see any formal communication between the two of you.” I was hurt by his feedback because it was unexpected—I thought I was doing such a good job and had put in so much effort. I understood part of what he said, but not all. As years passed and I became more knowledgeable and experienced, I came to understand what he meant: he had actually provided me with the next step.

By not providing Isabel with a communication system that could go beyond our routines and relationship, I had created a situation of dependency. The communication between us depended entirely on our interaction and activities. The moment I moved on, Isabel was left with what I hope was a positive experience, but not with a communication system. When Isabel started working with me, she already understood routine and cues, but had no formal communication system (e.g., tactile signing, coactive signing, objects and parts of objects). This kind of system would have allowed her to communicate in different situations and with different people.

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Do I regret not having given Isabel a communication tool? Sure, but what I did not know at the time, I know now. A communication system can liberate a student who is deaf-blind from dependency. It is essential to establish a relationship and a strong bond with a student who is deaf-blind, and to find ways to have fun together and to challenge the student. But as important as this is, it is also essential to teach this student a communication system

that will make it possible for her not only to communicate with you, but with others—not only in the routine and environment that you have created for and with her, but in other routines and in other environments. A communication system will open up a world larger than anything a single individual can ever provide—despite the best intentions.



Communication Between Family and School: Creating a Communication Notebook that Works

by Myrna Medina and Jackie Kenley, CDBS Family Specialists

A communication notebook or daily journal is a book that goes back and forth from home to school, and the idea has been around for a while. It seems to be something commonly used in special education.

It is important for parents to know what is happening with their children during the school day—regardless of whether or not their children have disabilities. Home-school communication is one of the most important and necessary factors in developing good relationships between classroom teams and families. Due to busy work schedules, lack of time, and transportation challenges, the opportunities to meet in person are limited.

Teachers and school teams benefit when parents share information about medical issues that may affect the student's behavior at school. It can be beneficial to the family and school team when they share ideas and successes with communication skills as well as other skills. Perhaps it is worthwhile to take a look at how we might better use this notebook tool with our students who are deaf-blind.

Educators and parents may see a picture in their minds of a beleaguered teacher at the end of the school day with a stack of notebooks that need to be written in. One possible solution for the team of the student who is deaf-blind may be if the student has a one-on-one aide or intervener; it may be useful to have that person writing in the communication book. The intervener/one-on-one will probably have spent most of the day with the student and be more attuned to what has happened at school.

Also they will be aware of the communication [system?] the student is using and the different therapies that (s)he participated in that day. The teacher may then be free to write about special things that have happened, or concerns about the student. Also the student's therapists such as Occupational therapist, Physical therapist, Orientation and Mobility, Speech and Vision therapists may find time to write on occasion and send messages home through the person writing in the notebook.

If the student has a home program it may be good to have the home staff write something in the communication book from time to time. Sharing ideas and strategies can be helpful to both the home and school teams.

It is, of course, important to send things—money, notices, emergency info—all sorts of things back and forth between home and school. These can be included with the notebook and this is a job the one-on-one might also help with.



Some teams may like to write long narratives but others may find that too time consuming. Most important is that the home school notebook is effective and it meets the needs of the child, team, and family; that it is used

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regularly; and is simple, honest, and positive, as well as understandable for all.

When writing in a communication notebook there are things we might want to consider. Things to consider are:

- ❖ Something the student did for the first time at home or school, or something the student is beginning to do on a more regular basis, whether or not we see this as positive or negative
- ❖ Something the student may be anxious about
- ❖ Something that occurred physically—illness, bowel movement, menstrual period
- ❖ What is going on at home—visitors, activities, work schedules, home staff
- ❖ How much sleep the student has gotten
- ❖ What the student has eaten or drunk and how that seems to affect him or her
- ❖ Who the student interacted with socially, and how (s)he seemed to feel about that—interaction with friends, classmates, family
- ❖ Who are the student's buddies—what activities do they share?
- ❖ Who the student has interacted with to work/learn, and how the student felt about that—staff, therapist
- ❖ Physical and communication patterns during the day/week that may show how the student is feeling
- ❖ What is happening on the bus?
- ❖ What happened today that was not so positive?
- ❖ **Very Important:** What happened today that was positive????!!



The minute you walk through the door...

by Jackie Kenley

When my daughter comes home from school on the bus, we have developed a routine through the years. She seems to do best with routines and these routines meet my needs as well (e.g., her basic need to get a drink and go to the bathroom and my basic need to find out what has happened that day at school). Because of her limited communication, the home-school notebook is a particularly needed resource for me. Each day, I reach for the notebook in her backpack and try to get an idea of what's up. Of course, life interrupts all routines, but I find this time well spent and it helps us with our plans for the rest of the day. It also helps me to know about things that need to be celebrated, things that need to be more clearly understood, and sometimes things that need to be addressed.

Some days I receive a quick note with the "basics" about her schedule, such as what she has eaten that day. Some days may be special because she has done something really exciting and new, or even comical...like throwing her folded cane in the trash can that has a permanent top! The team may have concerns about her health or there may be a cry for help from the school team about how tough things have been. This cry for help may just be a negative report but I have learned the importance of a follow up call. A longer note back to school—sometimes to schedule a team meeting—may also be helpful. Sometimes just letting members of the school team know that I understand and know they are trying their best seems to be very important to them. When I read about a less-than-positive persistent problem, the team and I can meet and often come up with ideas that support the team and help turn things around for my daughter. The home-school notebook can help facilitate comfortable, non-confrontational team meetings that are so helpful. It is something that I often wish for every child's team.

I have had the opportunity to speak with teachers in college classes throughout the years and I always emphasize the importance of using a home-school notebook to communicate with families. I suggest that they try to write about something positive that occurred during the school day. At times, this may be a bit tough for the school staff but it can be a good practice and it is certainly encouraging to families. How many school situations could be turned around by good communication? The home-school notebook allows families and teams to work together to make the system (and program) work more effectively for the student.

COPE-DB Holiday Party

by Myrna Medina, CDBS Family Specialist

A great time was had by all attending the annual COPE D-B Holiday Party on December 10, 2006 in Los Angeles. The day was beautiful and the folks at the Sports and Recreation Hall in the City of Commerce were very welcoming. Families decorated cookies, played games, and danced the limbo, and it was wonderful to see the children who are deaf-blind participating and having a great time. There was a tasty potluck dinner to satisfy everyone. Approximately 60 people attended and the holiday spirit was felt by all.

The families in attendance said that they look forward to this annual event to meet and enjoy each other's company. Families are able to share about their lives and the needs and successes of their children. There are always great opportunities for networking and encouraging one another! COPE D-B thanks the Hilton/Perkins Program of Perkins School for the Blind and the City of Commerce Sports and Recreation Hall as well as other donors for making this event possible. This is the true spirit of giving!



Mark Your Calendars!



The 8th International CHARGE Syndrome Conference

July 27-29, 2007

**Hilton Orange County
Costa Mesa**

A primary objective of the conference is to provide families information and support which will help them achieve the best possible outcome for their individual situations. The second objective is to create opportunities for medical and educational professionals to learn from the experts who will be speaking at the conference, and from families with CHARGE.

And YES, volunteers are needed!

Northern California COPE-DB Picnic



**Saturday, June 23, 2007
Tilden Park, Berkeley**

Come enjoy a day in the sun in a beautiful natural setting.

- ⇒ great food ⇒ activities for the kids
- ⇒ opportunities to meet new families and renew old friendships
- ⇒ learn more about COPE-DB, our statewide family organization

For details about either of these upcoming events, contact a CDBS Family Specialist at 800-822-7884 (Jackie Kenley at ext. 3 or Myrna Medina at ext. 5).

COCHLEAR IMPLANT STUDY

Ella Taylor

The Teaching Research Institute
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The Outcomes for Children Who Are Deaf-Blind after Cochlear Implantation (CIDB) Project is seeking approximately 250 children for participation in a study to determine the impact of cochlear implantation on auditory perception, language acquisition, and receptive and expressive communication. Currently, very little information is available about children who are deaf-blind and have cochlear implants. The primary goal of the study is to increase knowledge about this population. Children younger than 13 who currently use or are considering using a cochlear implant may be eligible to participate.

At the beginning of the study, four assessment questionnaires are completed for each child: three by family members and one by a state deaf-blind project staff member based on interactions with the child. Follow-up assessments depend on how long a child has had an implant. Children who have not yet received a cochlear implant or who have recently received one will have subsequent assessments every 12 months for 3 years. Children who have had an implant for less than 7 years will be assessed one more time after 12 months. Children who have had an implant for more than 7 years undergo no further assessments. A small stipend is given to families of children who qualify for participation in the study.

The CIDB Project is a joint effort by the Teaching Research Institute at Western Oregon University, the Beach Center on Disability at the University of Kansas, and the Midwest Ear Institute at St. Luke's Hospital, in Kansas City, Missouri. Several state deaf-blind projects are participating including California, Florida, Illinois, Indiana, Kansas, Kentucky, Maryland, Minnesota, Missouri, Nebraska, New Jersey, New York, Oregon, Pennsylvania, and Texas. This project (Grant #H327A050079) is funded by the U.S. Department of Education's Office of Special Education. For more information, visit <http://www.wou.edu/cidb>, e-mail CIDB@wou.edu, or call 877-660-CIDB (2432).

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