



reSources

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Developing Communication Systems That Meet Everyone's Needs

by Maurice Belote
CDBS Project Coordinator

Communication systems for individuals who are deaf-blind often include many modes of communication: pictures, photographs, objects, voice output devices, symbol cards, spoken words, signs, and combinations of any or all of these. Deciding how best to combine these modes may be one of the most critical tasks that face a child's team. Family members, friends, and service providers must come together to discuss degree of hearing and vision, degree of fine and gross motor skills, and many other factors that help guide this process. There are also excellent tools available that assist the team in looking at the child's communication from a broad perspective, such as the *Communication Matrix Communication Skills Assessment* by Charity Rowland, Ph.D. (CDBS has copies available free of charge to interested teams.)

How the child communicates, however, is just one piece of the challenge of designing a communication system for an individual who is deaf-blind. A child has to have something to communicate about, and a child has to have someone to communicate with.

Whether you are choosing signs, pictures, phrases on a voice output board, or any other mode, there are three important factors to keep in mind so that the system is balanced and meets everyone's needs.

What we want the child to communicate. This is the category that meets our needs as family members and service providers. When I think back to the countless communication systems I have helped to design, I

realize that I may be the most guilty of focusing almost exclusively on what I (or other team members) wanted the child to be able to communicate. For example, as a teacher, I would like the child to be able to tell me he or she needs to use the restroom. This cuts down on accidents and the need for changing clothes at inopportune times. I would like students to be able to communicate that they are finished with their work or that they need a short break, so that they are less likely to throw the materials all over the floor to express the same thing. These are things that make a teacher's life easier and less stressful.

What the child wants to communicate about. Of course the child wants to communicate about basic needs, such as the need to use the bathroom, to be changed, to change position, or to have something to eat or drink. These are basic functions that must be built into a system. Beyond these, however, may be a host of other communication topics that are equally important to the child. These may be age appropriate or they may not. They may be topics that the child communicates about incessantly, and that we may secretly wish the child would find something else to communicate about. But if the child wants to communicate about these things, he or she will, and there is little we probably can or should do to eliminate them until we give the child broader and richer experiences from which to draw conversational topics.

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The child who is deaf-blind might want to communicate physical feelings or expressions related to emotions. One of the most common of these is “I want to be left alone”. Other common expressions might have to do with expressing happiness, joy, frustration, boredom, jealousy, or anger. An expression that is often overlooked is the sadness at the loss of a friend or service provider. When staff changes at a child’s school and the child has a new one-on-one assistant, how often do we build into the child’s communication system a way to say “I miss ____ and wish I could see her again”? The ability to express physical pain is another important component to include in a communication system. It is reported that a significant percentage of teenagers experience headaches that are frequent and at times severe. The team must ensure that the student is given the opportunity to express pain such as headaches, menstrual cramps, or other ailments that aren’t readily visible such as blisters or sores.

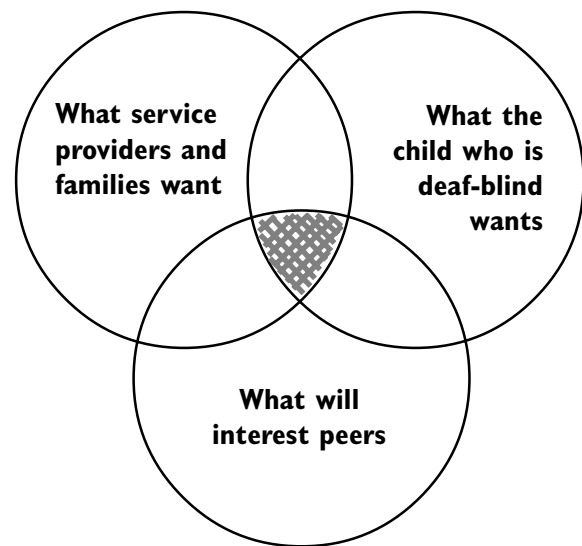
Until peers discover the countless things they have in common with a child who is deaf-blind, they may look at that child as the deaf-blind student, the student who uses a wheelchair, the student that leaves class many times a day with specialists, etc. It is when peers discover that the child who is deaf-blind has pets, or has brothers or sisters, or has their bedroom decorated with a particular cartoon character, or likes to go boating and camping, or whatever else they have in common that the foundation for meaningful communication develops. For example, a voice output board might have a phrase that says “My dog’s name is Fuzzy and he likes to lick my face” or a communication card set might have a picture of the child’s bedroom with a caption that reads “This is my bed. It’s next to the fish tank because I like the sound/sight of the water”.

What the child’s peers want to communicate about.

This category includes topics that will interest others, and will help the child be interesting to others. What we want the child to communicate, and what the child wants to communicate may have little to do with what children the same age want to talk about. There is no better way to find out what is hot and current than to ask a group of children who are the same age as the child who is deaf-blind. These topics may include music, electronic games, chat rooms, pets, movies, romantic crushes, dance steps, trading cards, books, or anything else that is—for the time being—cool. And we know that fads go out of fashion as quickly as they come in. By allowing the child’s communication system to

include some of these hot topics, we increase the likelihood that the child who is deaf-blind can have conversations that go beyond “hello”.

The following graphic illustrates these three categories. Our challenge when designing systems is to ensure that the system includes opportunities for expressive communicative attempts from each of the circles. It is the middle shaded area that constitutes a system that meets everyone’s needs.



This may be more challenging than it seems. Consider a voice output board that has eight possible messages. Normally the team would sit down together and say, “What are the eight most important things the child should be able to say?” With only eight messages, is the team willing to give up one in order to allow the child to say that he really likes fire trucks? Would they be willing to give up yet another that would allow the student to ask peers whether or not they collect and trade Pokémon cards? This would leave six messages for the basics. This balancing act arises regardless of the communication modes used by the student. For a student who uses object communication, including all three circles from the graphic above may require adding objects to a system that the team feels has too many objects already. For a child who uses signed communication expressively and who also has limited fine motor coordination, the child’s team may have to more carefully choose the signs that will be included in the system due to similarities in sign parameters (i.e., hand shape, movement, palm orientation, and location).

Developing (continued from page 2)

If a child uses picture/symbol cards, it may require adding cards to an already bulky system.

Our challenge as support providers to children and youth who are deaf-blind is to provide them the rich and varied opportunities we provide all children, and then to make certain that the child's peers have a way to discuss these experiences with the child. We have seen many instances where peer relationships improved significantly when the peers had a better understanding of the child who is deaf-blind beyond simply understanding the disability. Friendships sometimes grow out of unexpected shared interests, and each of the three components of a child's communication needs must be present in order for these interests and life experiences to be revealed.

Don't forget to check the CDBS website regularly to keep informed of upcoming events!



***Point your browser to:
www.sfsu.edu/~cadbs***

Creating Communication Rich Environments

*by Elizabeth Hartmann
CDBS Intern, Boston College*

Have you ever noticed how people never seem to communicate with each other in the morning as they ride on public transportation? It is as if there is a "no speaking or direct eye contact" rule between the hours of 6 and 9 am. We all know we could communicate with each other, but we choose not to and often avoid it at all costs. Through my many hours on public transportation I have come to realize that the environment created by public transportation is not conducive to human interaction and connection. Although most of the time it serves its purpose of getting people from point A to B, it will never be known as the place for lively conversation.

For individuals who are deaf-blind, classroom environments have the potential of being similar to public transportation. Although all classrooms have communication, students, inability to access their environment because of their dual sensory loss can leave them isolated and detached from their classrooms. Professionals and paraprofessionals spend hours of their valuable time avoiding this problem by creating augmentative communication systems and calendars for these children and young adults, but what is forgotten is the environments they are used in. Without

this, students who are deaf-blind are left with little reason or motivation to communicate. They are left in a world similar to that of public transportation~no interaction or connection.

In creating communication rich environments, we have to focus on three main aspects of environments: space, people, and time. These three factors give environments structure and make them more conducive to meaningful communication. Once structure is established, space, people, and time can then be used as tools in creating more creative and interesting opportunities for communication to occur.

Space

The space we communicate in has a major impact on our comfort and ability to communicate. We begin to understand what space is by first understanding ourselves. As we move beyond our personal space to the space around us, there are many people, things and events that motivate us to communicate. Without access to these interesting factors, there is no reason to connect with others or express ourselves. In a classroom, the

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design of the space can directly effect whether or not the individual who is deaf-blind is able to move beyond themselves and into their environment to make communication exchanges. In creating a communication rich space, one must ensure that the classroom space is accessible and conducive to communication. This can be done by always making the learner,s communication system accessible to them, and teaching them how to access it from the different areas in the classroom. Create ways to label the student's shelves, cabinets and personal space so that they know where their things are and how to get them. Have the students explore their learning spaces independently-on their own terms-so that they can come to their own understanding of the classroom.

Once this basic knowledge and structure of the classroom space is achieved, think of different ways that the space can be altered which will lead to increased communication. For example, place preferred materials out of reach or in a novel place. Leave interesting materials that will require assistance from another in the learner,s space. Using the materials in their space, create unfair situations with preferred materials. All these situations will challenge the deaf-blind learner to explore their environment and then use communication as a tool to change it.

People

Communication is impossible without a communication partner. In the school environment of the deaf-blind learner, there are many people to communicate with but usually only a few can be considered true communication partners. These communication partners are the people who understand and use the deaf-blind learner,s communication system effectively. The main reason why their communication attempts are received and reciprocated is because they are respectful, patient, trusted by the deaf-blind learner. A communication rich environment needs multiple communication partners to motivate the deaf-blind learner to connect. Furthermore, this ensures that the deaf-blind learner has a choice to people to communicate with. A variety of partners-including peers-creates exposure to communication models that will further develop their communication. Begin by finding ways to increase the number and variety of communication partners within the classroom and school environment. Create ways for all the professionals, paraprofessionals and peers of the deaf-blind learner to know his/her communication

system and how it is used effectively. Provide opportunities for the deaf-blind learner's communication system to be taught to those who need to use it.

For those who are already fit the role of a communication partner, there are a variety of ways to increase meaningful communication interactions. The easiest, and often most fun way is to be silly or absurd. Imitate the student,s behavior, or vocalizations and turn this into a playful game that will strengthen both communication and turn taking skills. Create communication by wearing something that is out of character like a funny scarf or hat. Use silly songs, voices or dancing. Allow time to interact with the learner in non-structured, playful, and casual ways. Taking these types of risks with the learner will provide interactions that create new and engaging opportunities to communicate. They will also will strengthen and create more personal relationships. Create a one page laminated sheet with all of the basics of the student,s communication system. Place it in their backpack or wheelchair bag so those who meet the deaf-blind learner for the first time will know the best way to communicate. During a snack time or lunch time routine, accidentally "forget" to provide the student with food, but give it to all the other students. See how they respond to the unfair situation.

Time

Finally, a communication rich environment needs to consider time. Deaf-blind learners need to feel safe and secure in their environment. Understanding time and schedules leads to greater anticipation and emotional security. Time can provide the structure in which the deaf-blind learner feels comfortable enough to receive and express communication. Within the classroom, time is always of the essence. To establish a rich communication environment by using time, the deaf-blind learner must have a schedule or calendar that they use to understand their day. Anticipation of classroom activities not only leads to emotional security and understanding, but also to increased opportunities to communicate. Try scheduling the school day in a way that provides the learner has enough time to explore and use their calendar system, especially around transition times. Throughout the school day be aware of the pacing of the activities and the amount of time given to receive, process and express information. Be

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Fact Sheet

How to Create a Communication Dictionary

It is common for teachers as well as other education and service providers to meet an individual with deaf-blindness and/or multiple disabilities for the first time, and not know how to communicate with that individual. They don't know the individual's means of communication. A communication dictionary can address this communication issue. A *communication dictionary* is a detailed "guide" to communicating with an individual who is deaf-blind.

Individuals who are deaf-blind often use a variety of means (or forms) of communication. These forms reflect the communication needs and abilities of the individuals. These forms often do not match the standard means of communication used by the larger society. Examples of some of the forms of communication used by individuals who are deaf-blind include: gestures, vocalizations, touch and object cues, photos and line drawings, and adapted signs/spoken words.

The team of family members and professionals supporting an individual who is deaf-blind should consider designing a multi-faceted communication system for the individual. This system should be based upon a communication assessment of the individual which includes: the individual's preferences and needs; the individual's already established forms of communication; the individual's motor and cognitive abilities; and environmental conditions such as communication partners, resources, and culture. This team effort often involves a lot of planning, trial and error, and on-going re-assessment.

It is highly recommended that the communication system of an individual who is deaf-blind be documented in some kind of easy to use "dictionary"—particularly if the individual's communication system utilizes more than one means or form of communication. This dictionary will enable people working with the individual with deaf-blindness—right from the start—to communicate more easily and effectively with this individual.

Besides the individual's name and basic information regarding the individual's vision, hearing, support needs, etc., a communication dictionary should include any or all of the following, as appropriate:

- A written introduction on how to use the dictionary.
- A list of tangible symbols (e.g., photos/line drawings, object cues, etc.) and their meanings.
- A list of touch cues used and their meanings.
- A list of the individual's various communicative behaviors, their meanings, and the appropriate responses to be made by people supporting the individual with deaf-blindness.
- A list of all signs used. For further clarification, a line drawing of each sign should be included. If no line drawing exists, then a description of how the sign is made should be provided. In addition, it should be stated if tactile signing should be used.

Fact sheets from California Deaf-Blind Services are to be used by both families and professionals serving individuals with dual sensory impairments. The information applies to students 0–22 years of age. The purpose of the fact sheet is to give general information on a specific topic. More specific information for an individual student can be provided through individualized technical assistance available from CDBS. The fact sheet is a starting point for further information.

Hoja de Datos

Cómo crear un diccionario de comunicación

Es común para los maestros al igual que para otros proveedores de servicios y educación, conocer por primera vez a un individuo con sordo-ceguera y/o discapacidad múltiple y no saber cómo comunicarse con ese individuo. Ellos no saben de que forma se comunica este individuo. Un diccionario de comunicación puede ayudar a superar este problema. Un *diccionario de comunicación* es una detallada “guía” de comunicación con individuos que padecen sordo ceguera.

Los individuos con sordo-ceguera muchas veces usan una variedad de maneras o formas de comunicación. Estas formas o maneras reflejan las necesidades y habilidades de los individuos. Estas formas o maneras de comunicación, muchas veces no concuerdan con el sistema de comunicación, usado por la sociedad mayoritaria. Algunos ejemplos de las formas o maneras de comunicación de un individuo con sordo-ceguera son: gestos, vocalización, indicaciones táctiles y con objetos, fotos, dibujos, señales adaptadas y palabras.

El equipo de apoyo para el individuo con sordo-ceguera, integrado por familiares y profesionales, debería considerar el diseñar un sistema de comunicación multi-facético para el individuo. Dicho sistema debe basarse en una evaluación de la comunicación del individuo, el cual incluya: las preferencias y necesidades del individuo; las formas o maneras de comunicación del individuo; las habilidades motoras y cognitivas del mismo; condiciones ambientales como compañeros de comunicación, recursos y cultura. Este duro esfuerzo del equipo implementa planear, tratar y errar, y hacer continuas re-evaluaciones.

Es altamente recomendado que este sistema de comunicación (diccionario) de un sordo-ciego, sea documentado en una forma fácil de usar y entender, particularmente si este sistema de comunicación utiliza más de una forma o manera de comunicación. Este diccionario hara posible a la gente, a utilizar la forma correcta de empezar a trabajar y comunicarse más facil y efectivamente con el individuo.

Además del nombre del individuo y la información básica sobre la visión, audición, necesidades de apoyo, etc., un diccionario de comunicación debe de incluir una o todas de las siguientes sugerencias, según sea la apropiada.

- Una introducción escrita de como usar el diccionario.
- Una lista de símbolos tangibles (fotos, dibujos, objetos, etc.) y su significado.
- Una lista de señas táctiles y su significado.
- Una lista de los comportamientos que el individuo usa como formas de comunicación y su significado, y las respuestas apropiadas que el personal de apoyo del individuo con sordo-ceguera debería de emplear.
- Una lista de todas las señas que el individuo usa.
- Para mejor aclaración debería incluirse un dibujo de cada seña, si no existe ningun dibujo, entonces debe proveerse una clara explicación de la seña. Aún más se debe especificar si señas táctiles deben ser usadas.

Las hojas de datos de Servicios Para Sordos & Ciegos de California son para ser usadas por ambos familias y profesionales que ayudan a individuos que tienen does sentidos incapacitados. La información aplica a estudiantes 0-22 años de edad. El propósito de la hoja de datos es para dar información general sobre un tema específico. La información más específica para un estudiante individual puede proveerse mediante la asistencia técnica individualizada disponible desde CDBS. La hoja de datos es un punto para comenzar una información adicional.

sensitive to the amount of wait time the deaf-blind learner may need and inform others who interact with the student of this wait time.

After an understanding of time is established, use it to create a need to communicate. Delaying or removing prompts that are used consistently is one way to create opportunities for spontaneous communication. If a deaf-blind learner understands that her favorite activity is next and needs you to take her there, delay and make her request. Give her the opportunity to ask for what she wants so that she can realize that her voice has power in his/her life. If you always begin circle time with a greeting or prompt, accidentally "forget" these cues and see how the students respond. See if they will correct your mistakes.

Deaf-blind learners have the right to rich communication environments. One can achieve this by first establishing security through structure of their environment and then adapting the structure in small but creative ways that encourage and motivate the learner to communicate. Through this process, dynamic, interesting and enjoyable environments can be created and maintained.

California Deaf-Blind Services Announces New Staff and Offices!

New Staff

CDBS is pleased to announce the arrival of one new Family Specialist and two new Educational Specialists to the project's staff.

Myrna Medina joins our staff as a Family Specialist and works from her home office in the city of Monterey Park (Los Angeles County). For the past nine years, Myrna's professional life has been as a legal secretary and administrative assistant with a Los Angeles law firm. With the birth of her son Norman (now 4 years old) who is deaf-blind, she became involved in numerous activities related to deaf-blindness, including Project PLAI at California State University Northridge. Myrna and her husband Juan also have a daughter, Deloris, who is 6 years old and loves being a big sister to Norman. Myrna, who is English/Spanish bilingual, has been a wonderful asset to CDBS in its effort to more effectively serve Spanish speaking families and their children's programs. Her personal interests (when she has the time!) include roller coasters, music, and TV.

Jackie Kenley, who has served for over four years as a CDBS Project Assistant, has moved into a Family Specialist position. Jackie is the mother of three children, one of whom is Laura who is 15 years old and has CHARGE Association. Jackie has been involved with CDBS for years, and served on the CDBS Advisory Committee for many years prior to joining the project. Jackie has also been a long time member of the California Low Incidence Disabilities Advisory Committee (LIDAC). She brings to CDBS a wealth of experience with navigating school systems and the regional center system. She has participated in and/or organized many of the national and statewide CHARGE events, and also serves as Treasurer of the Coalition of Parents & Educators – Deaf-Blind (COPE-DB). When Jackie isn't working, she enjoys family, music, church, and friends.

Educational Specialist **Larry Rhodes** joins our staff having served most recently as a consultant with the Missouri Deafblind Technical Assistance Project

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Title/Affiliation

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(CDBS's counterpart in that state). Larry has been involved in a number of CDBS activities over the past ten years, including statewide training of the INSITE model, and as a consultant with the 1992-95 CDBS TEAM Pilot Project (Transdisciplinary Educational Assessment Model). He holds a graduate degree in vision rehabilitation from the Pennsylvania School of Optometry, and is a contributing author of the VIISA and "Intervener" manuals published by the SKI*HI Institute. His personal interests include fine wines and traveling the IGRA rodeo circuit.

Educational Specialist **David Brown** has made a trans-oceanic journey to join our staff. For the past 17 years, David has been with Sense, the National Deafblind and Rubella Association of the United Kingdom. His most recent assignment was Head Teacher for the Sense Family Centre in West London. David was a member of the first graduating class from the University of Birmingham's deaf-blind program, which was England's first college training program in the education of children who are deaf-blind. David enjoys an outstanding international reputation for his work with children and families, and has been a frequent guest speaker and lecturer in the U.S. and around the world. He recently shared a keynote address with Prof. Jan van Dijk at the first ever Deafblind International Asia Conference held in 2000. David's personal interests include opera, exercise, and single malts.

New Offices

In May, CDBS moved into our new office. We are now sharing space with the Blind Babies Foundation "Off to a Good Start Program". For residents of the San Francisco Bay Area, the office is very centrally located, which will more easily facilitate the use of the extensive CDBS lending library which is now housed with the lending library of the Blind Babies Foundation. (Of course, the lending library continues to be available by mail to clients throughout the state). The office is located within walking distance of a BART and city subway station, and there are a number of city buses that stop within steps of our front door. We are thrilled with our joint venture with Blind Babies Foundation, and look forward to many years of effective and comprehensive collaboration on many of the project's activities.

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Our team is here to serve families and professionals of individuals who are deaf-blind, birth through age 21. Please get in touch if you have questions or feel that we could be of any assistance!

How to access our services

(800) 822-7884 Voice/TTY

Jackie Kenley, Family Specialist, ext. 21

Myrna Medina, Family Specialist, ext. 25

Gloria Rodriguez-Gil, Educational Specialist, ext. 26

Larry Rhodes, Educational Specialist, ext. 24

David Brown, Educational Specialist, ext. 22

Maurice Belote, Project Coordinator, ext. 23

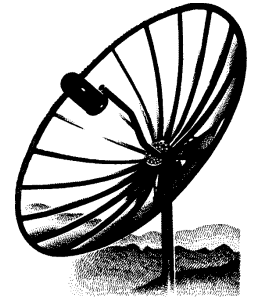


California Deaf-Blind Services Presents An Interactive Satellite Training

Identification of Hearing & Vision Problems: A Comprehensive Overview

Thursday, November 30, 2000 • 3:30 – 6:30 p.m. Pacific time

broadcast from San Francisco State University



Target Audience: Teachers, administrators, D.I.S. personnel, early interventionists, school nurses, psychologists, Regional Center employees, paraprofessionals, family members, care providers, university students/personnel, medical personnel, and others.

Training Content: Impact of a dual sensory loss; types of hearing and vision impairments; overview of clinical and functional assessments, and family involvement in the assessment process; risk factors and risk indicators associated with sensory loss; behaviors that might indicate a sensory loss; the educational and social benefits of having current and accurate information on hearing and/or vision; functional definitions of deaf-blindness; an explanation of the California Census of Children who are Deaf-Blind, and the benefit of including all children who are deaf-blind on the census.

Presenters:

Janna Smith Lang, Ph.D. is an audiologist who specializes in the diagnosis and management of hearing loss in infants and children. She is currently developing the newborn hearing screening, diagnosis, and intervention program at Santa Clara Valley Medical Center in San Jose, California.

Joan Houghton is the Project Director of the Kansas Project for Children and Young Adults who are Deaf-Blind, and prior to that was with the Helen Keller National Center Technical Assistance Project. She is a certified orientation and mobility instructor, and has many years of experience serving children who are deaf-blind.

David Brown is an Educational Specialist with CDBS. Prior to his arrival in the US, he served for 17 years as an educational specialist with SENSE—the National Deaf-Blind Association of the United Kingdom. He is a frequent guest speaker at national and international conferences related to deaf-blindness.

This is an interactive training. Viewers will have the opportunity to phone in questions to the presenters during the telecast. Participants in the San Francisco area are encouraged to join the studio audience at SFSU. The broadcast will be real-time captioned.

Please contact Maurice Belote at CDBS if you need assistance in locating a downlink site in California. You are welcome to downlink and tape the broadcast, and copy the tape for wider dissemination. CDBS will also have tapes of the telecast available. Please e-mail requests for tapes to cadbs@sfsu.edu and include the delivery address and phone number.

Please copy and distribute this flier to all interested individuals. To register for the training, complete the form below and mail/fax/e-mail to CDBS. In-state and out-of-state registration is free, **but registration is required to receive downlink technical information. Registrations must be received by November 16, 2000.**

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