

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

by Maurice Belote, CDBS Project Coordinator

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

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

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

Create the best communication system possible while the individual who is deaf-blind is still receiving special education services

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

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

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

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

Document the individual's communication system

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

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

If an individual's system includes objects, the exact objects will need to be documented so that if objects are lost in transition from one program to another, replacement objects can be gathered quickly.

Documentation of objects will need to include either photographs or very clear drawings of each object so that someone unfamiliar with the system will have a clear idea of each object.

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

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

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

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

communication system often becomes more complex and more complicated to use.

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

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

Develop a communication system that meet everyone's needs

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

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

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

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

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

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

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

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

- Teaching a student to give a physical location to the sign for “hurt” in order to differentiate between ailments may help that person not have to sit through a day of work when he or she has a terrible headache.
- Teaching calendar skills may allow an individual to make sense of the activities over the course of a day or week, and lessen or eliminate the frustration and anger that can develop when life is a constant surprise.
- Teaching reading may save the individual the embarrassment (and danger) of walking into the wrong restroom in public places.
- Teaching an individual to make and use experience books may give that individual the opportunity to experience the joy of reliving special occasions in a way that would otherwise be nearly impossible.
- Teaching the use of a sequence board may help an individual follow a complex job routine that would

otherwise require a full-time job coach using invasive physical prompts.

- Documenting a communication system may help ensure that new service providers understand adapted signs or systems that an individual who is deaf-blind has used—successfully—for years, such as a unique sign for bathroom or a symbol/word card that means “If someone doesn’t help me soon I’m going to lose it!”
- Considering peers when designing systems may allow the individual who is deaf-blind to make a new friend at a party or gathering by discovering a common interest or life experience.

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

Have you checked out...

www.projectsalute.net

Project SALUTE— Successful Adaptations for Learning to Use Touch Effectively—addresses the unique learning needs of children who are deaf-blind, who have severe visual impairments, and require a primarily tactile mode of learning. Project SALUTE is based at California State University Northridge and is directed by Dr. Deborah Chen and Dr. June Downing. The Project SALUTE website is a tremendously valuable resource for families and for educators serving children who are deaf-blind. The website includes articles, a bibliography, links to other sites, and information sheets on a number of topics, including:

Tactile Strategies

Tactile Communication Strategies
Mutual Tactile Attention
Tactile Modeling

Cues

Object Cues
Touch Cues

Symbols

Tangible Symbols
Textured Symbols

Signs

Coactive Signing
Sign On Body
Tactile Signing

Working with Spanish-speaking families

Working with Spanish-English Interpreters
and Translators

Working with Spanish-speaking Families
of Children who are Deaf-Blind



Fact Sheet

Strategies for Using Voice Output Communication Devices With Children who are Deaf-Blind

by Maurice Belote, CDBS Project Coordinator

What is a voice output device?

A voice output device is an electronic device that “speaks” for a child. When activated by the push of a button or using an adapted system, the child can expressively communicate one or more messages. The messages are recorded specifically for that child, so that they are relevant to the child’s needs and environment. These devices are typically commercially produced by manufacturers in the field of augmentative communication systems. Voice output devices have been used successfully by many individuals with combined vision and hearing problems, and there are instances where the use of a voice output device has provided a child or young adult with their first true success at expressive communication using a formal system. The device becomes an important component of the child’s expressive communication system, along with other possible expressive modes such as speech, objects, signed communication, pictures, gestures, etc. The touch pads on these devices can have printed words, line drawings, photographs, textures, objects, or any combination of these to represent the contents of each recording.

What are some strategies to consider when using voice output devices?

The following are some strategies that may be helpful when using voice output devices. Throughout these strategies, the term “user” will be used to refer to the individual who uses the voice output device.

1. Give careful consideration when choosing the person who records the messages. When possible, choose someone of the same sex and near the same age of the user. For users who are hard of hearing and young, however, don’t choose a child who is so young and has a voice so soft that it will be difficult for the user to hear it.
2. Make certain that the person who records the voice isn’t someone known to the child. It can only truly be the user’s voice if the recorded voice is a neutral party. It isn’t likely that most users want parents, siblings, or teachers to be their voice, except in occasional situations when no one else is available and a message is needed on the spot.
3. Pay close attention to any slang or vernacular used in the age group of the child, the use of which will give warmth and personality to the child’s communication.
4. It is extremely important that the device never “speaks” if the user isn’t the one who has pushed a button to make it speak. It is very confusing to a user to hear his or her voice output device say something that he or she

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.

didn't intend. For example, imagine a child sitting in his classroom and then hearing his voice output device from across the room say "I'm thirsty; I want some juice please". The child's reaction may be to think, "Wait, I never said I want juice—I'm happily involved in an activity right now!" If a service provider or family member needs to test the device, check its power, etc., the device should briefly be taken somewhere where the user won't hear the voice activated by others.

5. The user must have access to the device at all times. Opportunities for communication occur throughout the entire day. For some users, having a voice output device might provide them with their first real success at formal expressive communication and, while temporarily relishing the newfound power and control over their environment, they may activate a message over and over. In these instances, we might be tempted to put the voice output device on a shelf out of reach of the user, but we can't do this. Taking a user's voice output device away because it is annoying to us would be like taping a verbal child's mouth closed because the child says the same thing over and over throughout the day; instead, think of these situations as great teachable moments to reinforce the use of schedule/calendar systems, and explain to the user that while it may not be the appropriate time to do whatever it is the user wants, there may be an opportunity later in the user's schedule.
6. Children are naturally curious, and the classmates and/or siblings of the child with the device will probably want to touch, play with, and explore the device when it is first introduced to the classroom and/or home. In fact, there are some children who simply will not think about anything else until they have had a chance to touch the device. To satisfy their curiosity, give these children an opportunity to play with the device, perhaps during a morning circle activity or for a half-day in small groups. Make sure that the user is either a direct part of this or out of hearing and vision range to know its happening. After this activity, the other children can be told that they have had their opportunity, and they are never again allowed to push a button to make the device speak. Of course, if they're assisting the user to use the device effectively, that is another matter—we want to encourage natural peer supports whenever possible.
7. It will be necessary to teach the user how to use the device, but this instruction must be conducted in the context of naturally occurring, meaningful activities. It will be confusing to the user if he or she is expected to participate in drill activities in which the device is used purely for instruction.
8. When choosing the phrases/messages that will be included on the device, try to consider meeting everyone's needs, including the users. For instance, if a device only has nine possible phrases, it may be tempting to fill all nine with phrases that make life easier for caregivers and service providers, such as "I need to use the restroom". If the user has a particular interest, e.g., a favorite pet, a hobby, a collection, family members, a favorite place or activity, consider including a message or messages about these interests. Similarly, think about the user's age, and what other children at that same age are interested in. Be sure to include some of these interests on the device as well. This will give the user something to use as an icebreaker or conversation starter with peers.
9. For users who do not have enough residual hearing to hear what the device says, the team may want to adapt the device with a signal (light or vibrator) that lets the user know the device has "spoken" effectively. For example, it would be frustrating and counter-productive for a user to think their device has "spoken" when in fact the device's battery is dead. In this case, the user would be waiting for a response from their communication partner, and be confused by this lack of response.

Hoja de Datos

Estrategias de Cómo Usar un Aparato de Emisión de Voz Con Niños Sordo-Ciegos

por Mautice Belote, CDBS Coordinador del Proyecto

Qué es un aparato de emisión de voz?

Un emisor de voz, es un aparato electrónico que habla por el niño. Al activarse al oprimir un botón o al usar un sistema adaptado, el niño puede comunicar expresivamente uno o más mensajes. Los mensajes son grabados específicamente para determinado niño, para que éstos sean relevantes a las necesidades y ambiente del niño. Éstos aparatos son típicamente producidos comercialmente por manufacturas en el área de sistemas de comunicación aumentativa. Aparatos de emisión de voz, han sido usados exitosamente por muchos individuos con una combinación de problemas, de visión y audición, y han habido ocasiones donde el uso de un emisor de voz le ha proveído a un niño o un joven su primer éxito de comunicación expresiva usando un sistema formal. Éste aparato llega a ser un componente importante del sistema de comunicación expresivo del niño, al igual que otro modo expresivo como, habla, objetos, comunicación con señas, fotografías, gestos, etc. Él cojín para tocar estos aparatos pueden tener palabras impresas, dibujos, fotografías, texturas, objetos, ó alguna combinación de estos, que representen el contenido de cada grabación.

Cuales son algunas estrategias para considerar cuando se usa un aparato de emisión de voz?

A continuación son algunas estrategias que pudieran ser de ayuda cuando se usa un aparato de emisión de voz. A través de éstas estrategias, el término “usuario” se usará para referirse a los individuos que usan éstos aparatos.

1. Considerar cuidadosamente al escoger la persona quién grabará los mensajes. Cuando sea posible, escoger a alguien de el mismo sexo y aproximadamente de la misma edad de él usuario. De alguna manera, para los usuarios que son jóvenes y duros de oído, no escojan un niño pequeño que tenga la voz muy suave, ya que esto será muy difícil para que los usuarios lo escuchen.
2. Hay que asegurarse que la persona que grabe los mensajes, no sea alguien conocido para el niño. Ésto no sería verdaderamente la voz, si la voz grabada no es de una persona neutral. Ésto no es cómo si los niños quisieran que sus padres, hermanos o maestros fueran su voz, excepto solo en situaciones cuando no hay nadie disponible y un mensaje se necesita en ese preciso momento.
3. Ponga mucha atención al vocabulario usado en el grupo de la misma edad del niño, éste dará un toque cortez y de personalidad a la comunicación del niño.

Las hojas de datos de Servicios Para Sordos-Ciegos de California son para ser usadas por ambas familias y profesionales que ayudan a individuos que tienen dos 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.

4. Es extremadamente importante que él aparato nunca hable, si él no ha sido la persona que oprimió el botón para hacerlo hablar. Es muy confuso para el usuario oír su aparato de emisión de voz decir algo que ellos no quieren decir. Por ejemplo, Imagínese a un niño sentado en su salón escuchando su emisor de voz el cual está en otro salón diciendo “tengo sed, quiero jugo por favor” La reacción del niño sería pensar, “esperen yo nunca dije que quería jugo, yo estoy feliz en esta actividad ahora.” Si un proveedor de servicios o un miembro de la familia necesita probar el aparato, probar la luz, etc., el aparato deberá ser llevado por un momento a algún lugar donde él usuario no escuche la voz activada por otros.
5. El usuario debe tener acceso al aparato a toda hora. Oportunidades para comunicarse ocurren todo el día. Para algunos usuarios tener un aparato con emisión de voz podría proporcionarles su primer éxito real de comunicación expresiva, y mientras ellos temporalmente están disfrutando lo que es nuevo y tienen poder y control sobre su ambiente, ellos podrían activar su mensaje una y otra vez. En estas circunstancias, nosotros podríamos estar tentados a poner el aparato con emisión de voz en un estante fuera de el alcance del usuario, pero nosotros no deseamos hacer esto. Coger el aparato con emisión de voz y esconderlo porque nos molesta, sería como tapan la boca de un niño con cinta adhesiva porque el niño dice lo mismo una y otra vez durante todo el día; en lugar, pensemos en estas situaciones como grandes momentos para enseñar a re-enforzar el uso de el sistema calendario/horario, y explicarle al usuario, que mientras éste no sea el momento apropiado para hacer lo que quiera, pudiera haber una oportunidad mas adelante en su horario.
6. Los niños son usualmente curiosos, y los compañeros o familiares del niño con el aparato, querrán oprimir, jugar y explorar el aparato cuando éste se muestre por primera vez en la clase o la casa. De hecho, hay niños que simplemente no piensan en otra cosa hasta que hallan tenido la oportunidad de tocar el aparato. Para satisfacer su curiosidad, demosle a estos niños la oportunidad de jugar con el aparato, esto pudiera ser durante la actividad del círculo de la mañana o del medio día en grupos pequeños. Asegúrese que él usuario sea parte directa de esto o esté fuera de alcance visual y auditivo, para que no se de cuenta de lo que está pasando. Después de esta actividad se les puede decir a los otros niños que ya han tenido la oportunidad de usarlo y que no volverán a tener otra oportunidad de oprimir algún botón y hacer que hable el aparato. Por su puesto, si se le está asistiendo al usuario para que use el aparato efectivamente, éste ya es otro asunto, nosotros animamos el apoyo natural de compañeros cuando sea posible.
7. Será necesario enseñar a el usuario a usar el aparato, pero estas instrucciones serán conducidas en un contexto de actividades con significado cuando éstas ocurren naturalmente. Esto será confuso para el usuario. Se espera que él o ella participen en actividades repetitivas si el aparato es usado solo para instrucciones.
8. Cuando se escogen las frases/mensajes que se incluyan en el aparato, trate de considerar el satisfacer las necesidades de todos, incluyendo las de él usuario. Por ejemplo, si el aparato solamente tiene capacidad para nueve frases, esto será tentador para llenar las nueve con frases que faciliten la vida de los proveedores de cuidado y proveedores de servicio, tal como: “Necesito ir al baño”. Si él usuario tiene particular interés, por ejemplo: una mascota preferida, un pasatiempo, una colección un miembro de la familia, un lugar o actividad favorita, consideren incluir un mensaje o mensajes sobre éstos intereses. Similarmene, piense en la edad de él usuario, y en que se interesan otros niños de su misma edad. Asegúrese de también incluir alguno de estos intereses en el aparato. Esto servirá para que él usuario lo use para romper el hielo, y empezar una conversación con otros compañeros.
9. Para usuarios que no tengan residuos de audición para poder oír lo que dice el aparato, el equipo querrá adaptar el aparato con una señal (luz o vibrador) para que así el usuario sepa que el aparato acabó de “hablar” efectivamente. Por ejemplo, esto será frustrante y no productivo si él usuario estaría esperando una respuesta de su compañero en comunicación, y confundido por la falta de ella.

California Coming Together

Sponsored by California Deaf-Blind Services and NEEDS Outreach – San Diego



Dr. Jan van Dijk

The 2002 California Conference on Deaf-Blindness—California Coming Together—was held on May 16-18, 2002 in San Diego, and by all accounts was a huge success and a tremendously valuable experience for the 167 registrants who attended. The conference provided an opportunity for participants to delve deeply into issues concerning deaf-blindness, with workshops offered in three concurrent strands: infant/preschool, school age, and transition. The conference featured fifteen workshops, three keynote presentations, a family panel, a poolside reception, and plenty of time for meeting colleagues and sharing strategies.

Participant evaluation comments

What I found most useful was...

“So many people with knowledge of deaf-blindness. All the different speakers sharing their individual knowledge. The three strands allowed me to focus on what I needed to hear most.”

“Hearing topics focused specifically on dual sensory impaired. Not getting basic information, but more advanced topics.”

“The parents’ attendance and participation in the workshops.”

“The common thread of family perspectives was so impressive and meaningful.”

“Dr. van Dijk... the need to have fine detailed observation and how key that is makes me think about the kids I see and how much work I need to do to implement it.”

“It was very real and spoke from the heart.”

A special thank you...

to all the presenters, keynote speakers and family panel members who helped to make the conference a tremendous success: Judy Anderson, Teresa Beccera, Maurice Belote, Dr. Susan Brotherton, David Brown, Dr. Deborah Chen, Nancy Cornelius, Nancy Deutsch, Dr. June Downing, Wendy Keedy, Jackie Kenley, Kim Lauger, Bob McQuaid, Myrna Medina, Larry Rhodes, Cindi Robinson, Gloria Rodriguez-Gil, Stacey Rogers, Joan Schmidt, Sandy Staples, Kat Stremel, Sandra Suitor, Dr. Jan van Dijk, Dr. John Vaughn, and Shelley Barron for outstanding conference coordination.



Amy Cornelius (left) and Kendra Keedy

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