

Strategies for Creating Communication-Rich Environments for Children who are Deaf-Blind

by Maurice Belote, CDBS Project Coordinator

Core Beliefs

Everyone communicates. Children who are deaf-blind are communicating all the time. Some children communicate in very obvious ways: speech, signed communication, sign language, pictures and drawings, voice output boards, etc. Other children may communicate in more subtle ways: moving you to an object, standing near a desired object, eye gaze, withdrawal, change in muscle tone, self-injurious behaviors, etc. In many cases, the challenge to service providers and family members is to give the child a more socially appropriate way to communicate. The new system, however, must work as well for the child as the way she or he has communicated in the past or the child will have little motivation to use the new system.

Everyone has the right to a formal communication system. A communication system is formalized when it is documented so that it follows the child who is deaf-blind from program to program. The system must be accessible to the child at all times, so it must be portable, and it must be appropriate to the child's wants and needs. A communication system isn't something that happens when the right person is hired, adequate funding is secured, or the next IEP is convened. Once a child's team has developed the system, some parts of the new system can probably be implemented almost immediately.

True communication is dependent on trust. Many children who are deaf-blind live in a world of surprise, contradiction, and confusion. One of the ways that service providers and family members can help a child to organize her or his world is to establish a relationship built on and respectful of trust, and to be mindful of the need for relationship repair if the trust is at risk.

Key Points

Does the child have a way to communicate about the abstract, e.g., the past, the future, people who are not present, etc.? An important benefit of a well-designed communication system is that it allows the child to share past experiences, future plans, and his or her feelings. Non-symbolic forms of communication do not typically allow for this; they are effective mainly for communicating about the present, such as immediate wants and needs.

Does the child have opportunities to be a passive observer of other people communicating using the same system that the child uses? Children with sensory impairments may not realize that those around them are also effectively communicating, and communication is not always directed to/from the child. The child might not only find amazement in this discovery, but it may be an important component to her or his learning.

Fact sheets from California Deaf-Blind Services are to be used by both families and professionals serving individuals who are deaf-blind. 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.

Has the child experienced success and found joy in the ability to be clearly understood by others? Communicating effectively should be a wonderful experience and should not be stressful, at least at the start. Think about the way you communicate under stress: a job interview, an awkward social situation, a foreign language in which you are just marginally proficient. Choose a system that doesn't require too much learning—at the beginning—in order to be successful. As much as you can, build in success.

Does the child have access to the communication system at all times? A communication system must be accessible in each of a child's environments—home, school, transit, workplace, recreation sites, etc. The system, or at least a component of the system, must therefore be portable. A point to remember about access: the child might communicate something over and over as she or he relishes this newfound power of communication. During this time, access to the system cannot be denied simply because the system is annoying. Validate the communication even when you can't honor the specific request.

Does the communication system meet everyone's needs? A well-rounded system must not only include what adults would like the child to communicate about. It must also allow the child to talk about his or her interests—no matter how repetitive or peculiar the topics may be. The system must also take into account what others of the same age are interested in communicating about, so that the child who is deaf-blind is seen as an interesting potential communication partner to non-disabled peers.

Is the child's communication system documented? The system can be documented with videotape, written descriptions such as a personal communication dictionary, or a combination of these and other methods. Without documentation, some children are forced to learn new ways of communicating every time they transition to a new school, agency, foster home, etc. There may be someone on the child's educational team who is uniquely suited to maintain this documentation, such as a speech and language specialist who doesn't feel qualified to provide direct instruction to the child. There is probably an important role for any service provider who is written into the child's educational plan.

Is the child given opportunities to make choices throughout the day? There are many ways to build in choice making, even in structured situations. In school, if the child is required to complete a number of tasks, is it possible to allow the child to choose the order of these tasks? At home, is it possible to allow the child choice in clothing, food, meal times, etc.? To help with this process, try making a mental list of all the choices you make from the time you get out of bed in the morning. You may be surprised to discover how significantly your day might be affected if opportunities to make simple choices were taken away, e.g., having to wear an uncomfortable pair of socks all day, or being forced to drink too much at breakfast knowing that a bathroom will not be available during a long commute to work.

Have you given yourself credit for your interest in this subject? Never underestimate the value of helping someone learn to communicate clearly. It may be the most important gift you can give, and will improve a person's quality of life immeasurably.

Further Reading

Remarkable Conversations: A Guide to Developing Meaningful Communication with Children and Young Adults who are Deafblind, edited by Barbara Miles and Marianne Riggio. Published in 1999 by Perkins School for the Blind, Watertown, Massachusetts. 308 pages.