



In His Own Words: Deaf Blindness & Assistive Technology

IN THIS ISSUE...

Nationwide, their numbers are relatively small: 70,000 individuals nationwide are deaf-blind, including approximately 10,000 children ages birth-21. Yet although children with deaf-blindness comprise but a small slice of the disability population their impact belies their numbers: 73% of children with deaf-blindness also have multiple severe disabilities, including cerebral palsy, epilepsy, various orthopedic problems and muscular disabilities. Their condition limits their ability to communicate mainly to their fingertips, through which they can read sign language and Braille. Increasingly, however, assistive technology offers children with multiple disabilities means through which they can connect with the world around them. This issue examines the affect of AT on children with deaf-blindness and resources available to understand, acquire and use it.

Jeff Cook Speaks

His hearing loss was detected at age five. He was eventually diagnosed with Usher's Syndrome type 2, a hereditary degenerative condition that results in moderate to severe hearing impairment and eventual blindness. By age 32, his hearing loss finally became life changing. Jeff Cook's vision did not fail him until age 42.

"I was a Baptist minister in Idaho with a 32-decibel sensor neural hearing loss. Within six months I had dropped to 132 decibels, the lowest end of the audiometer test, the lowest level anyone can be tested for. With my hearing aid on full power and the volume control on the phone turned up to the max, I was lucky if I could hear a dial tone. The church became very concerned because I was no longer able to use the phone. I was fired."

Undeterred by his worsening disability, Mr. Cook and his wife, Lavonna, who now interprets for him, returned to their Kansas City birthplace. There he met a woman who was a retired teacher of sign language to deaf students and learned to sign. He parlayed that new advantage into admission to Gallaudet University in Washington, DC where, in 1993, he earned a Masters degree in developmental psychology. A year later he was the school psychologist at the Kansas School for the Deaf in Olathe, KS.

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Deaf Blindness & Assistive Technology

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Jeff Cook -

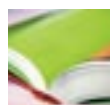
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By then, however, his sight was failing too. "I had already driven my car into a ditch. Then I landed in the emergency room four times in a year as a result of serious cuts I suffered doing Ozark woodcarving, a cherished hobby of mine." His wife insisted he visit an ophthalmologist.

"I had a vision field test, where you stare at a central point and press a button when you see lights flash on the periphery. I sat there waiting for the test to start. I didn't see any flashing lights. I asked the attendant, 'When are you going to start this test?' but the test was over" He was then given an electroretinogram (ERG) at Kansas City's Children's Mercy Hospital. "I was 42 years old, the youngest 'kid' there." Again, he was asked to identify flashing lights, but again he saw none. "I was the first person ever to fall asleep during that test." The next day, the ophthalmologist who had sent him for the test called him. "She came in on her day off to make the call," he remembers, "because she knew she was bringing a deaf person the news he dreaded most: I was going blind."



The final straw, he says, occurred when he was driving to Kansas School for the Deaf the week before classes began in September. "The sun was coming up as I neared the school. For people with Usher's Syndrome, sunlight makes everything seemed washed out, like a white screen. The white screen descended right then and it scared me to death. When I was very young, a five-year-old neighbor was hit by a car. I had visions of the same thing happening, with me as the driver." He pulled his car to a stop, blinded. "I crawled across a four-lane highway on my hands and knees in rush hour traffic and reached a convenience store. I asked the manager to call my wife. She came and took away my keys. I never drove again."

Still, he had some sight remaining in his right eye. "The world I see is one you would see if you hollowed out a ballpoint pen and looked through it. So, in the world of the deaf-blind, I'm one of the fortunate ones."

Supporting our interview with Mr. Cook are resources to assist parents of deaf-blind children, as well as children with multiple severe disabilities, in better understanding the benefits of AT. We also feature members of our Knowledge Network. The members spotlighted this month focus on AT's impact on deaf-blindness and companion multiple disabilities. We invite you to contact these members for further information.

Please share this newsletter with other organizations, families and professionals who may benefit from it. We invite you to contact us at <http://www.fctd.info>. We welcome feedback, new members and all who contribute to our growing knowledge base.



"ONE CANNOT CONSENT TO CREEP WHEN ONE HAS AN IMPULSE TO SOAR." - Helen Keller

In His Own Words: Deaf-Blindness & Assistive Technology

*An Interview with Jeff Cook,
Director, Kansas Deaf-Blind Project*



A Baptist minister as an adult, until that career was halted by encroaching deafness, and an academic and school psychologist until impending blindness nudged him toward his life's calling, Jeff Cook is director of the Kansas

Deaf-Blind Project in which he seeks out deaf-blind children throughout his state in order to provide them with the help they need, including access to assistive technology. Much of his focus is devoted to locating deaf-blind children in remote rural regions of Kansas. The FCTD Newsletter interviewed Mr. Cook by phone through a certified interpreter, Marsha Lorenzo, who translated an interviewer's prepared questions for Mr. Cook by voice and through tactile sign language. Mr. Cook then responded in the authoritative voice of the educator and minister he once was. Honoring that process, our lead article this month appears in the original question-and-answer format.

Tell us what "Deaf-Blindness" means.

Deaf-blindness is the combination of both vision and hearing loss so severe that an individual can't be educated in a classroom or other setting that would be dependent on either or both senses. You would need services that impact both senses, which would affect that individual's education to such as a degree that it would adversely impact one's abilities to be educated in a classroom for either the vision or hearing impaired.

Do deaf-blind children usually have other disabilities?

In Kansas, 73% of deaf-blind children have other severe disabilities, including cerebral palsy, epilepsy, various orthopedic problems or muscular disabilities. Many of these children were categorized as at-risk children at birth.

How many children are identified as deaf-blind in the U.S. and/or Kansas?

In Kansas there are 125 children certified as deaf-blind. Those are only the ones we've identified. We are constantly striving to identify more and more kids as we use the Kansas Deaf-Blind Project to get the word out about these children. In the U.S., one child out of 100,000 will be deaf-blind, according to the Helen Keller National Center. Of the estimated 70,000 individuals nationwide categorized as deaf-blind, 12,000 are children ages birth-21.



What are the primary needs of these children?

Their primary needs are communication and exposure to the world. For deaf-blind children, the world is literally at their fingertips. That's how they get their information. When a child experiences vision or hearing loss, it's very difficult for that child to experience the same stimuli that others take for granted. Take social skills, for example: A child learns how to order a hamburger at McDonalds mainly by watching mom or dad or a sibling and imitating them. A deaf-blind child can't see or hear that interaction and must be specifically taught. Likewise, if they're not provided with some tactile stimulation, they are not receiving any stimuli.

How many deaf-blind children are using assistive technology?

The number is constantly increasing. In Kansas, of the 125 children classified as deaf-blind, about 84% use some form of AT. The AT ranges from high tech devices like I use, a Freedom Scientific PDA device, Pac Mate, for Braille reading to a low tech device like a magnifying glass.



How might AT projects like yours better utilize AT resources in their states to help deaf-blind kids?

All 50 states are covered by deaf-blind projects funded by the U.S. Department of Education's Office of Special Education Projects (OSEP). Each project, including ours, is required by OSEP to have a high priority AT deaf-blind component to aid children's education. An important part of that AT component is an effort to educate individuals, schools and government entities at all levels about assistive technology, about what AT can – and cannot -- do.

How might these projects increase awareness and access to AT for deaf-blind children and their families, knowing that so many deaf-blind children also have other severe disabilities that require AT?

One of the ways we can improve is to allow families to meet other consumers – like me – who are deaf-blind as well as professionals who know and understand this technology and can use it. We have to be able to get what's available out to these children and their families, help them look at a person-centered approach to AT. For example, what works for me as a deaf-blind adult who's almost 50 years old – who had some vision until age 40 – will be very different for a child who is born with vision and/or hearing impairment. We have to be focused on the individual needs of that child.

THE TERM DEAF-BLIND IS A BIG UMBRELLA. IT ENCOMPASSES MANY DIFFERENT CONDITIONS. AS I SAID EARLIER, 73% OF OUR DEAF-BLIND CHILDREN HAVE MULTIPLE DISABILITIES.

The term deaf-blind is a big umbrella. It encompasses many different conditions. As I said earlier, 73% of our deaf-blind children have multiple disabilities. So when we look at a child we need to look at all aspects of that child's overall condition. This requires the assistance of many professionals and a lot of support that must be provided to the children's families to enable the families to make a wise choice vis a vis AT. All this help and advice is absolutely necessary for families, because AT isn't cheap. The price keeps going up. Yes, technology geniuses are doing some fantastic things with AT, but you have to be realistic about what AT can and cannot do and how it can be tailored to the child's needs.

The truth is, most of the AT that's been created was not created with deaf-blind children in mind. The equipment is not ready for these children right out of the box. It must be adapted to suit a specific child's particular needs, including the deaf-blind child's other disabilities. So it takes professionals and families working together to focus on the needs of that child.

What are the barriers to providing these children access to AT in Kansas, for example?

One barrier is that individuals with expertise in AT are only available in or near major metropolitan areas which, in Kansas, are the Kansas City, Topeka and Wichita areas. That's only three areas in a good-sized state, where it takes you all day to drive from the

eastern border to the western border. When you get out into the rural areas, where most deaf-blind youngsters live, finding a professional who has expertise in AT is very difficult. The speed of AT evolution is good for everyone, but keeping up with that evolution is another thing entirely. The products change so rapidly that it's very hard for those people out there in rural areas to be able find the right devices to meet a unique child's needs. It's very important, from my perspective with the Kansas Deaf-Blind Project, to make individuals with expertise available to use project monies to travel to those rural areas and offer their help and support to help select the right AT.

Your state apparently has a deaf-blind fund that's used to support AT needs for deaf-blind fund. Tell us about that.

Our Kansas Deaf-Blind Fund is afforded by an Act of the Kansas state legislature. We get about \$110,000 annually that's dedicated to deaf-blind children whose condition has been certified by the Kansas Deaf-Blind Project and the Kansas State Department of Education (KSDE). These children are then eligible through their school district where they can apply for \$3,000 for the use of any type of assistive technology that the team has found might be of help to the child's education program and IEP. The AT can come in many forms, but it has to be tied to the child's educational goals and outcomes.

In the past year we have been able to meet the AT needs of 84% of the certified deaf-blind children in Kansas in some way. We do this on a first-come, first-served basis. Unfortunately, given the expense of AT, \$3,000 per child only amounts to a drop in the bucket. But at least it's something. The Kansas Deaf-Blind Fund is to be used only as a last resort.

We try to obtain funding from family's' private insurance. We try local philanthropic and civic groups, like Lion's Club and United Way, to see if there's any funding available there. Then we use the Kansas Deaf-Blind Fund. We try to make it very easy for the schools to access the fund because we know that when the schools come to us they really need help. We want to be able to be there to help with the money, but the money is usually gone pretty fast. Sometimes the request is for a nifty device that may eat up the entire \$3,000 per child quota. Sometimes families need lower cost equipment. It seems to be a cyclical thing.

We do all that we can to make that money available. The state legislature has been funding this for more than 20 years and the legislators are very committed to the program. We can prove through our state's achievement scores in reading and math

show that AT does indeed make a difference in the lives of these children

Do you consider cost to be a factor in determining which devices and/or services are appropriate for deaf-blind children?

Sometimes it is. Unfortunately, that is a reality. The fact is, the cost of AT is prohibitive for some children's families. In such situations, we try very hard to assist them through programs like AT for Kansans, an organization featuring social workers whose job is finding alternative funding sources for AT for any Kansas resident who qualifies.

Through these programs we can find out, for example, if a farming family retired and sold the farm and left a sum of money to the program because the family had a nephew or niece or son or daughter who was disabled and the money can be used as a grant to help offset some of the cost of AT. United Way of Kansas has been wonderful to us in many ways. But United Way, too, has a limited amount of funds. Recently I was talking to the makers of Pac Mate, which I use. It's a Braille PDA and costs \$5,600. Unfortunately, the Kansas Deaf-Blind Fund can only pay for \$3,000 of that cost. We'd have to find another \$2,600 in funding for a child to acquire that equipment. Sometimes the parents can come up with difference. Sometimes it's United Way or Lion's Club, but we have to collaborate with many groups and individuals because we're all in this together to help these children.



When there's a shortfall, when a child's family, aided by other organizations, is unable to meet the cost of AT, is the child then denied access to the AT he or she clearly needs?

It's happened several times. I hate that. Usually, when it appears as if that situation is developing, we talk to a number of vendors who will then try everything they can to bring the equipment cost down to the minimum price they can possibly charge to the point where they may not make any profit in the sale of the equipment.

If communication is an essential and critical need for most deaf-blind children, which it is, do AT tools exist that can augment tactile approaches to communication and might AT interfere with communication development if it's not selected and used carefully?

Yes, such tools exist. There are many types of AT. For example, let's say a child is deaf-blind and has multiple disabilities and

needs to be able to make wants and needs known. There's a wristband device consisting of a mechanism that enables a child to push picture buttons with the message, for instance, that "I want to go to the restroom now" or "I'd like some milk." This mechanism provides basic needed communication.

I have a cochlear implant. Before I had that device I was truly deaf-blind. Not everyone signs. Sign language is a wonderful thing, but not everyone does it. Also, not everyone is comfortable with giving me his or her hands, which enables me to feel the sign language as someone is speaking to me. There's a Braille device that permits me to type out, on a normal keyboard, the speaker's words and sentences. I can use my Pac Mate the same way. Say, you were visiting my office. I'd have you type into a laptop which would convert your message to Braille. These technologies, and others, exist, but they are very expensive. They also require numerous skills and technical assistance to support the student who's using them and make that student comfortable using them.



Technology can do amazing things, but without the people behind it to educate and support the kids who are using it, AT alone won't achieve the objectives we expect from it.

Might AT interfere with communication development if it's not selected and used carefully?

Yes, it might. As I said, one barrier is the support that a child gets in learning how to use an AT device. Every piece of AT I've ever used or seen used, takes a lot of support. There's a steep learning curve, which requires that the person providing support is patient in showing a student how to make the right decisions and determining whether the device is within a child's ability to use it. Then the support person is going to have to work closely with the child to make sure the child gets the full use from the device. That in and of itself can be an IEP goal.

EVERY PIECE OF AT I'VE EVER USED OR SEEN USED, TAKES A LOT OF SUPPORT. THERE'S A STEEP LEARNING CURVE, WHICH REQUIRES THAT THE PERSON PROVIDING SUPPORT IS PATIENT IN SHOWING A STUDENT HOW TO MAKE THE RIGHT DECISIONS AND DETERMINING WHETHER THE DEVICE IS WITHIN A CHILD'S ABILITY TO USE IT. THEN THE SUPPORT PERSON IS GOING TO HAVE TO WORK CLOSELY WITH THE CHILD TO MAKE SURE THE CHILD GETS THE FULL USE FROM THE DEVICE.

It takes time to learn to use these devices. For example, I read about 200 Braille words a minute on my Pac Mate, but, to be honest, it's taken me a year to get the full use from the equipment because I had to learn how to use it, which required a lot of patience and time and the help of good support people. Another barrier is being able to find someone with the right expertise to provide that support, someone who has the time to travel long distances in sparsely populated areas in states like Kansas. Yet kids in those areas have very real and compelling needs.

In your experience, do you feel that most children are afforded AT consideration and assessment by a qualified team process? If not, what limits this?

A lot of people with any disability, including deaf-blind, are often afraid to ask for help. There's no sin in asking for help. If someone tells us, 'I need some help with this equipment; I need someone to come to me and show me how it works,' we will find the appropriate people to send. We'll send them out at the cost of the project. There'll be no cost to the school district.

Many times a deaf-blind student will come into a classroom and that will be the first time the teacher has ever dealt with such a student, even if the teacher has been in-service for 20 or more years. The teacher is overwhelmed. The teacher does not know what resources are available to help with this student. The teacher doesn't know who to go to for help. As a project, we have to be able to show what the resources are that we can offer to teachers. As soon as that child is identified, we can share information about resources with the child's family and teachers. Our goal is to keep teachers and parents from feeling overwhelmed.



Too many children are not afforded AT consideration and assessment by a qualified team process. We do well with the students that we can get to. The demand is great. The demand for people to get and give a good assessment for AT is huge. Unfortunately, the demand outstrips our ability to supply an adequate number of qualified professionals to provide assessments. This is a field where we need young people to come in and help us.

In Kansas, this is a difficult problem. There's a shortage of teachers for the vision impaired. There is a shortage of professionals who are AT specialists. We need more help. The number of deaf-blind kids is increasing all the time. With the number of kids

we are finding to be deaf-blind, it is hard to find enough qualified professionals to help them. We do the best we can with what we have.

How might AT help deaf-blind children be included more in regular education?

By making things more accessible for the child. For example, a deaf-blind child who understands Braille can now use a computer, thanks to AT programs. I would not have been able to use the Internet just a few years ago. I would have been forced to give up my job entirely. I was a school psychologist at one time. Then when my vision became so diminished that I couldn't see – I worked mainly with deaf children –when I was unable to see the interpreter or the kids or the material, I had to retire from that field and do something else.

AT makes everything more accessible for children. It gives them information that they could not have acquired in any other way.

Most deaf-blind children see and hear something, but the information they acquire is not useful information because they can't make out what it is. Consequently, being able to use AT gives children stimuli that does make sense to them. With training, education, support, AT gives them something where they had received nothing before.

AT MAKES EVERYTHING MORE ACCESSIBLE FOR CHILDREN. IT GIVES THEM INFORMATION THAT THEY COULD NOT HAVE ACQUIRED IN ANY OTHER WAY. BEING ABLE TO USE AT GIVES CHILDREN STIMULI THAT DOES MAKE SENSE TO THEM. WITH TRAINING, EDUCATION, SUPPORT, AT GIVES THEM SOMETHING WHERE THEY HAD RECEIVED NOTHING BEFORE.

As I mentioned, I wear a cochlear implant. That cochlear implant does not make me a hearing person, but it does some wonderful things. I can talk one-on-one without any background noise. Sometimes I can even hear on the phone, with voices I know well, like my wife's. Yet that capability does not make me a hearing person. Why not? Because my batteries go out at the wrong time and then I'm more deaf than ever! At an airport, for example, where there's a lot of background noise, I can't make out what someone is saying. I can't lip read because I can't see.

How does AT help deaf-blind kids with the socialization process?

It helps them access information from the computer. It helps them access information provided by a friend, or by an individual who

does not know how to communicate with a deaf-blind child. For them, even the blind person's white cane is AT, because it helps that person become more independent, which produces self-pride, self-esteem. When individuals with disabilities have that level of independence, they can say to themselves, "I am a person." That is so very important to young children as they mature.

Do you think educators know how or what AT might be used to meet testing or alternate assessment requirements?

Educators are becoming more educated in the uses of AT, but we've only scratched the surface of how AT can be best utilized for testing, for state assessments or achievement testing. We have a long way to go in educating the educators, but we're going in the right direction. We're all learning together about what devices are available and how they can be most effectively employed. As we continue to move forward, however, the collaboration between AT professionals and educators must be there. In that regard, I believe we can do better.

Which state or national organizations might best help families of deaf-blind children to learn more about AT?

Groups that should not be overlooked include: the National Family Association of the Deaf-Blind (NFADB); National Technical Assistance Consortium (NTAC), which is supported by all of our state deaf-blind projects as well as the Helen Keller National Center (HKNC). These organizations work together and have online listservs so that parents can get online and ask questions of individuals who are deaf-blind themselves. I talk with kids from across the country and their families. Their questions include the following:

- My child is acquiring a cochlear implant. Do you have advice on these devices?
- When is the earliest that my child should learn Braille? Is there AT that would accelerate my child's Braille learning process?
- My child has severe cerebral palsy and is deaf-blind. She doesn't have good motor control. What AT would be most appropriate for her?

State deaf-blind projects are very helpful. In Kansas, for instance, we have an affiliation with the SKI HI Institute that works closely with Project SPARKLE (Supporting Parent Access to Links Resources and Education). Project SPARKLE provides 24/7 online support for parents 365 days a year.

The problem for parents of deaf-blind children is that these parents are very, very busy. Since such a high percentage of deaf-blind kids have other disabilities, their parents are very preoccu-

ped. The parents are both probably working at more than one job to be able to cope with all the bills related to their child's condition. They are taking their kids to various therapy sessions, doctors' appointments, all of which are combined with the obligations associated with their other kids who aren't disabled. So the best time for these very busy parents to find what they need is when all the kids are in bed, online. That's how Project SPARKLE helps them. Information on cochlear implants, communication boards and Braille, plus much more, is all there. Project SPARKLE also has listserv capacity so that parents can pose a question and receive a response.



Communicating with doctors in a doctor's office is always a challenge. Most parents don't think of the questions they really need answers to until after a doctor's appointment. Project SPARKLE enables parents to get online and ask questions of doctors, who are on the listserv. Parents can contact those doctors and have their

questions answered within 48 hours in terms that are clear and understandable to them.

Many of the deaf-blind kids are also in wheelchairs. Parents wonder how their child will get around if he or she can't use a white cane and how the child will learn orientation and mobility. Project SPARKLE helps with this too by sending parents videos that show how a child in that situation learns orientation and mobility. The convenience and responsiveness provides parents with the spirit of empowerment.

What was your first experience with AT, and what was the technology?

I go way back to the time when hearing aids were in the dark ages. I started wearing one when I was in kindergarten. I can remember going to school with a body-type hearing aid, back when they made one-size-fits-all hearing aids. It was like an old-fashioned transistor radio: You had to put it on with a harness. The harness was white and an awful looking thing. You could spot a kid wearing one three blocks down the street. The wire would come up and connect into my ear. It was like placing a huge loud-speaker right next to a kid's ear. It didn't help decipher the sound or do anything positive.

I can remember putting on the white harness and joking that I was wearing a bra. Kids said that to me. It was tough. I certainly had my playground battles because of that. I had to learn to live with it and work with it. Many of those kids had no idea what to make

of me. They'd never seen a deaf student before. There was no mainstreaming then.

I didn't go to deaf school. I qualified for it but I didn't go because my mom didn't want me to learn that way. I was mainstreamed before the mainstreaming concept existed, and AT helped me in that process.

When you lost your sight, was it gradual or was it sudden?

My type of Usher Syndrome is very aggressive. I have Usher Syndrome Type 2, which means that vision is gradually lost as you lose your hearing.

I was detected with hearing loss at age five when I failed the health screening at school. That's how I got a hearing aid. I never saw well. I had thick glasses to begin with. Back then, though, we looked at one disability at a time. We know now that it is very likely that there will be other disabilities besides deafness and/or blindness. I probably never saw better than 40 degrees, which is like wearing a pair of binoculars. There is no peripheral vision at all. I could see just straight ahead. The funny thing is, as a kid, I thought everyone saw that way!

Right now I see hardly anything in my right eye, just light perception. In my left eye I see just three degrees, which is like looking through a pinhole.

Looking ahead, five to ten years, what do you see as the future for AT use for deaf-blind kids, especially those who have multiple disabilities?

I hope to see AT go beyond Braille and other tactile aids and instead encourage the use of all available senses. For example, GPS is a huge help for the blind, because the blind can hear and can be told where they are and how to get to a specific destination. GPS is not accessible to a deaf-blind person. There's a Braille version of GPS, which is like my Pac Mate, but it's extremely expensive. The user has to be very sharp with Braille to know how to read it. I won't use my Pac Mate that way because I'm afraid of dropping the device. I think that devices with GPS and other auditory AT will be made available in tactile form in order to help the deaf-blind. As time passes and research and development improve, we'll be able to learn how to produce these devices in consumer-friendly form and make them more affordable.

The deaf-blind population is a small one. Suppliers are reluctant to develop these devices for such a small group of people. How-

ever, Freedom Scientific, for instance, which manufactures Pac Mate, is making more devices for the deaf-blind than ever before. Why? Because the word is getting out that there are more deaf-blind people like me who can use it. There are other companies now that are also stepping up production of AT for the deaf-blind and for vision and hearing impaired.

It will take intense collaboration between parents of deaf-blind kids along with deaf-blind adults like me to tell manufacturers what our needs are and then let the technology whizzes go to work. Those of us who are deaf-blind, as well as anyone who uses and needs AT, must not be afraid to explain to manufacturers, and even Bill Gates, what our needs are and what we need them to do. Give them feedback on what works and what doesn't work. That we way all learn together.



Deafblind Manual Alphabet



Block Alphabet

RESOURCES

ARTICLES

Communication Interactions: It Takes Two

By Kathleen Stremel

Mississippi Statewide Project for Individuals Who Are Deaf-Blind - 2000, revised August 2004

Developed from a fact sheet, the article provides a definition of communication and explains the importance of communication to deaf-blind children. Ms. Stremel advises, "The more a child communicates, the better he/she will communicate. How does he communicate more? Children communicate more when they are provided frequent opportunities to communicate. Opportunities to communicate should be included across functional activities and caregiving routines."

For the younger child, she explains, these functional activities may include eating, bathing, changing clothes and playing with a sibling. For an older child, functional activities can include swimming, cooking, and working. Providing opportunities and being responsive are two of the most frequent methods to increase a child's communication, she writes.

<http://www.dblink.org/lib/comm.htm>

Oh, Yes, You Can: How Creativity and Assistive Technology Helped My Child to Do Class Reports

By Yolanda Scarlett

Texas School for the Blind and Visually Impaired - 2005

This article was written by the mother of a boy with multiple disabilities who found that through creative thinking and the use of technology, her son could complete the same projects as his general education peers. She describes the effects of his disabilities on his academic abilities and the thrill of discovering that her son's teacher expected him to complete the same assignments as the other children in the class.

With a vivid description of the various projects and her family's creative approaches to helping the boy complete and present his projects in class, this mother gives hope to all parents struggling to help their child be accepted and successful in a general education classroom. She includes both high-tech and low-tech solutions that enabled her son to deliver his own presentation to the class, with a little help from his brother and his classmates.

<http://www.tsbvi.edu/Outreach/seehear/spring05/yes.htm>

Large Print: Guidelines for Optimal Readability

American Printing House for the Blind - 2004

This article provides specifications and guidelines for large print books and documents.

<http://www.aph.org/edresearch/lpguide.htm>

Multimodal Presentation as a Solution to Access a Structured Document

By Philippe Truillet, Bernard Oriola, Nadine Vigouroux
Institut de Recherche Informatique Technologique (IRIT) - 2004

Although translated from French and somewhat complex, this article shows how, by way of a multimodal presentation, the blind can efficiently and effectively access and read World Wide Web documents. The authors describe software currently available to help assist visually impaired persons access the web and some of the problems that may be experienced when these methods are employed. The authors describe a presentation model called SMART and explain the reasons it has proven successful. An extensive list of references has been reviewed for this article and may assist a person studying this new presentation approach.

http://www.ra.ethz.ch/CDstore/www6/Posters/758/758_POST.HTM

A Standard Tactile Symbol System: Graphic Language for Individuals Who Are Blind and Unable to Use Braille

By Linda Hagood

Texas School for the Blind and Visually Impaired - 2000

The author describes a new model for augmentative and alternative communication for blind or severely impaired individuals unable to use Braille. This system, which may also be useful to deaf-blind individuals, requires users to have communicative intent and symbolic development. They need to be able to use real objects, gestures, or signs in order to have maximum success.

The article outlines indicators that help decide if an individual can be successful with the system, which is based on a series of backgrounds and objects attached to the categorized backgrounds. When the article was written only 300 symbols had been designed, but a personalized communication system can be created for experienced users following the rules of the Tactile Symbol System. A link to the list of 300 symbols is available on the website.

<http://www.tsbvi.edu/Outreach/seehear/archive/tactile.html>

FACTSHEETS

The TTY and Relay Fact Sheet

Temple University Institute on Disabilities - 2000

This fact sheet defines ways for deaf/hard-of-hearing, deaf-blind, and speech-impaired people to communicate over the telephone or through the computer. It describes TTY and Relay services and provides information to get Relay numbers throughout the nation. Braille information for TTY is provided for deaf-blind consumers. Voice and Hearing Carryover programs are also described with information on phone equipment given. The sheet also describes the many new ways to communicate via the computer and Internet. Video relay and direct video signing are explained. Links for products are provided.

<http://www.temple.edu/instituteondisabilities/piat/faqs/tty.html>

NIDCD Fact Sheet: Cochlear Implants

National Institute on Deafness and Other Communication Disorders (NIDCD) - 2000

This fact sheet discusses the features of a cochlear implant and how the implant works after surgery. Sources are listed for additional information. For more, contact:

NIDCD

1 Communication Ave

Bethesda, MD 20892-33456

Phone: (800) 241-1055 (toll free)

<http://www.nidcd.nih.gov/health/hearing/coch.asp>

Braille

American Foundation for the Blind - 2004

This fact sheet is an introduction to Braille and includes a description of Braille and historical information. In addition, the fact sheet explains the methods of creating Braille, including labeling units and Braille writers. For more information, contact:

American Foundation for the Blind

Phone: (212) 502-7642 800; (800) 232-5463 (AFB-LINE)

http://www.afb.org/info_documents.asp?collectionid=6

RESOURCE GUIDES

Making Educational Software and Websites Accessible: Design Guidelines, Including Math and Science Solutions

By Geoff Freed, Madeleine Rothburg, Tom Wlodkowski - 2003

New policies, including the No Child Left Behind Act, require software developers, curriculum publishers, colleges, web sites, and teachers to present materials that are accessible to students with a variety of disabilities. This resource guide provides a basic understanding of the needs of users with various disabilities, summarizes various approaches to serve them and identifies specific solutions for designing more accessible

software. The guide includes information on making multimedia presentations accessible to deaf or blind students and offers examples of writing image descriptions for blind students. The authors also describe solutions for making forms and data tables accessible, and provide information on making electronic and online textbooks accessible. Information is detailed, specific and accurate. Links provide further information. Cost: none, if ordering fewer than 10 copies. Print copies are available from Mary_Watkins@wgbh.org.
<http://ncam.wgbh.org/cdrom/guideline>

WEBSITES

deaftv.net

This website is focused on communication and video entertainment for deaf people. It consists of a variety of blogs to which users can post after creating an account, a large list of anime features that can be accessed, video editing guides and resources, subtitling equipment and resources, and American Sign Language (ASL) movies and humorous videos. Ideal users are adults seeking to explore deaf entertainment and humor. Several of the video offerings are somewhat advanced for children.

<http://www.deaftv.net>

[Listen Up!](http://www.listen-up.org)

This large though simple to navigate website has value to parents of children who are deaf or hearing impaired. Originally created to be a "one-stop shop" for the parent-designed Listen-Up! and Talk It Up! programs, the website expanded, building a remarkable parent listserv and dozens of information resources grounded in advocacy and support. <http://www.listen-up.org>

[Raising Deaf Kids](http://www.raisingdeafkids.org)

Deafness and Family Communication Center
Children's Hospital of Philadelphia - 2005
Raising Deaf Kids is authored by deafness and rehabilitation professionals but guided by an advisory panel of parents. The site features copious information about hearing loss, communication, resources and parenting. A technology section focuses on devices available to assist deaf children in family life and school. Devices include hearing aids, assistive listening devices such as FM or Sound Field, other assistive devices such as TTYs, closed captioning, text pagers and vibrating alarm clocks. The site includes a broad discussion of cochlear implants, videos of deaf people talking about their experiences and stories from children and parents. There are many links to other resources. The site is well-designed and easy to navigate. <http://www.raisingdeafkids.org>

[RERC on Hearing Enhancement](http://www.hearingresearch.org)

Lexington School for the Deaf and Center for the Deaf - 2004
The RERC on Hearing Enhancement addresses accessibility problems of individuals with deafness or hearing impairment, by developing and evaluating a range of cost-effective technological aids. Attention is given to the differing needs of people with moderate hearing loss, people with severe or profound hearing loss, young children, older adults and people with both vision and hearing loss. <http://www.hearingresearch.org>

[Braille Bug Site](http://www.afb.org/braillebug/)

American Foundation for the Blind - 2004

This educational website teaches Braille through the use of fun activities and reading clubs. Developed by the American Foundation for the Blind, the site is accurate and accessible. Color and font can be changed to accommodate low vision users and is easily read by a screen reader. The site is effective for those who are learning about Braille and for those teachers looking for ideas and fun activities to support Braille reading. Vision loss and blindness links abound. Information is provided on downloading and printing site information in Braille form.

<http://www.afb.org/braillebug/>

PRODUCT REVIEWS

[Assistive Technology at Home and in the Community for People Who Are Deaf and Hard of Hearing](http://www.nau.edu/ihd/aztap/deaffact.shtml)

This short overview of devices for the deaf or hard of hearing provides examples of devices and their use, including devices for alerting or signaling (i.e., doorbells, alarm clocks, smoke alarms), telecommunications (i.e., modified telephones), assistive listening devices such as FM systems, induction loop and infrared transmitters, and telecaption decoders. For more information, contact:

Arizona Technology Access Program
Institute for Human Development
Northern Arizona University Box 5630
Flagstaff, AZ 86011
Phone: (520) 523-8141

<http://www.nau.edu/ihd/aztap/deaffact.shtml>

[AT for Blind Students](http://atto.buffalo.edu/registered/ATBasics/Populations/Blind/index.php)

By Katie Beaver and Gail Vaughn
AT Online Project - 2000

Designed to provide AT information to vision impaired students, this review presents detailed information on low and high tech products for reading, math and computer access. Each product is described and a link is provided for more information.

<http://atto.buffalo.edu/registered/ATBasics/Populations/Blind/index.php>

KNOWLEDGE NETWORK MEMBERS

National Technical Assistance Consortium

NTAC assists families, service providers and State Deaf-Blind projects, as well as other local and state agencies, in their efforts to improve the quality of early intervention, education and transition services to children and young adults who are deaf-blind.



This is accomplished by providing technical assistance on effective practice and promoting collaborative partnerships for meeting the unique and diverse needs of children and young adults who are deaf-blind and their families.

NTAC recognizes the potential that assistive technology offers these children and their families in the development of critical skill areas such as communication, socialization, mobility, literacy, self-determination, and others. As such, NTAC is committed to increasing awareness about assistive technology via family workshops, individual state technical assistance, and dissemination of materials via DB-LINK, the National Information Clearinghouse on Children Who Are Deaf-Blind. In addition, NTAC will be hosting a national conference in April, 2006 on assistive technology and Deaf-Blindness in an effort to increase knowledge and effective practices among its constituent groups.

The NTAC mission is to link effective practices to States, early intervention systems, school systems, adult service agencies, and families in order to assist local programs and families in the provision of high quality education for children and young adults who are deaf-blind. NTAC assists states to improve results for children and youth who are deaf-blind so that they meet challenging standards and are prepared for employment and independent living. This mission is carried out by providing technical assistance to families, teachers, administrators, early intervention personnel, related personnel, paraprofessionals, and transition personnel and results in improved practices. NTAC promotes the need for a federal presence in meeting the unique and diverse needs of the population who is deaf-blind by collaboratively increasing national, local, state family and consumer capacity to meet those needs.

For more information on the National Technical Assistance Consortium, please contact:
National Technical Assistance Consortium for Children and Young Adults Who Are Deaf-Blind
Western Oregon University
345 N. Monmouth
Monmouth OR 97361
Fax: (503) 838-8150 (OR) TTY: (503) 838-9623 (OR)
Website: <http://www.tr.wou.edu/ntac>
Contact: Kathleen Stremel, Project Director
Email: stremelk@wou.edu
Phone: (913) 677-4562 (KS)

National Family Association for Deaf-Blind

The National Family Association for Deaf-Blind (NFADB) is a non-profit, volunteer-based family association. Their philosophy is that individuals who are deaf-blind are valued members of society and are entitled to the same opportunities and choices as other members of the community. NFADB encourages the founding and strengthening of organizations dedicated to assisting families of persons who are deaf-blind in each state.



They advocate for all persons who are deaf-blind of any age and cognitive ability. NFADB also shares information related to deaf-blindness and provides resources and referrals. Finally, NFADB publishes a tri-annual newsletter which addresses topics and activities of interest to parents and

family members.

For more information on the National Family Association for Deaf-Blind, please contact:
141 Middle Neck Road
Sands Point, NY 11050
Toll-free: (800) 255-0411
Fax: (516) 883-9060
<http://www.nfadb.org>
Contact: Sheri Stanger, President
Email: NFADB@aol.com

The Kansas Project for Children and Young Adults Who Are Deaf-Blind



The Kansas Project for Children and Young Adults Who are Deaf-Blind is committed to making sure that children and young adults with deaf-blindness, their parents, families, and educators receive the technical assistance and services that they need and/or desire when they need and/or desire it. They do this by promoting research-based "best practices," better documenting student/service

provider outcomes, building on systematic change efforts, and working towards aligning services for children and young adults with deaf-blindness.

This project is constantly busy focusing on their various activities. On a continuous basis, they are identifying more children and young adults who need their services. Once they have identified who needs help, they implement other activities. They provide family support through collaborative systematic networking using technology as a tool. They also provide quality results-based professional development that fosters collaboration and builds local capacity. It is very important for this project to have the support of their colleagues and other similar organizations. According to Jeff Cook of the Kansas Project for Children and Young Adults who are Deaf-Blind, this support does exist and therefore, they are able to continuously offer programs for the deaf-blind community and develop products that contain proven effective educational practices.

For more information on The Kansas Project for Children and Young Adults Who Are Deaf-Blind, please contact:

Kansas State Department of Education

120 SE 10th Avenue

Topeka, KS 66612-1182

TDD: (785) 296-0917

Fax: (785) 296-1413

<http://www.kansped.org/ksde/deafblind/deafblind.html>

Contact: Jeff Cook

Email: jcook@ksde.org

Helen Keller National Center for Deaf/ Blind Youths & Adults



The Helen Keller National Center for Deaf-Blind Youths and Adults (HKNC) is headquartered in Sands Point, NY. The Center is federally funded and is the only national program that exclusively provides services to youths and adults who are deaf-blind. The training program provides evaluation, short-term comprehensive vocational rehabilitation training and assistance to consumers in obtaining employment, housing and community supports. The Center also provides professional internships.

Field services include 10 regional offices, over 40 affiliated agencies and an Older Adult Program. The National Training Team conducts professional training seminars. HKNC is a partner in the National Technical Assistance Consortium and the National Information Clearinghouse of Children who are Deaf-Blind, DB-LINK. HKNC supports the National Family

Association for Deaf-Blind and maintains a national registry of individuals who are deaf-blind and publishes a tri-annual newsletter, Nat-Cent News.

For more information on the Helen Keller National Center for Deaf-Blind Youths and Adults, please contact:

141 Middle Neck Road

Sands Point, NY 11050

Voice: (516) 944-8900 TTY: (516) 944-8637

Fax: (516) 944-7302

<http://www.hknc.org/>

Email: HKNCinfo@hknc.org

Project SPARKLE (Supporting Parent Access to Resources, Knowledge, Linkages and Education)



Project SPARKLE is a program of individualized learning that enhances the ability of parents of children who are deaf-blind to fulfill their roles in the development and education of their children. Through Project SPARKLE, parents have access to information, training, and resources in their homes via DVD technology and the Internet.

The SPARKLE training program is provided to parents utilizing DVD technology and supported with a Parent Guidebook and the SPARKLE website. The training program focuses on: deafblindness, vision, hearing, touch, concept development, intervention, and communication.

In addition to parent training, they offer a child profile database program which supports the family in collecting data and information specific to their child. Parents use what they have learned and develop a profile unique to their child. They can then share this profile with the educational team, service providers, medical personnel, and others.

SPARKLE offers a vast amount of additional resources on their website. They have a Family Room component where parents can access a collection of family stories for support. They also have a LISTSERV so that parents can interact with other parents for additional support. Finally, they offer a unique video library where parents can watch presentations by professionals in deaf-blindness from their home computers. This resource section also includes a glossary of terms.

For more information on Project SPARKLE, please contact:

Utah State University

6500 Old Main Hill

Logan, UT 84322-6500

Toll Free: 1-(888) 800-1487

Phone: (435) 797-5600 TTY: (435) 797-5584

Fax: (435) 797-5580

<http://www.sparkle.usu.edu/>

Contact: Linda Alsop, Project Director

E-mail: sparkle@cc.usu.edu

DB-LINK The National Information Clearinghouse on Children who are Deaf-Blind



According to Gail Leslie of DB LINK, "This organization is more than just a website, and is in the business of providing information to parents, teachers, educational teams, medical personnel, etc." This federally funded project offers information and referral services that identify, coordinate, and disseminate (at no cost) information related to children and youth who are deaf-blind (ages 0-21 years). Their purpose is to ensure that information about practices, programs, and available services are readily accessible to the people who need them.

DB-LINK has the largest and most complete collection of information related to deaf-blindness, historical and contemporary, organized anywhere in the world. It is a vehicle through which access to information about children and youth who are deaf-blind is made available. This organization strives to provide access to information through a balanced presentation of resources to meet the unique informational needs of individuals. People who are deaf-blind have a right to lead fulfilling lives. They believe an informed populace is essential to the realization of this right.

For more information on DB-LINK, please contact:

Teaching Research

345 North Monmouth Ave.

Monmouth, OR 97361

Phone: (800) 438-9376 TTY: (800) 854-7013

Fax: (503) 838-8150

<http://www.dblink.org>

Contact: Gail Leslie

Email: dblink@tr.wou.edu

Connections Beyond Sight and Sound

Connections Beyond Sight and Sound is a collaborative project between the Maryland State Department of Education and the University of Maryland. Connections is the only project in Maryland to provide specialized technical assistance to enhance the capacity of local education systems to meet the intense needs of these children. The primary focus of this project is to deliver technical assistance and training throughout Maryland to foster systems change, build partnerships, and increase the capacity of local systems to provide educational services



that will result in improved outcomes for these children.

In order to reach their goals, they do a lot. They first conduct ongoing, statewide, multilevel needs assessment to determine the array, type and intensity of technical assistance and training necessary to sustain students with deaf-blindness within the educational system as outlined in the provisions of IDEA and No Child Left Behind. After they know where the needs are in the state, they provide technical assistance and consultation to families, Local School Systems (LSS), Local Infants and Toddlers Programs (LITP), State Operated Programs (SOP), private agencies, and rehabilitation programs. In addition to technical assistance and consultation, Connections also provides pre-service and in-service training to administrators, educational professionals, paraeducators, and agency personnel that focuses on research-based, effective, and promising practices, and contributes to the State's provision of highly-qualified personnel.

Connections Beyond Sight and Sound works outside of the school system and for the people of Maryland in general. They enhance state and local capacity to improve services and outcomes for children with deaf-blindness and their families.

They also provide training and support to families of children with deaf-blindness to meet their needs in the context of the family, extended family, neighborhood, school, and community. Finally, Connections facilitates ongoing coordination, collaboration and dissemination among families, MSDE, local school systems, national projects, and other relevant agencies and organizations to promote service integration, systematic change, and interagency cooperation.

According to the Project Director, Diane Kelly, they will be expanding some of their services into DC because of the recent supplementary grant awarded to the Maryland project. These services will include consultation and training to DC Public Schools to support students who are deaf-blind.

For more information on Connections Beyond Sight and Sound, please contact:

University of Maryland

1308 Benjamin Building

College Park, MD 20742

Phone: (301) 405-7915 Fax: (301) 314-9158

<http://www.cbss.umd.edu/>

Contact Diane Kelly, Ph.D, Project Director

Email: dmkelly@umd.edu

**Florida Outreach Project for Children and Young Adults
Who Are Deaf-Blind**

Florida Outreach Project

For Children and Young Adults Who Are Deaf-Blind

The Florida Outreach Project for Children and Young Adults Who Are Deaf-Blind is committed to promoting educational practice that leads to the full participation of people who are deaf-blind as active members of the community. This is accomplished through person-centered approaches focused on building the capacity of local teams and fostering self-determination of the individual. The Project offers four main services: Technical Assistance and Support, Lending Library, Training, and Collecting Census Data. For Technical Assistance and Support, the project staff coordinates with the Centers for Autism and Related Disabilities in Florida to provide effective and efficient technical assistance through on-site visits, dissemination of resource materials, and crisis intervention via telephone or electronic mail. A person-centered teaming approach is used to provide assistance, build partnerships among students, family members, interventionists, educators, social workers and others.

For more information on the Florida Outreach Project for Children and Young Adults Who Are Deaf- Blind, please contact:
P.O. Box 100234

Gainesville , FL 32610-0234

Phone: (352) 846-2757

Toll-free: (800) 667-4052

TTY: (352) 846-2759

Fax: (352) 846-0941

<http://www.deafblind.ufl.edu/>

Contact Donna Gilles, Ed.D., Director

Email: gilles@mbi.ufl.edu

Anne Carlsen Center for Children

The Anne Carlsen Center for Children in Jamestown, N.D. nurtures individuals with physical, mental and health impairments through creative combinations of

special education and training, therapy, supportive medical care and, above all else, the unconditional love, understanding and sense of belonging every child longs for and deserves. The Center offers medical services, residential services, a caring staff, a family friendly environment, educational services, rehabilitation services, and outreach services. Their rehabilitation services include: physical and occupational therapy, speech/language pathology, Dysphagia treatments, therapeutic swim-



ming, equestrian (horseback riding) therapy, sensory integration, and adaptive equipment or assistive devices.

For more information on the Anne Carlsen Center, please contact:

701 3rd St NW

Jamestown, ND 58401

Toll-free: (800) 568-5175

Fax: (701) 952-5154

<http://www.annecenter.org>

Contact: Dan Howell, CEO

Email: dan.howell@annecenter.org

Newsletter Editor: Thomas H. Allen

Design and Distribution: Ana-Maria Gutierrez



Family Center on Technology and Disability

1825 Connecticut Avenue, NW

Washington, DC 20009

Phone 202-884-8068

Fax (202) 884-8441

fctd@aed.org

www.fctd.info