

Auditory Neuropathy Spectrum Disorder and (Central) Auditory Processing Disorder

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Although auditory neuropathy spectrum disorder and (central) auditory processing disorder are different types of disorders, they share similarities that may lead professionals to confuse them unless appropriate testing is used. Accurate diagnosis is essential because these two types of hearing disorders originate from different sites within the auditory system and, therefore, cannot be treated the same way. This article reviews the main characteristics of each disorder and the types of tests that are necessary to differentiate one from the other.

Auditory Neuropathy Spectrum Disorder

Auditory neuropathy spectrum disorder (ANSD) is a specific type of hearing loss thought to be present in about 10% of children who have been diagnosed with sensorineural hearing loss. It was officially recognized less than 15 years ago (Starr, Picton, Sininger, Hood, & Berlin, 1996). In a normally functioning ear, sounds reaching the cochlea in the inner ear activate a specific type of hair cell, the outer hair cells. These cells act as the ear's natural amplifier. Their job is to increase the volume of sounds entering the cochlea so that they can be detected by a second type of hair cell, the inner hair cells. The inner hair cells transmit sound to the auditory nerve, which carries it to the brain for interpretation.

Hearing tests of children with ANSD usually show normal amplification of sounds in the cochlea, indicating that the outer hair cells are functioning. However, upon further testing, these children are found to have absent or abnormal responses in the part of the brainstem that is devoted to sounds. This means that there is a problem with the inner hair cells, with the connection between the inner hair cells and the auditory nerve, or with the auditory nerve itself.

The causes of ANSD are not known for certain, but risk factors in the newborn period include very high bilirubin levels, decreased oxygen levels (anoxia), and infections (Starr, Sininger, & Pratt, 2000). A genetic factor is believed to play a role in approximately 40% of cases (Starr, et al., 2000).

Diagnosing ANSD

When a child has difficulty processing sounds, it is important to pinpoint exactly where within the auditory system the problem is occurring. Two common tests to do this are the otoacoustic emission (OAE) test and the auditory brainstem response (ABR) test. These tests are commonly used together to achieve a diagnosis. They are also used independently or sometimes in combination to screen babies for ANSD and sensorineural hearing loss shortly after birth.

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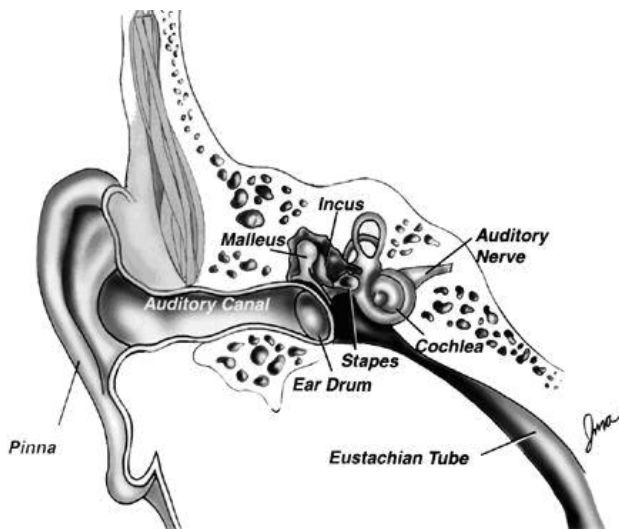


Image of the Inner Ear (Source: National Institute on Deafness and Other Communication Disorders)

In OAE testing, a small probe is placed in the ear canal and delivers sounds into the ear. A miniature microphone inside the probe records any feedback sounds or echoes coming from the cochlea. These echoes or feedback sounds, called otoacoustic emissions, are produced when outer hair cells respond to sounds coming into the ear (Kemp, 1978). When present, otoacoustic emissions indicate that the outer hair cells are working properly.

The ABR test involves placing electrodes on the skin over the areas of the auditory pathways. Sounds are introduced into the ear, and the brain's response to these sounds is measured as they travel the auditory pathways. This test can determine whether sounds are being processed properly by the inner hair cells and whether the

auditory nerve and hearing centers in the brainstem are working appropriately.

ANSD and sensorineural hearing loss are differentiated by the site of damage. In the majority of sensorineural hearing loss cases, otoacoustic emissions are absent or greatly reduced, indicating that the outer hair cells are not working properly. In these cases, hearing aids are usually appropriate depending on the severity of the damage. Even if the outer hair cells are no longer amplifying sounds, the hearing aids will increase the loudness of sounds enough to activate the inner hair cells. In more severe cases, a cochlear implant is used to replace the function of both the outer and inner hair cells and to directly stimulate the auditory nerve.

In children with ANSD, otoacoustic emissions are usually present, indicating that amplification of sounds is still occurring naturally inside the cochlea. However, ABR waves are either absent or abnormal. Since the ABR measures stimulation of the auditory pathways in the brain, this implies that sounds are not traveling through these pathways in an effective manner. In contrast to individuals with sensorineural hearing loss, the majority of those with ANSD do not receive enough benefit from hearing aids alone to support speech and language development. However, they do often benefit from the use of cochlear implants.

Implications of Missed or Delayed Diagnosis

ANSD occurs in degrees ranging from mild to profound. In profound cases children show no or very little sound perception. In mild cases there may be normal hearing sensitivity in quiet environments and children may develop spoken language at a normal developmental rate without

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specific intervention. They will, however, have difficulty understanding speech in noisy environments. This characteristic can make it seem as if these children have an auditory processing disorder (APD) as described below.

Although 5% to 7% of children with ANSD will develop language normally and start speaking within 1 year to 18 months (Berlin, Hood, Morlet, Rose, & Brashears, 2003), despite their abnormal ABR results, this is not true of the majority of those who have ANSD. Numerous newborn screening programs are still based on OAE tests only (this is mostly the case in well-baby units), and as a result the majority of children born with ANSD will not be flagged for follow-up by newborn screening. Among them are those who do not have any sound awareness and those who cannot develop speech and language without specific intervention. These children will eventually be referred for further testing once it has become apparent to the parents and/or a pediatrician that there is a hearing problem. However, children who do not show major delays in the first few years of life may be completely missed. Some will later be inappropriately diagnosed with an APD (or other type of learning disability).

Auditory Processing Disorders

Auditory processing refers to the way our brains process the sounds we hear. This includes locating where sounds are coming from; discriminating between sounds; and distinguishing speech, music, or other pertinent sounds in environments where there is background noise, such as a television at home or a noisy heating vent in a classroom.

When auditory processing abilities are impaired, children are labeled as having an APD, also commonly called central auditory processing

disorder (CAPD). Failure to hear well in the presence of competing speech or background noise affects the majority of children with APD. Unfortunately, background noise is present in most real-world listening situations. A person with normal hearing can “tune out” such noise, but individuals with APD cannot. They also have difficulty when an important sound is degraded such as from a badly tuned radio or through a bad phone connection. These problems can lead to difficulty understanding what other people are saying and cause delays in language development. APDs are often associated with other listening and learning deficits, such as specific language impairments and dyslexia, and may also occasionally occur with neurological conditions such as tumors, delayed maturation of the central auditory pathways, and developmental abnormalities (Bamiou, Musiek, & Luxon, 2001).

Diagnosing APD

Children with APD typically respond normally to sounds when tested in a quiet environment (Chermak, Hall, & Musiek, 1999; Jerger & Musiek, 2000; Bamiou et al., 2001; Chermak, 2002). However, they may show problems locating where sounds are coming from and discriminating between sounds, and/or they may have difficulties with temporal processing—which is the ability of the auditory system to process sounds that are coming very quickly, one after the other (ASHA, 1996).

Diagnosing APD is complex, and a diagnosis is not often made until learning deficits are well established and have been impairing a child’s development for several years. Screening for APD is usually not appropriate until a child is 3 or 4 years old, and caution in the assessment of children under the age of 7 is recommended because of a high degree of variability in their performance on APD

	ANSD	(C)APD
Tympanogram (tests the integrity of the middle ear)	Normal	Normal
Middle ear muscle reflexes	Abnormal or absent	Present
Otoacoustic emissions	Present or absent (over time)	Present
Auditory brainstem responses	Abnormal or absent	Normal
Pure-tone thresholds	Normal to severe/profound	Normal
Word recognition (quiet)	Excellent to poor	Excellent
Word recognition (noise)	Poor	Fair to poor

Comparison of Test Results for ANSD and APD

tests. Children with weak language skills will have more difficulty with some of these tests (those requiring more sophisticated language processing), and the use of nonverbal stimuli is then suggested. Development of more efficient screening tools to identify children at risk for APD at a very early age is definitely an important challenge for researchers and clinicians.

There is no one specific test to diagnose an APD, but rather there is a series of tests (ASHA, 1996). The recommended assessments include a case history, a complete audiological evaluation to rule out disorders such as ANSD, and a variety of tests that use both verbal and nonverbal stimuli to examine different levels of auditory processing and the central auditory nervous system. Most of the evaluation for an APD is done by an audiologist, but ideally a team of professionals is involved, including an audiologist, speech language pathologist, psychologist, and neurologist. Together, they can determine which APD tests are best for a particular child.

Part of the audiological evaluation should involve differentiating APD from mild cases of ANSD if the child's hearing has not been thoroughly tested previously using OAE and ABR tests. As noted above, some children with mild ANSD have hearing behavior that is similar to children with an APD, including delayed development of speech and language, normal understanding of speech in quiet environments, and difficulty understanding speech in noisy environments. Other similarities include poor reading and spelling skills, low classroom participation, social withdrawal, inappropriate responses to things that other people say, poor receptive and expressive language skills, and attention problems.

On testing, both categories of children have normal or near normal hearing thresholds in quiet environments and speech discrimination scores that are normal or near normal in quiet environments, but poor in noisy ones. Additionally, otoacoustic emissions are present in both groups, meaning they have normal amplification mechanisms in the cochlea.

If only hearing thresholds and otoacoustic emissions are tested, it is difficult to tell the difference between ANSD and APD and it is likely that the appropriate diagnosis will be missed. There are, however, tests that can detect the distinct differences between the groups. These include middle ear muscle reflexes testing and ABR. Middle ear muscle reflexes testing is important for all children suspected of having an APD. These reflexes are normal in children with APDs, but absent in

those with ANSD. If middle ear muscle reflexes are found to be absent or elevated, an ABR will then be necessary to evaluate for ANSD. ABR responses are absent or abnormal in ANSD but normally present in children with an APD. Because ABR testing is more time consuming and costly than middle ear muscle reflexes testing, it is recommended to start testing suspected children with the middle ear muscle reflexes.

Conclusion

It is essential to differentiate ANSD from APD so that children with these disorders receive the treatments and educational interventions they need to enhance communication and learning. Evaluating a child for a potential APD should start with the use of appropriate hearing tests to rule out disorders such as ANSD. A hearing evaluation that includes only those tests for which both categories of children perform similarly will potentially lead to a misdiagnosis. This is why an early evaluation that includes middle ear muscle reflex and OAE testing is strongly recommended for all children being evaluated for an APD (Berlin, Morlet, & Hood, 2003).

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Camping with Laci Faith

Matt Lowell

My wife, Becky, and I used to go camping all the time. It wasn't the crazy "hike to the summit of a mountain, out in the middle of nowhere, and pitch a tent and live off the land" type of camping, but it was still camping. We would pick a weekend and schedule a camping cabin at a KOA Campground. We would spend the week prior to the trip getting ready. We would get our food list straightened out, get our groceries, prepare our bedding, and plan what we wanted to do. In Corpus Christi we visited the U.S.S. Lexington. In Asheville we went to Chimney Rock and mountain-biked in the Pisgah Forest. We had a pancake breakfast in Mississippi and over time, passed through many more campsites. In late 2002 and early 2003 we went camping at a popular 4-wheeling spot in Marble Falls, Texas, called "The Slab" and did some crazy off-road driving. We enjoyed camping and being outdoors, but most of all, we enjoyed being together.

In late 2003 I deployed to Baghdad, Iraq, with the First Cavalry Division out of Fort Hood, Texas. I returned in early 2005, and soon after I got out of the Army I accepted a job offer as a police officer at Fort Sam Houston in San Antonio. Shortly after we moved to San Antonio, Becky got a job in Seguin, Texas, as an office manager for a wonderful ear, nose, and throat doctor. Things were going great, and we decided it was time to have a baby. In November 2005, Becky became pregnant, and we were ecstatic. However, in May 2006 during her first sonogram, we learned that our daughter would have a cleft lip and palate. We were a little worried at first, but then we realized that it was not really that big of a deal and, with modern medicine, it could be taken care of. So we were happy again. In late June 2006, Becky developed preeclampsia and was put on bed rest. Very soon

after, Laci Faith Lowell was born on July 2, 2006. Laci Faith was born in New Braunfels, Texas, and weighed 3 pounds, 15 ounces. She was quickly airlifted to Christus Santa Rosa, a hospital in San Antonio. Over the next two months we would learn that she was deaf and blind, had heart problems (VSD, ASD, PDA, and pulmonary stenosis), and had severe bilateral cleft lip and palate. On top of all this, she had to be fed through a gastrostomy tube (G-tube). Our happiness had left us, but the three most important things remained—faith, hope, and love.

Over the next three years we would not do any camping. I would dream about the day when we could take Laci Faith camping, but I knew it would take awhile. I am sure Becky got tired of my bugging her about camping, but she was very patient with me, and we waited. We eventually set the goal that when Laci Faith could walk she would camp. Not a moment sooner. What fun is it to camp and have to carry around a little bundle? You want your children to walk around and explore Mother Nature for themselves. Not only that, those three years were filled with many surgeries—15 to be exact. So we waited.

Laci got a cochlear implant; had heart, lip, and palate surgeries; and had her G-tube removed. And eventually she walked. It was a very wobbly walk, but it was a walk nonetheless. So in late September 2009, we made plans to camp, and on the 1st, 2nd, and 3rd of October 2009, we made our first family camping trip to Junction KOA in Junction, Texas! Just like before, we spent the entire week prior to the trip preparing. There were lists to be made and food to be purchased. We brought camping equipment out of storage and loaded the truck. The only addition to the preparation was the time we spent talking about the camping trip to Laci. Becky would talk about it in the mornings. I would talk about it in the evenings. And we would both talk more about it at bedtime. We talked about the camping cabin, we talked about campfires, and we talked about bugs. Before making the trip, Becky and I discussed the activities we wanted to do on our trip, and we decided that all we really wanted to do was hang around the campsite and do little "projects." We planned to catch bugs and look at them under a lens, to make leaf pictures (putting a leaf under a sheet of paper and rubbing it with the side of a crayon to make the shape of the leaf appear on the paper), to fish, to build campfires, to play on the campground playground, and to go for walks. This trip would be different from our other trips. We were going to slow things way down.

We decided to do this because we did not want to overload Laci with too many activities, and because we hadn't been camping in so long that we needed a "dry run" to shake off the cobwebs. Looking back, I am glad we kept the activities simple, because those were the things Laci liked to do, and now she will associate fun things with camping. I am sure that someday she will want to mountain bike and hike and boat, but for now, its bugs and leaves.

We got to the campground Friday afternoon and immediately took a walk so that Laci could begin to get comfortable with her surroundings. We soon discovered some ducks living at the campground, and Laci fell in love with them. We had made many trips to a local park to feed the ducks, so she knew all about feeding ducks! Soon after the ducks, it was time to build a fire and make dinner. Laci and Becky helped out while I cooked. After dinner, we made s'mores. Laci didn't take too well to them, but she loved the chocolate and graham crackers separately. She did think it was cool how Daddy's marshmallow kept catching on fire. We showered, and then it was time for bed. Becky and I sat out at the campfire, in awe of how tired we were, thinking about past trips when we never really got *that tired*.

After a great night's rest with rain outside, we woke up, and I made breakfast while Becky and Laci got dressed. We spent the whole day just hanging around the campsite doing our little projects. We played on the playground, played with some "moon" sand, went fishing, and made some leaf drawings. The campground manager had noticed Laci's interest in the ducks. He said that he watches the children and picks the most well-mannered to help feed the ducks and corral them into their cage for the night. He told us that he really liked Laci and that he wanted her to help with the ducks. So he bestowed upon her the badge of the "Duck-meister." It was an actual pin with a duck on it and beneath it the word "Duck-meister." So Laci helped feed the ducks and put them in their cage, and she had a great time doing it. Before we knew it, the day was done, and we went through our "time for night-night" routine. Laci did really well both nights. I think it was because she got really tired. She had many new experiences to register in that little brain of hers, and it showed.

On Sunday, we woke up, ate breakfast, loaded up the truck, and came home. Laci helped put stuff away as she always does. She didn't stop talking about the trip for a couple of days, and she shared the experience with her classmates. We



will go camping this upcoming summer, for sure. And honestly, there won't be any mountain biking, or running, or hiking, or even 4-wheeling. But there will be a lot of projects. I imagine they will be whatever Laci Faith is into at the time. I would like to make another trip back to Corpus Christi—not to see the U.S.S. Lexington, but just to see the beach, because Laci has never been to an ocean.



Making Online Technical Assistance Connections

The Kansas Distance Mentorship Project

Peggy Malloy, NCDB

Four-year-old Blaine is sitting in front of a large computer screen with a picture of a colorful car. With assistance from his teacher, he touches the screen and then laughs out loud as the picture changes to one of a tractor. Blaine's dad is a farmer, and his mom, Jaclyn, says that Blaine is a big farm boy. He loves tractors, cows, and cattle. He also likes cars, trucks, football, basketball, and swimming. He loves to be read to, and he cracks up when his sisters fight or get into trouble.

Blaine, a triplet, was born prematurely at 24-weeks gestation. Because he has cortical visual impairment and auditory neuropathy, he has trouble processing what he sees and hears. He also has cerebral palsy, uses a wheelchair, and needs assistance to use his arms or hands. The scene of Blaine at the computer is captured on a short videoclip that his teacher, Brandi Smith, posted on a secure website called "Blaine's Clubhouse." The site can only be accessed by Blaine's educational team members and by external consultants who assist the team. The videoclip posted by Brandi is one of a series of clips on the website that show Blaine using a computer to play games that teach the concept of cause and effect. The availability of the

videoclips on the website makes it possible for consultants in Lawrence and Kansas City, both more than 100 miles away from Blaine's school in Clay Center, to observe him at the computer and provide advice to Brandi and other team members about positioning and supporting him during computer activities.

Blaine is one of three students who are the focus of a new distance learning initiative in Kansas called the Distance Mentorship Project (DMP). Using Internet technology, the DMP makes it possible for educational team members to interact online with a team of consultants who have expertise in deaf-blindness. The goal of the project is to use distance technology to help educators learn the skills they need to work with children like Blaine, who have complex disabilities that include hearing and vision loss.

The DMP was developed by Megan Cote, the project coordinator at the Kansas Deaf-Blind Project; Bob Taylor and Anne Nielsen, educational consultants at the Kansas State School for the Blind; and Jon Harding, a technical assistance specialist at the National Consortium on Deaf-Blindness (NCDB). Each of the agencies they represent provides what is known as technical assistance (TA). TA providers in the field of deaf-blindness use training and consultation to help schools, families, and educators obtain the skills and knowledge they need to provide quality educational



Screen shot of a video in Blaine's video library

services to children who are deaf-blind. The Kansas Deaf-Blind Project, like deaf-blind projects in other states, is funded by the U.S. Department of Education's Office of Special Education Programs (OSEP), and it is the primary provider of TA for children and youth in Kansas who are deaf-blind.

The Kansas State School for the Blind (KSSB), through its outreach department, provides TA for educators of children with visual impairments, some of whom are deaf-blind. In 2008 these two agencies, with assistance from NCDB (also funded by OSEP), began to work together to explore creative ways to deliver TA using new distance technologies, and in the fall of 2008 the Distance Mentorship Project was born. For this article I interviewed Megan, Bob, and Jon to find out details about the project and what they have learned so far. I also interviewed Blaine's teacher Brandi and his mother Jaelyn Pfizenmaier, who, in addition to being Blaine's mom, is the principal at Garfield Elementary School in Clay Center.

Connecting Teams Using Distance Technology

The DMP consists of three key components: (a) the exchange of videoclips of a student engaged in specific routines, (b) a secure website where an educational team and external consultants share videoclips and other resources and post comments, and (c) monthly web-based video conferences between the educational team members and consultants. Although the DMP does not replace the need for onsite visits by consultants, it does make the need for visits less frequent and provides ongoing opportunities between visits for in-depth discussion and decision-making.

The student's educational team is known as the **core team**. All members of a student's team (e.g., primary teacher, paraprofessionals, parents or guardians, related service providers) are invited to participate, but teachers, paraprofessionals, and parents tend to be the most engaged in the DMP on a regular basis because they work most closely with the focus child on daily routines.

A key feature of the DMP is that it is not just consultation *to* a team, but also consultation *from* a team. The TA specialists who provide the mentorship and consultation are known as the **extended team**. The primary members are the professionals who developed the DMP—Megan Cote, Bob Taylor, Anne Nielsen, and Jon Harding. Megan has also included other staff members from the Kansas Deaf-Blind Project and, on occasion, master teachers from the Inclusive Network of Kansas who are mentors for teachers of students with profound disabilities.

Consultants with specific expertise, such as communication experts and pediatric ophthalmologists, serve as additional extended team members and join the group as needed. "Having a

group of consultants leads to better recommendations," says Jon Harding. "As consultants, we know we are not in it alone. Because we all have different backgrounds and areas of expertise, we can give better advice."

DMP Components

An arrangement between the DMP and an educational team begins with a meeting at the child's school between one of the DMP consultants and the core team. Onsite visits, especially initially, are important. As Bob says, "You can never do this entirely by distance. Someone on the consultant team has to have hands-on contact." Megan, Bob, and Anne are each case managers for children who have been involved in the project so far, while Jon Harding's primary role has been to coordinate the development of the project and facilitate meetings. All four participate in the online consultation and web-conferencing for each child.

Once an agreement has been reached between a school and the DMP, Bob Taylor helps the core team learn how to create effective videos and use the web-based technology. Bob, who has worked with distance technology for a number of years and has great enthusiasm for its possibilities, has been the driving force behind the DMP's use of technology. The following sections describe this technology, which as noted above, the DMP uses to achieve three purposes—exchange of videoclips, online team collaboration using a secure shared website, and monthly web-based video conferences.

Exchange of Videoclips

The consulting model used by the DMP is built around routines. Core team members are asked to videotape their student during key routines and post them to the team collaboration website. The videoclips make it possible for everyone on the core and extended teams to really see what is happening when a child is engaged in a routine. Bob recommends that videoclips be no more than 3 to 4 minutes long, and he encourages teachers to narrate what is happening and to ask questions while the tape is running (e.g., "This isn't working very well. What could we be doing differently here?"). "If you follow this formula," he says, "you get very good information. Even short videoclips create opportunities for discussions and demonstrate the right way to do things." He says that it usually takes about three videos to get a routine structured. Final videos demonstrating the best techniques are posted in the "video library" on the team collaboration website. Blaine's video library

currently contains clips for a variety of routines including book reading, concept-building, and eating. There is also a series of videos in which Blaine's physical therapist demonstrates how to move and position him during activities.

Team Collaboration Site on the Web

The second component is a team collaboration site on the web where videoclips and other resources are posted and viewed. These sites also provide a place for the educational team members and external consultants to post questions and comments so that they can conduct online discussions, often focused around the videoclips.

Free software programs that make it easy to create team collaboration sites (often called "wikis," which means "quick" in Hawaiian) are available on the Internet. Bob says they have had success using a program called Google Sites, but a number of other programs are also available. The project used an internal site developed by the school district for one of the students but found it to be inconsistent and difficult to use. Megan Cote says that, going forward, the project will only work with school districts that allow them to use an external site.

Good organization that makes the sites easy to navigate is important. For example, the following are some of the sections the DMP has found to be useful:

- ◆ Discussion Avenue—for questions and comments.
- ◆ Town Hall Meeting—a place to post videos, action plans, and the schedule for the web-based conferences.
- ◆ Library—a place to organize the final videoclips that demonstrate effective strategies and to store information resources (e.g., fact sheets) and forms (e.g., IEP forms, assessment forms).

The structure of the team collaboration sites is designed to support both immediate information-sharing and data capture over time. "The site," says Megan, "opens communication and gives everyone a better understanding of the child and what they are learning. Families absolutely love it because they feel like they are gathering a running portfolio of their child and can see the evolution of their learning." Brandi, who is a new teacher for Blaine this year, found the information on the website to be enormously helpful in getting to know Blaine and understanding his needs. "Because I had access to the wiki," she says, "I was

able to see what they had started last year and could see how to get through classroom tasks and teach Blaine independent skills. And it is awesome to have the extra support for what we are doing and what we need to be doing; to get new ideas and other people's perspectives."

Monthly Web-Based Video Conferences

The final DMP component is web-based conferences. Bob says that any type of web conferencing software program works (e.g., Skype, Polycom), depending on its availability in a particular school. The purpose of the meetings is to give team members a chance to speak live and get questions answered in a face-to-face format. They review previous plans and recommendations, as well as new topics that have been generated on the website; and the consultants make new recommendations and offer advice.

Future Directions

To date, the DMP has worked with educational teams for three students in three different Kansas towns. In the process of developing and beginning to use this model, the TA providers have learned a great deal about what does and does not work when providing distance mentorship and consultation. Overall, Jon, Megan, and Bob all say that the project has made it possible for them to provide much more intensive and meaningful technical assistance. "It augments traditional forms of TA and creates opportunities for increased engagement that you don't typically have with intermittent onsite visits," says Jon, "and it builds relationships between consultants and educational teams." Jaclyn Pfizenmaier agrees. "I can't imagine where Blaine would be without it," she says. "It has given easy access for people who are a couple of hundred miles apart to communicate. As a principal, I can see how it holds the classroom accountable. As a parent, I get to talk to professionals much more often or get on the wiki. I constantly know what is going on at the school and the progress Blaine has made."

In addition to building relationships between external providers and core team members, the DMP has fostered interagency collaboration between the Kansas Deaf-Blind Project and the KSSB. At the time they began to develop the DMP, KSSB was just beginning to explore distance mentorship options, and the Kansas Deaf-Blind Project was a new project with new personnel after the project moved from the state's Department of Education to the University of Kansas in 2008. In his work as an NCDB technical assistance spe-

cialist, Jon Harding, who already had relationships with both agencies, was able to facilitate the collaboration.

Developing the roles and responsibilities of the consultants involved in the project has been challenging at times. Project collaborators have found that a combination of informality and structure is necessary for effective work as a group, but the four primary extended team members—Megan, Bob, Anne, and Jon—have found it easy to work together using this model. "There is a danger," says Megan, "in having too many cooks in the kitchen, because you can have too many opinions and consensus would never be reached. Having four people has worked well though. There has never really been any argument for what should be done. From that standpoint it has just been amazing."

While noting that distance mentoring will not replace traditional TA, Megan says that the ultimate goal for the Kansas Deaf-Blind Project is to use it as a key part of their TA delivery structure, and Bob and Anne at the Kansas State School for the Blind have adopted the model for their entire outreach program for children with visual impairments and multiple disabilities. "This is the type of virtual community," says Bob, "that teams need to help them solve problems. I don't think schools can ever be effective for kids with unique learning needs by having one consultant going to a school. You can't take a child as far as they can possibly go without help. It is much more effective when you use these team collaboration sites and draw in specialists as needed."

Jon, Megan, and Bob say they hope that this model will spread to other states. "I think every deaf-blind project should do this," says Megan, "It's a lot of fun and it is just going to have to be a new way to deliver TA because our projects have a limited number of staff members and limited time. Plus I truly believe it's a way of delivering richer technical assistance. Now, I just want all TA to be this rich."

*For more information about the DMP, contact Jon Harding. Phone: 913-677-4562, (V/TTY).
E-mail: jon.harding@hknc.org*



Reflections From the Field

Reflections from the Field” is a new column in which we ask experts in the field of deaf-blindness to share their thoughts on important issues. This first column features Maurice Belote, project coordinator at California Deaf-Blind Services. We asked Maurice to tell us a little about his background in deaf-blindness and then respond to the following questions:

As a new decade begins, what is your perspective on the availability and quality of services for children who are deaf-blind and their families? How do you think things have changed for better or worse over the past ten years, and what, if anything, do you think needs to be done to improve services in the future?

Maurice Belote



I attended the training program for teachers of the deaf-blind at San Francisco State University. My first job was as a one-on-one teacher for a 17-year-old boy with Congenital Rubella Syndrome. The two of us spent every school day

together for two years, and people used to be shocked to see one of us without the other. I then taught at the California School for the Blind for eight years as a transition teacher and, while there, developed apartment-living and community-based job training programs. I've been with California Deaf-Blind Services since 1992, first as an educational specialist and then in 1996 as the project coordinator. In addition to managing the program, I maintain a caseload of about 30 students because it's what I really love to do and it helps keep my training activities relevant and honest (I hope!).

There are many changes over the past decade that I would include on a short list for improvement. One would be the shortage of qualified educators as universities struggle to support teacher-training programs that don't attract large numbers of applicants and don't generate the revenue that other programs do. There has also been a shift away from some effective practices for reasons that to me are unclear. For example, there is less focus on conducting in-home family interviews to better understand students' lives outside of school. There have been many instances in which I couldn't understand what students were

trying to tell me about their nights and weekends until I observed for myself their lives beyond school. The family interview was conducted regularly a few years ago but now seems to be almost forgotten. And I would have to include on this list of changes the general malaise that hangs over California and, as I've heard from colleagues, over other parts of the country as well. It may be a result of challenging economic times, tensions over national security, or perhaps a consequence of our digital information overload, but many people just seem tired and less willing to take on yet another activity or obligation.

The trend that I would most like to highlight here, though, has to do with the inevitability of specialization and how it is reflected both in my professional life and in the educational programs I serve. Compared to high-incidence disability areas, deaf-blindness is a very small field. Because of this, I feel guilty that I can't be knowledgeable about everything related to deaf-blindness. I recently fielded a technical assistance request related to assistive technology. A high school student needed help with his refreshable Braille display so it would better interface with his laptop computer and screen reader. I tensed up as I listened to this student's needs because this isn't one of my areas of strength, to say the least. I knew the best I could offer was to search for someone who could help me wade through the complicated world of technology. When I first started teaching, it seemed that really understanding deaf-blindness was specialization enough and most of my students had the same etiology, Congenital Rubella Syndrome. Now in my role as a technical assistance and training provider, I serve students with multiple needs that are highly complex, and these children represent many different etiologies. I recently saw a new student with an etiology that has been identified in only 500 people in the world. I have to remember that increased specialization is something we see in almost every field, from medicine to computers to auto repair. As the world becomes more complex, I guess we survive by doing a few things well instead of by doing many things poorly.

The other area of specialization I've seen develop over the past decade, that concerns me, is the increase in the number of specialized educational programs. More and more, I encounter programs that are based on one narrowly focused educational philosophy or set of methods and strategies. For example, school representatives will tell me they have a PECS (Picture Exchange Communication System) class, a MOVE® (Mobility Opportunities Via Education) class, or classes fo-

cused primarily on sensory experiences, daily living skills, or vocational education. For students who are deaf-blind, narrowly focused programs may not always meet their widely ranging needs. To use the analogy of forcing square pegs into round holes, it seems that this is a case in which the squares keep getting bigger while the holes keep shrinking.

One way to address program specialization is to look more carefully at the role of interveners or one-on-one assistants. I'm always surprised to see students sitting through irrelevant classroom activities (e.g., a morning circle routine that is visual and auditory in nature) when these students have the benefit of interveners or dedicated one-on-one assistants. From my perspective, an intervener represents freedom—freedom from having to participate in activities that aren't meaningful to a child with deaf-blindness. It might be as simple as giving the intervener and other members of an educational team permission to deviate from the classroom routine so that time can be better spent addressing student-specific IEP goals and objectives (e.g., participating in an on-campus or off-campus work experience or integrating into a general education program with same-age peers). For example, consider the young child who is being rushed through snack preparation so he or she can get to recess. Young children who are deaf-blind need whole experiences—activities that have a beginning, middle, and end. This is a critical component to concept development. It might make more sense for this child to stay behind and finish the activity in a thoughtful and deliberate way if getting out to recess on time isn't critically important.

It isn't that students who are deaf-blind should be off on their own doing separate activities all day long, but team members must constantly analyze activities and learning environments to determine what really matters to the children they serve. We need to give family members and educators alike the tools to develop and support truly individualized programs, regardless of focus or philosophy.

Editor's note: If you know of a professional in the field whom you would like to see featured in a future edition of "Reflections from the Field," please let us know by e-mail at dbp@wou.edu, or by calling 800-438-9376 (Voice) or 800-854-7013 (TTY).



Skyways

A Deaf-Blind Man's View From Above

John Lee Clark

I'm sure there are many who say they love the city of Saint Paul, Minnesota, but for me to say that would be an understatement. That's because living anywhere outside of downtown Saint Paul would be like being in jail. I live in the heart of the skyway system in downtown (one of the four largest networks of skyways and tunnels in the world), and for me it is freedom. You see, I am both deaf and blind.

Many deaf-blind Americans live within invisible prison walls, not because of deaf-blindness itself, but because many places don't have the transportation, services, and access that would make it possible to be independent without hearing and sight. So in many places, deaf-blind people feel stuck, just as those without legs would feel stuck if there were no wheelchairs and no sidewalks outside. But Saint Paul isn't one of those places that are bad for people with slightly different bodies. Minnesota has some of the nation's very best transportation services and other apparatus for accessibility.

The skyway system, though, is the frosting on the cake. It is so much easier to get around through skyways than by crossing streets outside. It is not safe for me to cross a street on my own, so to do that I must hold up a card and hope someone will come along soon, see it, read it, and then offer to help me across. That works, and I do that if I am traveling beyond the skyways, but it's so wonderful when I don't need to hold up that card and wait in the cold.



John Lee Clark
(Photo by Taras J. Dykstra)

Thanks to the skyways, I can experience the same ease that most people do. Most things out there are designed for hearing and sighted people's convenience. If you are in that group and feel like having coffee, you can drive to a nearby coffee shop. But many of my fellow deaf-blind citizens don't have that privilege. They have to call paratransit to book a ride three days in advance. Imagine how bad their hankering for that mocha latte must be by the time they get there! But I can just get up and go, take the elevator down from my apartment on the thirty-second floor to the skyway level, and then tap the tip of my white cane on the variously textured surfaces of buildings along my route on the skyway system.

After living here for five years, I know downtown Saint Paul like the back of my hand. But the landscape in my mind is very different from what you might see and store in your mind. I wouldn't be surprised that there are many ugly sights such as those bland yet garish logos of fast-food chains.

Perhaps the skyways feel claustrophobic to some, and to others they may just be another gray patch of corporate America. But for me, they're more than pure beauty. They're freedom.

Editor's note: This essay first appeared in Nightingale, K. (Ed.). (2009). 2010 Saint Paul Almanac. St. Paul: Arcata Press. It was reprinted with permission from John Lee Clark.



Conferences and Training Events

We had so much great information in this issue of *Deaf-Blind Perspectives*, that we ran out of room for announcements of upcoming events. For a list of upcoming conferences and trainings, go to nationaldb.org or call DB-LINK Information Services at NCDB. Phone: 800-438-9376. TTY: 800-854-7013. E-mail: info@nationaldb.org.

Assessment Intervention Matrix (AIM)

Concepts and Curriculum

Enid G. Wolf-Schein, Ed.D.
CCC-SLP, University of Alberta

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University of Alberta and
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The Assessment-Intervention Matrix (AIM) is a curriculum designed to enable severely disabled individuals to achieve optimal independence in activities of daily living at home, school, and work (Wolf-Schein & Schein, 1995, rev. 2009). AIM was initially developed at New York University as part of the Communication Abilities Project. The project's purpose was to create a curriculum to assess and develop the communication abilities of children with deafblindness, and it was funded by the U.S. Office of Education from 1978 to 1982. The project's team of teachers and other professionals familiar with the complexities of deafblindness determined that the best way to improve language and communication was to provide students with opportunities to do things that are inherently satisfying and interesting to them, in familiar places during everyday activities. Because students who participated in the project had in common the need to develop better daily living skills, the team designed the curriculum to teach communication and daily living skills at the same time.

It was a priority to create a curriculum for children with a wide variety of abilities and challenges, including those with very severe disabilities who do not communicate well and are unable to cooperate during typical assessments. Based on a literature review and interviews with families and teachers, the team designed the AIM curriculum to focus on daily living skills in seven areas—drinking, eating, dressing, toileting, personal care, housekeeping, and food preparation. The project field-tested the curriculum with teachers in 19 schools and revised it based on feedback about its clarity, organization, and general usefulness (Schein, Kates, Wolf, & Theil, 1983).

Since its initial edition, AIM has been revised and edited several times to make it more succinct and up-to-date. The 2009 edition is on a CD and allows teachers to reproduce those materials that best address areas of importance for their students who are deafblind, as well as those with other

types of disabilities, including autism, intellectual disabilities, and traumatic brain injury.

AIM Curriculum Components

The curriculum divides activities of daily living into two parts. Part I covers drinking, eating, dressing, and toileting. Part II introduces more complex accomplishments—personal care, house-keeping, and food preparation—that not only provide a degree of independence, but may help students acquire skills they can use to obtain employment. In both parts, the curriculum includes instructions and forms to conduct an initial assessment, to perform structured activities designed to teach new skills, and to chart ongoing progress on a daily basis.

Initial Assessment

The first step in using AIM is to determine a student's current level of functioning and mode of expressive vocabulary in each of the seven skill areas. The assessment is based on observations during daily activities by teachers and others involved in a student's education. The assessor looks at each skill area and rates the student's current functioning using the following simple scale: 0 = no response; 1 = total assistance required; 2 = some physical assistance required; 3 = only prompting required; and 4 = without assistance or prompting. For example, there are 19 levels that relate to eating skills. Level 3 is "chew and swallow semisolid foods." If a student's performance at this level is a 3 or 4 on the scale, then he or she can begin on activities related to level 4, "chew and swallow solid foods." If the student is at a 1 or 2 on the scale, then skills for eating semisolid foods still need attention.

The assessment also evaluates a student's expressive and receptive communication skills related to appropriate vocabulary for each area of daily living—vocabulary that contributes to communication generally and to skill acquisition specifically (Wolf-Schein & Schein, 1997). AIM does not require students to have communication skills at the start of teaching, but it is designed to establish and strengthen communication in whatever forms suit a particular student.

Intervention

Assessment findings lead directly to interventions targeted to achieve specific long-range goals (see the sidebar for a list of long-range goals related to eating). Detailed step-by-step instructions

AIM Long-Range Goals: Eating

1. Swallow semiliquid (strained/blended) foods.
2. Swallow semisolid foods that do not have to be chewed.
3. Chew and swallow semisolid foods.
4. Chew and swallow solid foods.
5. Eat finger foods.
6. Eat holding a spoon with the fist.
7. Eat holding a spoon with the fingers (standard position).
8. Eat holding a fork with the fist.
9. Eat holding a fork in the standard position.
10. Spread with a knife.
11. Cut foods with a knife.
12. Cut foods with a knife and fork.
13. Eat a variety of foods.
14. Eat with elbows off the table.
15. Use a napkin.
16. Open containers or unwrap food and remove food.
17. Serve food to self.
18. Pass food to others.
19. Select and use appropriate utensils for different types of foods.

describe how to teach skills and evaluate a student's progress toward each goal. Information about readiness activities as well as the vocabulary covered (e.g., "eat," "spoon," "chew," "good," "watch," "feel," "swallow") and a list of necessary materials (e.g., chair, table, bowl, spoon, semisolid food) are also provided for each long-term goal.

The intervention steps are tailored to the needs of students with widely varying abilities and challenges, and students can move through the steps at their own pace. For example in the area of drinking, some students may need help learning to suck from a bottle, while others require help holding a glass independently. Each area begins with very basic skills so that all students can experience success. The curriculum is flexible, and because AIM deals with typical daily activities, it is possible to work on skill development in several areas during the day.

Daily Assessment

The AIM curriculum uses daily assessment forms to keep track of a student's goals and record his or her progress. They can be shared with all adults who interact with a student (e.g., family members, caregivers, and educators) to keep everyone informed about the student's skills. Daily assessment identifies instructional tactics that fail as well as those that succeed. By reviewing assessment findings over a number of days, educators can determine whether their specific strategies are suitable for a student and the tasks being taught.

Sometimes educators become impatient when they hear that they are expected to do regular assessments. They may also feel they have enough paperwork already and do not need more. In our experience, these attitudes dissipate once AIM is put into place and used for a brief period of time. Teachers and other classroom staff easily learn the assessment process. They find it takes little time, and the time it does take is amply repaid by the information gained. The assessments lead directly to interventions, so their value quickly becomes apparent.

Reassessment

Fundamental to AIM is the cycle of assessment-intervention-reassessment. The initial assessment form has several columns, so at any point teachers can conduct reassessments to see how much progress a student has made (Wolf-Schein 1998). Continuous monitoring promotes and maintains progress toward desired goals.

Conclusion

AIM provides frequent opportunities to develop daily living and communication skills in realistic, meaningful contexts at home and at school. Because learning occurs within activities such as eating, dressing, and personal care, in which most students are typically involved everyday, instruction does not require special times or preparation. It takes advantage of times of the day that are not often considered to be teaching times. AIM can be fun for teachers because they can use it to help students become more independent, and by giving immediate feedback through continuous assessment, AIM enhances success for both educators and learners.

For more information, contact Dr. Enid Wolf-Schein. Phone: 954-978-1368. E-mail: scheinej@aol.com.

Editor's note: Dr. Jerome Schein, a co-author of this article and one of the developers of AIM, passed away on April 16, 2010. Dr. Schein contributed greatly to the fields of deafness and deaf-blindness and we are very sorry to hear of his passing.

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For Your Library

Clerc Scar (Online Magazine)

Clerc Scar is an online publication of the signing community run by John Lee and Adrean Clark. It includes essays, poetry, fiction, and artwork by deaf and deaf-blind authors and artists. Web: www.clercscar.com.

Child-Guided Strategies: The van Dijk Approach to Assessment (Guidebook & DVD)

Catherine Nelson, Jan van Dijk, Teresa Oster, & Andrea McDonnell. *American Printing House for the Blind*, 2009.

This product consists of an easy-to-use guidebook with an accompanying DVD that follows the assessment of a baby, a young child, and a teenager using the Van Dijk approach. Available from the APH. Phone: 800-223-1839. E-mail: info@aph.org. Web: aph.org.

Environmental Description for Visually and Dual Sensory Impaired People (Book)

Riitta Lahtinen, Russ Palmer, & Merja Lahtinen. A1 Management UK, 2010.

This book presents techniques to provide environmental description of experiences to deaf-blind people, ranging from life activities to artistic interpretations. It includes ideas for getting started, practical tips for various categories of descriptions, and examples that illustrate describing the environment in real-life situations for different individuals. Available from the Ear Foundation in the UK (www.earfoundation.org.uk/shop).

CHARGE Syndrome: An Overview (Webcast)

This webcast explains the physical, sensory, and neurological issues shared by many children with CHARGE and how these issues can affect their success in school.

Web: www.perkins.org/resources/webcasts

Run, Play, Move: A Planning Model to Create Physical Education Activities for Individuals with Disabilities (Book)

Matt LaCortiglia. Perkins School for the Blind, 2009.

This book and companion DVD provide an overview of the Foundation, Awareness, Implementation, Evaluation, Refinement (FAIER) model to create and adapt physical activities for individuals with disabilities. To order go to www.perkins.org/publications or call 617-972-7308.



Announcements

National Leadership Consortium in Sensory Disabilities (NLCSO) Project

This project, funded by the U.S. Department of Education's Office of Special Education Programs, will provide a unique doctoral study experience for up to 25 qualified individuals committed to the education of infants, toddlers, children, and youth who are deaf/hard of hearing, blind/visually impaired, or deaf-blind. Full tuition and a minimum of \$20,000 annual living stipend will be provided to NLCSO Fellows for up to four years of full-time on campus study while they earn their doctorates at consortium universities. For more information go to www.salus.edu/nlcsd/index.html.

Workshops on the Communication Matrix

Oregon Health & Science University's Design to Learn Projects is offering low-cost workshops, offered in 1 ½-hour and 3-hour formats, on using the *Communication Matrix*. The costs are as follows:

- ◆ Free for organizations within 2-hour driving time of Portland, Oregon;
- ◆ Flexible pricing for non-profits and school districts in the Pacific Northwest, based on travel costs;
- ◆ For distant sites: \$2,000 for 1 ½ hours or \$2,500 for 3 hours, including travel costs.

These workshops are offered with support from the U.S. Department of Education, grants H327A070047 and H133G070129. For more information contact Darlene Schultz (503-494-2732 or schullda@ohsu.edu).

Research Participation Opportunity for Parents of Children With CHARGE Syndrome

Laurie S. Denno, MA, BCBA is a doctoral candidate in applied behavior analysis at Simmons College in Boston. She is starting her dissertation research in deaf-blind education and will be working with parents of children with CHARGE syndrome who are considering a psychiatric consultation because their children have not responded adequately to other treatments (e.g., behavioral, communication). As part of the project, Laurie will provide a self-teaching program to parents to assist them in speaking effectively with a psychiatrist during a consultation. For more information, contact Laurie at laurie.denno@verizon.net or <http://mysite.verizon.net/vze14kmrc>.

Described and Captioned Media Program Initiatives

The Described and Captioned Media Program (DCMP) is pleased to announce the launch of two initiatives to raise awareness about the importance of accessibility:

- ◆ Listening is Learning (www.listeningislearning.org) and
- ◆ Read Captions Across America (www.readcaptionsacrossamerica.org)

Visit the DCMP website to learn more about why captioning and description are beneficial to literacy and enhance the educational benefits of classroom media at www.dcmp.org.

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