

North Dakota
Deaf-Blind Services Project

D - B I N F O R M E R

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BUT MY CHILD IS SO INVOLVED, WHERE DO WE BEGIN!?!

By Sherri Nelson, Deaf-Blind Coordinator



The ND Deaf-Blind Project and the National Consortium on Deaf-Blindness sponsored a three day event in Jamestown, September 12-14, 2007. Mark Campano, Director of the Virginia Deaf-Blind Project in Richmond, VA, consulted with the staff from Anne Carlsen Center and Technical Assistants with the Deaf-Blind Project regarding three children that are on the Deaf-Blind Census. This consultation entailed previous viewing of student's videos and educational plans, observing in their natural environments, sharing information and resources related to

communication, and brainstorming with staff to create a plan of action specific to communication strategies for the students. In addition, one entire day was devoted to a state-wide workshop open to all parents, families, providers, and professionals that work with individuals with moderate/significant cognitive impairments and dual sensory impairments (vision and hearing).

Over 70 individuals from throughout North Dakota took advantage of this opportunity to attend this excellent presentation. Participants were introduced to non-traditional functional sensory/assessment tools and the techniques of "Wait Time", "More Responses (van Dijk)", "Hand under Hand Technique", and "Tangible Symbols/Communication boxes". It was reinforced that these particular techniques encourage student exploration through interaction with their environment and those within it. Numerous video clippings were utilized to highlight the above information.

Follow-up sessions will be held with the staff from Anne Carlsen Center, NCDB, North Dakota Deaf-Blind Services, and Mark Campano through the use of video conferencing to ensure that all professionals are supported in their efforts to implement strategies learned from this training.

First, I would like to thank **Jon Harding**, our Area 2 Representative with the National Consortium on Deaf-Blindness (NCDB) for all his assistance with this



Mark



A division of the North Dakota
Department of Public Instruction
Dr. Wayne G. Sanstead
State Superintendent



Campano

BUT MY CHILD IS SO INVOLVED, WHERE DO WE BEGIN!?! By Sherri Nelson, Deaf-Blind Coordinator

consultation. Without the support from NCDB, this training would not have happened. In addition, I would personally like to thank the **Anne Carlsen Center and parents of the children** for allowing us to work with their child and the staff at the Center and for providing their facility as a host for the workshop. Recognition also goes to **Lanna Slaby** and **Linda Ehlers**, Technical Assistants with the Deaf-Blind Project, who provide services at the Anne Carlsen Center for those children with vision and hearing losses. They worked for months on completing and coordinating all the details that needed to happen prior to and throughout the entire consultation. Great job and Many Thanks!! Without the Outreach staff from the School for the Deaf and North Dakota Vision Services/School for the Blind, this Deaf-Blind Project could not exist. Lastly, I would like to thank **Mark Campano**, for bringing his experiences and knowledge into our state and sharing them with us! I feel that this workshop had **a very positive impact** on the lives of these three students, with ripple affects down to many others. **Thanks again, Mark, and come back to North Dakota!**



American Sign Language and Interpreting Studies Program By Lilia Bakken

Individuals who are interested in working with children and adults who are deaf and hard of hearing have an opportunity to pursue this career option at Lake Region State College (LRSC) in Devils Lake, ND. LRSC provides a two-year associate's program called *American Sign Language and Interpreting Studies (ASL & IS)*. Lake Region College, with assistance from staff at the North Dakota School for the Deaf, has established and is providing this program to help address the need for more qualified sign language interpreters in the state and nation.

Sign Language interpreters are highly skilled professionals that must be fluent in two languages, English and American Sign Language. An interpreter must be able to listen to another person's words, inflections and intent and simultaneously render them into the visual language of signs. The interpreter must also be able to comprehend the signs, inflections and intent of the deaf consumer and simultaneously speak them in articulate, appropriate English. Interpreters must understand the cultures in which they work and apply that knowledge to promote effective cross-cultural communications.

Students interested in becoming sign language interpreters and who enroll in the *American Sign Language and Interpreter Studies* program are required to complete various course levels of American Sign Language as well as courses in Deaf culture, linguistics and interpreting.

Contact the admissions office at Lake Region State College to obtain a fact sheet that will provide additional information about the *American Sign Language and Interpreting Studies* program and the course requirements. An admissions counselor at Lake Region State College may be contacted toll free at 1-800-443-1313 or by email at <http://www.lrsc.nodak.edu>

CHARGE SYNDROME CONFERENCE BY JODY NEVA

I wrote a story last fall for this Newsletter about a life-long journey. This road trip started eight years ago with the birth of my daughter, Eden. Although someone chose this road trip for me, I feel blessed to be a part of every rest stop.

When Eden was 4 years old, she was diagnosed with CHARGE syndrome. This diagnosis came from a Geneticist who co-wrote the CHARGE manual. This manual is a guide to help parents and medical professionals manage a child's treatment plan. Because this syndrome consists of many different medical conditions, families have to work with many different medical specialists. The manual works as a journal to exchange information back and forth between the medical professionals and the families.

In July, I had the opportunity to attend the 8th International CHARGE conference in Costa Mesa, California. This conference is offered every two years. With the help of the North Dakota Deaf-Blind Project, I was able to network with other parents and gain some insight from the medical professionals working with the children of CHARGE. These kinds of conferences are great for bringing families together that are living through the same types of things.

CHARGE syndrome is a combination of many different characteristics. Each letter in CHARGE stands for one or more of these characteristics and can be mild to severe. The two main characteristics are malformations of the eyes and ears. Most people living with CHARGE, have a combination of vision and hearing loss. Although Eden has limited hearing and vision she is not totally deaf or blind.

This syndrome is very rare. As far as I know, Eden is the only known CHARGE diagnosis in North Dakota. It is no surprise that my amazing, rare little diva would have an amazing, rare condition. Eden is definitely one-of-a-kind. Her unique abilities continue to amaze us.

I cannot speak for other families about their feelings on this conference but I can share mine. I feel lucky to be a part of this unique group of individuals. The participation by mothers, fathers, siblings, and grandparents was genuine and equal in their desire to learn more. The presenters at this conference shared their research and ideas with us. However, I got the impression they were there to learn from us, the parents, who live with this everyday. There are so many unknowns about these children. I am not searching for answers or a cure for Eden. I accept her fate and attempt to make her life more fulfilling. Maybe I am in denial or maybe I just don't care to dwell on the unknown. Eden has CHARGE, but that doesn't define who she is as a person. She is caring, smart, and genuine...and so much more.

I was honored to attend this conference and look forward to 2009, when I can bring my family.

Sincerely,



Jody Neva, Mom to Eden



"100 YEARS OF EXCELLENCE!"

BY CARMEN GROVE SUMINSKI, SUPERINTENDENT OF ND VISION SERVICES/ND SB

Greetings to You!

The year of 2008 will mark the commemoration of 100 years of services for the School for the Blind. Our theme is "100 Years of Excellence!" It is truly an honor to be a member of this staff as we celebrate this important milestone. You are cordially invited to attend events that are being planned throughout the year. The 2008 events include the following:

- January 4 Happy Birthday to Louis Braille (1809 – 1852)
- February 15 Goalball Tournament at NDVS/SB
Acknowledge NDVS/SB Founders Day
- February 22-23 Family Weekend, Quality Inn, Jamestown
- May 7 – 9 Dakota AER/Vision Conference, Grand Forks Holiday Inn
Jim Gandorf, AER Executive Director, Keynote speaker
Topics: Vocational, Transitions, Diabetes Education
Banquet on May 7 at 6:30 p.m.
- June 27 Celebration of the Life of Helen Keller
(June 27, 1880 – June 1, 1968)
Pioneer Room, State Capitol, Bismarck
9:00 a.m. to 12 noon; Program at 11:00 a.m.
- September 12 All School Reunion at NDVS/SB, Grand Forks

We welcome this opportunity to learn, network and celebrate! Please join us!

Additional information will be made available on our website and in future mailings.

My sincere appreciation to the staff of the ND Deaf-Blind Project, the teachers of the School for the Blind and the School for the Deaf, the students with whom we work along with their families, consumers, educators, rehabilitation staff, members of the Deaf-Blind Advisory Team, legislators, personnel with the Department of Public Instruction and Department of Human Services, medical personnel and related entities. With continued collaboration, we can make a difference for the children who are Deaf-Blind in the state of North Dakota!

Hold Everything! Twenty "Stay-Put" Places for Infants, Preschoolers, and Developmentally Young Children with Sensory Impairments and Other Special Needs.

Clarke, Kay. (2004). Columbus, OH: Ohio Center for Deaf-Blind Education.

This booklet offers detailed instructions and illustrations for building 20 play spaces for children with sensory impairments. Based on Lilli Nielsen's Active Learning approach, these play environments are characterized by high interest, multi-sensory materials, easy adaptability, and the capacity to facilitate repeated, self-initiated exploration. A quick reference chart for skills targeted for each play environment is included.

Available on the web: <http://www.sscsco.org/> **Click on Ohio Center for Deaf-Blind Education, then Products**

Resources for IDEA 2004

By Nancy Skorheim

On December 2004 the Individuals with Disabilities Education Improvement Act, IDEA 2004, was signed into law by President George Bush. In August 2006, the U.S. Department of Education issued final regulations for IDEA 2004.

The IDEA 2004 emphasizes that an effective education system, now and in the future, must maintain high academic standards and clear performance goals for children with disabilities. Further, these standards and performance goals must be consistent with those required for all students in the educational system. They provide for appropriate and effective strategies and method to ensure that students with disabilities have the maximum opportunities to achieve those standards and goals. Accordingly, the IDEA 2004 provisions relating to evaluation and the individualized education programs place greater emphasis on the involvement and progress of all children with disabilities in the general education curriculum.

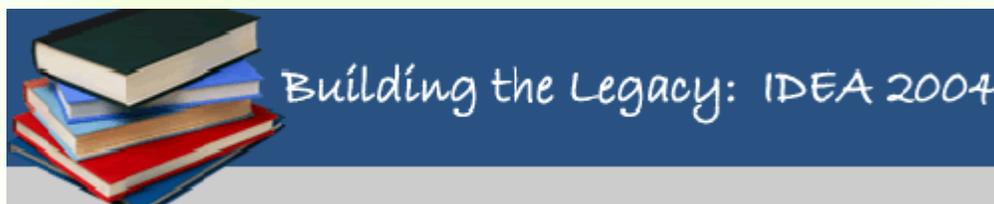
The IDEA 2004 provided the opportunity for the ND Department of Public Instruction (ND DPI), Office of Special Education to review and revise guidelines relating to the education of students with disabilities in North Dakota schools. Input from personnel from special education units, parents, and other organizations and agencies was gathered and carefully considered to provide a range of perspectives on these Guideline documents.

On July 31, 2007, ND DPI staff presented a training regarding the revised Guidelines. The training focused on the changes within the Guidelines relating to IDEA 2004. Copies of the training Power Point and the revised Guidelines are found at the following ND DPI websites: <http://www.dpi.state.nd.us/speced/general/idea/process.pdf>

<http://www.dpi.state.nd.us/speced/guide/index.shtm>

In addition to the revised ND Guidelines, another valuable training resource regarding IDEA 2004 is the *Building the Legacy: Individuals with Disabilities Education Act Amendments of 2004* training curriculum. These resources provide authoritative information about, and training materials on, IDEA 2004 and its final Part B regulations and can be found at <http://www.nichcy.org/training/contents.asp>

The *Building the Legacy* training curriculum is a product of the National Dissemination Center for Children with Disabilities (NICHCY), produced at the request of the Office of Special Education Programs (OSEP) at the U.S. Department of Education.



United States Department of Education, Office of Special Education Programs (OSEP)

A New “Focus” for NCDB by Jon Harding

What is NCDB?

The National Consortium on Deaf-Blindness (NCDB) is a national technical assistance and dissemination center for children and youth who are Deaf-Blind. Funded by the U.S. Department of Education's Office of Special Education Programs (OSEP), NCDB builds on the technical assistance activities of NTAC, the information services and dissemination activities of DB-LINK and adds a third focus related to personnel training. NCDB brings together the resources of three agencies with long histories of expertise in the field of Deaf-Blindness, [The Teaching Research Institute \(TRI\)](#) at Western Oregon University, the [Helen Keller National Center \(HKNC\)](#), and the [Hilton/Perkins Program](#) at Perkins School for the Blind. NCDB works collaboratively with families, federal, state and local agencies to provide technical assistance, information and personnel training.

What are the “focus areas”?

Last fall (October 2007), NCDB was awarded a 5-year (3+2) grant by the Office of Special Education Programs. Although NCDB has traditionally provided technical assistance across many different domains (and will continue to do so), the intention is to have a national impact by identifying five “focus areas”. Each of these is listed below.

- (1) Improve **early and appropriate identification** of children who are Deaf-Blind.
- (2) Increase student achievement in **language arts, math and science**.
- (3) Increase achievement of meaningful **post-secondary** goals through coordinated, measurable and annual transition services.
- (4) Increase effective involvement of **families** representing different cultural, ethnic, linguistic and socioeconomic backgrounds.
- (5) Improve accountability through effective **evaluation** strategies and the collection and analysis of data.

Why were these selected?

These areas align with federal initiatives and are the most frequently identified needs of children, service providers, and families. By targeting these areas (in concert with State DB Projects), NCDB can make a greater impact with limited resources.

Does this represent a ‘new direction’ for NCDB?

While items #2 and #4 are relatively new emphasis, the other items have been a significant part of the NCDB Technical Assistance repertoire for years. States may have other significant identified needs that may not fall within the ‘focus areas’. NCDB will continue to provide Technical Assistance to other identified areas of need, regardless if they are part of the “focus areas”.

What are the implications for the North Dakota Deaf-Blind Project?

Although the ND DB Project does not have these same focus areas targeted in the current grant cycle, the North Dakota DB Project is encouraged to examine the needs of families and children, look for opportunities to align with these areas, and work collaboratively with NCDB to address the needs.

D-B Advisory Board Members

Sherri Nelson	Deaf-Blind Coordinator
Joni Andre	Teacher
Jody Neva	Parent
Lisle Kauffman	Director of Education of the Deaf
Jodi Appelt	Education of the Deaf
Carmen Grove Suminski	ND Vision Services Supt
Dennis J. Fogelson	ND School f/t Deaf Supt
Karalee MacIver	Parent
Carol Lybeck	NDSO PIP/Outreach Coordinator
Connie Hovendick	Lake Region Special Ed
Vicky Whitcomb	SE KIDS Program
Nancy Lundon	Vocational Rehabilitation
Michael Marum	Developmental Disabilities
Pamilla Schauer	Anne Carlson Center
Nancy Skorheim	ND Public Instruction
Kari Chiasson	UND Vision Training Program
Melissa Elspenger	NDSO nurse
Lanna Slaby	Vision Outreach
Tami Iszler	Deaf Outreach
Ramona Gunderson	NE KIDS Program
Dr. Craig Bratvold	Optometrist
Linda Ehlers	Deaf Outreach
Nicole Witikko	Deaf Outreach

Cochlear Implants: The Basics

By Matthew Frisk, AuD, Clinical Audiologist

Society is becoming more aware of cochlear implants as they are increasingly reported in news stories and more and more patients are receiving them. It may sound incredible but cochlear implants have been around since the early 1970's. It is only recently that the speed of computer technology has allowed a hearing impaired person to carry a computer that is so small, so powerful and technologically advanced that it is possible to hear "bionically".

The concept of stimulating the ear with electricity goes back to as far as the 1790's where a few of Volta's experiments resulted in "noises" that were heard inside a subject's head when connected to electrodes. In the early 1950's, more experimentation led to that fact that electrical pulses could indeed stimulate the hearing nerve of a deaf person and some type of sound could be "heard". The 1960's introduced computers which gave engineers the tools for coding speech sounds into something meaningful to electronics. At that time, computers were the size of entire rooms and weighed a couple of tons. As the computers became smaller and faster, it opened the doors to a potentially wearable computer that would allow a hearing impaired person to enter society with some type of mono-electrode where environmental sounds could be heard. Single electrodes lead to multiple electrodes and eventually to smaller computers. The cochlear implants in the mid 1980's would allow person to wear a small backpack computer with enough batteries for approximately 6 hours. Fast-forward to today; we now have cochlear implants that are worn at the ear level delivering sound in real-time with rechargeable batteries that last all day.

The FDA approved cochlear implants for distribution in the United States in 1984. Thus, cochlear implants are no longer experimental and have helped approximately 100,000 people worldwide. In fact they are becoming more and more popular that most insurance companies will cover a good portion of the cost of implantation.

To understand how an implant works lets review how normal hearing works. In normal hearing, sound enters the outer ear canal and travels to the tympanic membrane and into the cochlear via the middle ear bones. Inside the cochlea, specialized "hair" cells are stimulated by the movement of sound waves. These hair cells then stimulate the auditory nerve endings within the cochlea. The nerve endings send electrical impulses up the nerve into the brain where the brain deciphers what the sound is and we hear!

With a sensorineural hearing loss, the sound will travel into the cochlear but the hair cells are damaged and non-functional or are no longer present. This can occur with noise exposure, ototoxic substances or in some cases, due to and inherited hearing loss trait. In most cases the nerve endings are still in good working order, however they are not innervated due to the loss or damage of the actual hair cells. A hearing aid will amplify the sounds to try to stimulate as many surviving haircells as possible. If the cochlea has a significant amount of haircell damage, even the most powerful hearing aid won't be able to stimulate enough haircells for adequate communication.

With a cochlear implant, an electrode is positioned in the area of the hair cells and basically replaces the function of the haircell. The electrode stimulates the acoustic nerve ending directly by applying a small voltage at various areas along the cochlea. By stimulating smaller areas in the cochlear, it is possible to create different pitches and loudness levels. The corresponding acoustic nerve endings are stimulated by the electrode and sounds are delivered up into the brain.

A cochlear implant most likely will benefit anyone who receives little or no benefit from hearing aids. Thus, to determine if a patient is truly a cochlear implant candidate, it is necessary to perform tests to see what auditory capabilities the patient has with hearing aids. The current FDA guidelines indicate that a person must have a severe hearing loss with 40% or less word discrimination scores in the best aided condition. Best aided condition means in quiet surrounds (sound-isolated booth) and amplified in both ears with the best means possible.

For Children, the FDA guidelines are at least 12 months of age or older and profound hearing impairment. Once identified with a hearing loss, an audiologist should fit the child with amplification for at least three months. The goal of amplification is to ensure that the child is responding to environmental sounds and is acquiring speech sounds necessary for speech and language development. Follow-up testing and parental information is necessary to indicate whether the hearing aids are truly providing benefit to the child. If it is determined that the benefit is poor, then a cochlear implant would most likely be recommended.

The age of identification and length of deafness is crucial for a child. The first 4 to 5 years of life are the window in which speech and language are learned. The child's brain literally uses the input of the five senses to "wire" itself. Touch, sight, smell, taste, and sound are all coded and learned in the brain. Without an input of sound, the brain cannot "wire" and learn what the spoken language sounds like. Amplification allows this input. If the hearing loss is too severe and the amplification is not suffice, then a cochlear implant would be the next step. The cochlear implant is only the beginning

Cochlear Implants: The Basics Continued. . .

process for speech and language development. Since the cochlear implant is not a perfect sound (far from perfect), auditory rehabilitation and speech therapy is needed to make sure that the child receives every bit of benefit from the sounds he or she is hearing.

The decision to implant is never easy, be it a parent or an adult with a severe hearing impairment. Implant candidacy testing is necessary for the simple fact that once an ear is implanted with a cochlear implant, you cannot use a hearing aid in that ear ever again. It is still possible to use a hearing aid on the opposite ear, however. We want to make sure, beyond a shadow of a doubt, that hearing aids are truly not benefiting the patient and that there isn't anything else less evasive that would help this person before a cochlear implant were to be surgically implanted. For an adult, a rule of thumb with cochlear implant candidacy: if the hearing-impaired person no longer uses a telephone due to inability to hear on it, he or she is most likely a good candidate for a cochlear implant.

Once the determination is made that audiometrically a person is a candidate for a cochlear implant, surgical candidacy is reviewed. The implant surgeon will meet with the patient and will order a CT scan of the ears to make sure that the internal structure of the head will be able to handle the electrode and internal device. The surgeon is looking for any potential problems with the cochlea and surrounding structure that would hinder the implantation or use of the implant. The CT scan will also determine which ear to implant. Surgery can then be scheduled once the CT scan is completed and the surgeon clears the patient for surgery. Cochlear implant surgery usually lasts for 2 to 3 hours and the patient is under general anesthesia. There may be some mild pain immediately after surgery and possibly some mild dizziness for the first two days, but that will quickly subside.

The implant is given three to four weeks to heal before the initial stimulation is performed. At the initial stimulation, the implant is turned on for the first time and the patient will hear sounds possibly for the first time in years. Patients are informed that the first day is usually the worst day for sound due to the fact that the nerves are being stimulated for the first time in a very long time. These new sounds will sound strange but will be comfortable and not loud. The second day is usually better because the sounds will make more sense and the ear will have had time to adapt to the new stimulation. For a child, the new sounds can be intimidating however for them this is considered "normal" as they don't know what it shouldn't sound like. After two weeks another programming session is scheduled and after that once a month for 6 months. These programming sessions are necessary because the patient adapts to the new sounds and after a brief time, will need fine tuning because he or she is able to accept more electrical stimulation from the implant.

It all sounds very easy but a word of caution or better yet a take home message: With the use of a cochlear implant, the ability to *hear* using the implant is instantaneous, however the ability to *understand speech* takes time and patience. The patient will hear plenty of sounds both soft and loud, but it can take months and even years to re-learn how to hear and to make use of the implant for speech understanding.

Here is another take home message: Every cochlear implant patient responds differently with his or her implant. Some patient's quickly adapt to the implant and be able to use the telephone after one month of stimulation, and on the other side, some patients cannot understand speech after two years of implant usage. The candidacy and history of the patient will give the clinician a good idea of how he or she will perform with the implant compared to their use with hearing aids.

The success of a cochlear implant depends upon two critical factors: length of deafness and age of deafness. A person who is hearing impaired for 10 years before implantation will typically perform better than someone who has been impaired for 20 years and so on. Also the use of hearing aids and length of hearing aid usage is important as this is factored into the length of deafness.

A cochlear implant is a life changing event. It is a surgery that has great potential for improving one's ability to hear and communicate. If you are or someone you know is not receiving benefit from the use of hearing aids, they may be a good candidate for a cochlear implant. The only way to truly find out is to complete the cochlear implant candidacy evaluation with an implant audiologist.

Matthew Frisk , AuD
Hearing Solutions
2700 12th Ave S
Fargo, ND 58103
Phone: 701-232-2438



ABOUT TOUCH

Derived from: Eliot, L. (1999) What's going on in there? How the brain and mind develop in the first five years of life. Bantam Books

As you read each of the following facts about the sense of touch, consider a child who is Deaf-Blind. Why is this fact important to know? How might we make use of this fact when we are planning activities? What significance might this fact have when teaching a child to communicate? What difference might it make to how we teach a child to access his/her environment, explore space, or find something?

Facts about touch that should be considered as we teach children who are Deaf-Blind:

- ◆ In the embryo, touch is the very first sense to emerge.
- ◆ Although not fully developed at birth, the sense of touch is one of a baby's most advanced abilities—more so than sight, hearing or taste.
- ◆ Early touch experiences will mold later tactile sensitivity, motor skills, understanding of the physical world around, and will impact health and emotional well-being.
- ◆ Touch includes not one, but four different sensory abilities, each having their own neural pathways:
 - (a) cutaneous sensation-skin touching something
 - (b) temperature sensitivity (c) pain
 - (d) proprioception-the ability that allows us to determine where we are in space (via muscles, tendons, joints, and the skin).
- ◆ Sometimes, these may combine. An example is a child holding an ice-cold teething ring feels the "hardness" sensation as well as the "coldness" of the ring.
- ◆ Proprioception allows us to relate to the space around us. For instance, it allows us to know whether our arms or legs are crossed, whether we are walking up or down a slope-even with our eyes closed.
- ◆ The REAL ability to feel is not in the skin etc., but in the two strips of "somatosensory" cortex-one on each side of the brain.
 - ◆ The two "strips" combined have a "map" of the person's body surface-the strip on the

right side of the brain has a left-body surface map and vice versa.

- ◆ The amount of space allocated for various body surfaces depends on the sensitivity of the area-lips and fingertips taking up a disproportionate amount of space.
- ◆ Touch develops in a head-to-toe sequence-and is why, early on, the mouth is used to explore and tactilely discriminate, not just to taste! A baby can actually transfer tactile to visual information and visually pick the object he/she has been exploring with the tongue. Conversely, the hands do not work this way early on-and a baby will be unable to visually distinguish something he/she has touched only with the hands.
- ◆ Hand preference changes and develops over the first two years. Object discrimination is usually best done with the left hand (regardless of whether young or old). This means that even if we are right-handed, we generally use our right brain (or left hand) to understand shapes and their properties.
 - ◆ As hand-preference is emerging, a toddler's left brain becomes increasingly involved with language development.
- ◆ Generally, newborn girls are more sensitive to touch-and this gender-related characteristic continues into adult life.
- ◆ Touch sensitivity in boys is more "lateralized"-that is their non-dominant side (usually the left) is more touch sensitive than their dominant side; girls are more symmetrical in their touch sensitivity.
- ◆ The early "critical" period is not the final chance for plasticity in this system; experience continues to fine-tune perceptual maps throughout life.



HELEN KELLER NATIONAL CENTER

By Maureen McGowan

Authorized by an Act of Congress in 1967, the Helen Keller National Center for Deaf-Blind Youths and Adults (HKNC) is the **only national vocational and rehabilitation program exclusively serving youths and adults who are Deaf-Blind.**

Our services include comprehensive **Vocational Training Program** and **Residence** at our headquarters in the suburbs of New York City, and information, advocacy and referral through our national system of **Field Services**.

Any citizen of the United States who is 16 years of age and older with a **combined** hearing and vision loss is eligible to apply to the Center. Most consumers have a vocational goal. Each consumer's program is customized based on their goals, abilities and preferences.

All of our consumers – whether they were born Deaf-Blind or lost their vision and/or hearing later in life – have one thing in common: a desire to live more independently. Older consumers may want to learn adaptive techniques for daily living. Younger consumers may be exploring “life after high school” – continuing their education or exploring work options. Those who have recently lost hearing and/or vision may wish to learn additional communication methods or adaptive technology.

Because we work **exclusively** with adults who are Deaf-Blind, HKNC staff are uniquely qualified to work with consumers who use a variety of communication methods, including American Sign Language (ASL – visual and tactual), the manual alphabet, speech, and braille, to name a few. While immersed in an environment that fosters self-determination and self-empowerment, consumers come to the realization that, at HKNC, their options are open!

As a Regional Representative I can be available to attend IEP and Transition meetings on your Deaf-Blind student. I provide on-site assessments, consultation, training and suggestions for meeting individual goals. Informational materials and presentations about the needs and capabilities of students who are Deaf-Blind can also be provided.

For further information about the HKNC program and services available to North Dakota, contact:

Maureen McGowan

Regional Representative, Rocky Mountain Region

Helen Keller National Center

1880 S. Pierce Street, Suite #5

Lakewood, CO 80232

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E-mail: Maureen.Mcgowan@hknc.org

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ND Deaf-Blind Project Technical Assistance Team

ND School for the Deaf

Carol Lybeck => Devils Lake

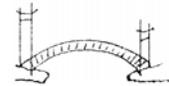
Linda Ehlers => Fargo

Position Open => Grand Forks

Tami Iszler => Bismarck

Nicole Wittiko => Minot

North Dakota



School for the Deaf

ND Vision Services

School for the Blind

Dianne Giessinger => Minot

Linda Kraft => Fargo

Lanna Slaby => Jamestown

Position Open => Devils Lake

Mary Verlinde => Bismarck

Katrina Wendel => Grand Forks

Ken Dockter => Grand Forks

Paul Olson => Grand Forks

Pat Hill => Grand Forks

Deb Johnsen => Grand Forks

Candy Lien => Grand Forks

Diane Mihulka => Grand Forks

Tracy Wicken => Grand Forks



Technical assistance request

forms are located at

www.nd.gov/deafblind/

or call 1-877-630-6214

Summer Families Connecting with Families Conference

By Karalee MacIver

Cory and I were given the opportunity to attend the Summer NAPVI conference in Omaha, Nebraska by funds provided from the ND Deaf-Blind Project. We feel truly blessed to be a part of this unforgettable weekend. NAPVI is an excellent resource for families and professionals working with children or adults whom are visually impaired.

The weekend began with an evening social event for parents and professionals along with opportunities for children to participate in games and other activities. The Nebraska School for the Blind and other volunteers provided entertainment and activities for the children throughout the weekend. They are a wonderful, energetic group!

Throughout the weekend, vendors were set up in the main area. There was a variety of Braille and large print materials available for purchase. The vendors also provided us the opportunity to try out many new technology pieces specifically designed for the visually impaired. It is amazing to see how far technology has come over the past few years.

Saturday was filled with keynote addresses and break-out sessions. We particularly enjoyed the sessions we attended. We were able to learn more about the importance of bringing books alive by tying it into the real-world experiences. Kaylyn has now begun preschool and we can relate this to her everyday experiences. Things simply make more sense when she has experienced situations through sensory exposure. We also learned more about the Mount Batten Brailier. We were very impressed by the different features and the testimonials from parents who have learned to use the Brailier. Cory was especially impressed with a break-out session just for dads. It was an opportunity for him to listen to other stories from a "dad perspective" and network with other fathers.

Saturday also brought an afternoon of round table discussions. Cory and I were part of the Deaf-Blind round table group. There were seven adults at the table, proof that this is a low-incidence disability throughout the nation. Most of the adults present were discussing issues related to the education of students with both visual and hearing impairments. The consensus is that most states are set up with two separate state schools. One specifically for visually impaired or blind students often called the School for the Blind and another which housed hard of hearing or deaf students referred to as a State School for the Deaf. Many parents of children with both visual and hearing impairments feel that it is hard for the two entities to work together to focus on both issues rather than just their area of expertise. A goal of most parents is to work together with professionals to improve services for those with dual-sensory impairments.

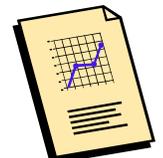
One of our favorite parts of the conference was hearing keynote speaker Mike May. Mike May's life experiences led him on a remarkable journey. He wrote a book called "Crashing Through", and has a movie already in production telling his story. Mike became blind at the age of three. In early adulthood he learned how to ski. Through skiing he had many, many adventures eventually leading to a trip to 1984 Olympics in Sarajevo. He later became the guinea pig for a new type of surgery that helped him regain some eyesight. This has been a development that has created a period of adjustment. His amazing story reminds us of all the things visually impaired individuals can accomplish if we let them. Mike credits his parents for his accomplishments. They always told him to strive for the impossible and they let him do things that would challenge him to make use of his strengths.

We enjoyed this opportunity and learned many, many new things. We are always inspired by the testimonials from adults with sensory obstacles and their stories of struggles and successes. We know that many people with dual sensory impairments can accomplish the impossible if we support their growth and challenge them to become whatever they aspire! We also formed new friendships and met professionals that will help us as Kaylyn grows and experiences new things!

CENSUS UPDATE



North Dakota Deaf-Blind Services Project, (NDDDBSP) conducts an annual count of all children from birth to age 21 in North Dakota who have both hearing and vision impairments. The annual mailing of information to the schools and Early Intervention programs occurs in January. The Census is important to us because state and federal agencies allocate the funds and this data is used to determine priorities and needs for each project. Information on the census is confidential, and only specific data is submitted to the federal government including cause of Deaf-Blindness, degree of vision and hearing impairments, and type of school placement. Student and parent names and home addresses are not submitted. This year we will be required to have documentation of the current hearing and vision evaluations for all children reported on the Census. The 2007 Census forms will have a few updates, which school administrators will be informed of next month.



UPCOMING EVENTS

✓ **CUSTOMIZING EMPLOYMENT FOR INDIVIDUALS WITH HIGH SUPPORT NEEDS**

By Steve Savage

Date: November 8, 2007

Site: Comfort Inn, Bismarck, ND

Contact: Cheryl Rystedt @ 1-800-233-1737



✓ **IMPLICATIONS OF STRESS ON CHILDREN WITH MULTIPLE DISABILITIES INCLUDING DEAF-BLINDNESS**

Presenter/Facilitator: Dr. Jan van Dijk

Room/Building: Wildwood Lodge

Address: 8511 Hudson Blvd, Lake Elmo, MN 55042

Date: 11/8/2007

Time: 9:00 am—3:00 pm Check in at 8:30 am

Contact—Program Questions: Cathy Lyle,

Cathy.Lyle@dbproject.mn.org

Contact—Registration Questions: Andrea Jayne,

Andrea.Jayne@metroecu.org

Fee: \$35 includes materials, lunch and refreshments

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 ☆ OUR TEAM ☆
 ☆ Our team is here to serve families ☆
 ☆ and professionals of individuals who ☆
 ☆ are Deaf-Blind, birth through age 21. ☆
 ☆ Please get in touch with us if you ☆
 ☆ have questions, or feel we could be ☆
 ☆ of assistance! ☆
 ☆ How to access our services: ☆
 ☆ **ND Deaf-Blind Services Project** ☆
 ☆ Sherri Nelson, Project Coordinator ☆
 ☆ 701-665-4401 or 877-630-6214 ☆
 ☆ **North Dakota School for the Deaf** ☆
 ☆ Outreach teachers 701-665-4400 or ☆
 ☆ 800-887-2980 ☆
 ☆ **ND Vision Services/** ☆
 ☆ **School for the Blind** ☆
 ☆ Outreach teachers 701-795-2700 or ☆
 ☆ 800-421-1181 ☆
 ☆☆☆☆☆☆☆☆☆☆☆☆☆☆☆☆☆☆☆☆☆



New Resources in the Deaf-Blind Library

Amazing Story-Visual and Hearing Impairments—Through Your Eyes

By Wendy Shepherd of MovieVine.com



This is the amazing story about the world's only known Deaf-Blind triplets. It is a story that is rocking the globe and bringing an educational awareness about visual and hearing impairments which many families deal with. Only their story is unique as there are three of the same age. . .

Emma, Sophie, and Zoe Dunn were born premature, at 25 weeks. All three became blind from complications related to Retinopathy of Pre-maturity. Sophie is legally blind, while Emma and Zoe are totally blind. The girls lost their hearing due to antibiotics that were administered in the NICU. They completely lost their hearing when they were about 20 months old. It was a very difficult time for the family. They didn't know what was wrong with their babies. But in spite of everything, the girls made significant progress their first year. They were about to start walking...they were saying "cup" and "mama"...then all of a sudden, they curled up on the floor in the fetal position. Every time they rode in the car they would throw up. These three happy babies became angry and began to bang their heads on the floor.

They also became distrustful during this time. They became clingy and wouldn't play anymore. They would become startled when you picked them up and they always seemed to be on edge. It has taken more than three years for them to recover and begin walking again. Most of the angry behavior is gone too. But the deafness was a huge setback. They lost at least two years of what they had learned.

The odds are stacked against them. There is no way for their parents to give them everything they need. The social services do not exist in this country to provide them with the necessary interveners. The extreme financial burden rests solely on the shoulders of their parents.

The legendary story of Helen Keller was the first to bring attention to these issues. It also brought to light how one-on-one interveners can help develop interactive communication in extreme ways. Technology has advanced in immeasurable ways...but funding in many cases still seems to be an issue.

The Dunn sisters do not have what HELEN KELLER received through Annie Sullivan, and they need three. Helen Keller's story shows us these girls can do anything they want, if they are only taught to unlock their minds.

The DVD is an 86-minute feature length film that comes packaged with a CD of the music which was used in the film. Narration is done by Michael Madsen and David Carradine. The DVD/CD combo can be purchased at <http://www.helpthetriplets.com>

Cortical Visual Impairment: An Approach to Assessment and Intervention

AFB Press



The current leading cause of visual impairment among children is not a disease or condition of the eyes, but cortical visual impairment (CVI)-also known as cerebral visual impairment-in which visual dysfunction is caused by damage or injury to the brain. The definition, nature, and treatment of CVI are the focus of great concern and widespread debate, and this complex condition poses challenges to professionals and families seeking to support the growth and development of visually impaired children. On the basis of more than 30 years' experience in working with hundreds of children of all ages with CVI, Christine Roman-Lantzy has developed a set of unique assessment tools and systematic, targeted principles whose use has helped children learn to use their vision more effectively. This one-of-a-kind resource provides readers with both a conceptual framework with which to understand working with CVI and concrete strategies to apply directly in their work.



We are on the web!
www.nd.gov/deafblind/

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www.nd.gov/deafblind/



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