There are currently 37 children in the state on the deaf-blind census. Outreach staff from ND Vision Services/School for the Blind and the ND School for the Deaf provide FREE technical assistance to children, families, and service providers across the state. The NDDSP maintains a lending library of resources with a wealth of information relating to vision and hearing impairments. The project website was updated this summer to include upcoming events, project brochures, technical assistance forms, and internet links. In the future, all resources will be listed on the website.

This newsletter provides a number of resources both statewide and nationally in the areas of vision and hearing. Thanks to all that contributed!

If any questions about the NDDSP, please call or email Sherri Nelson.

The North Dakota Deaf-Blind Services Project (NDDSP) is a federally funded resource designed to enhance the services of services for children and young adults, birth through age 21, who have the combination of vision and hearing impairments. The mission of NDDSP is to improve the education and services for children with dual sensory impairment and their families in North Dakota. This is accomplished through training, mentorship, resource dissemination, and technical assistance. All services are free to parents, families, and educators.

Carmen Grove-Suminski continues to be the project director. Carmen is the superintendent of ND Vision Services/School for the Blind located in Grand Forks, North Dakota. Kristen Votava worked as the project coordinator for NDDCP for one year. Starting in September, 2006, Sherri Nelson came aboard as the project coordinator. She has her office at the ND School for the Deaf. Sherri is a certified audiologist with years of experience with Early Intervention, clinical audiology, and a parent of four children, two with special needs. The project also employs a part-time support staff person, Sheri Hettwer, to assist with the newsletters, census, needs assessments, data collection with FileMaker Pro, and conferences. She also works part-time for the ND School for the Deaf as an Office Assistant. Sheri started with the project in September, 2005, and her office is also located at the ND School for the Deaf.

Carmen Grove-Suminski

Sherri Nelson

Sheri Hettwer
Parents of children who are deaf-blind require tools that can be used anytime (day/night) in the development and education of their children at home, and that can be shared with educators, service providers, and extended family members. Project SPARKLE is a unique model of individualized learning developed in response to requests from families. SPARKLE provides readily accessible and practical information that builds the capacity of families to effectively assist in their children’s education. SPARKLE combines DVD technology and the Internet to make deaf-blind-specific information, training, materials, and resources available on demand, and enable families to network nationwide.

The SPARKLE training program is provided to parents by means of DVD technology and is supported by a parent guidebook and the SPARKLE Web site at http://www.sparkle.usu.edu. The training program focuses on deaf-blindness, vision, hearing, touch, concept development, intervention, and communication.

Information taken from: DB-LINK: National Information Clearinghouse on Children Who Are Deaf-Blind, 1-800-438-9376, www.dblink.org, dblink@tr.wou.edu

When children experience combined hearing and vision loss, their access to the world around them is significantly impacted. Their ability to learn and to interact depends largely on the support and imagination of those responsible for guiding their development. Project PRIIDE (Providing Resources through Interactive Instruction in Deaf-Blind Education) uses innovations in DVD technology to provide information and Instruction to help families, teachers, service providers, and medical personnel gain a better understanding of the experience of deaf-blindness. The DVD allows for simulations of the full range of vision and hearing losses and for combining types of sensory loss to create customized simulations of dual sensory impairment. These simulations are situated in classroom, instructional, and day-to-day environments and illustrate the impact of deaf-blindness on a child’s ability to learn and to communicate. The program has proven to be a successful tool for parents and educators. Having a very concrete experience of what deaf-blindness means for an individual child has improved the ability of both families and teachers to provide successful accommodations and adaptations at home and in the classroom. Project PRIIDE’s DVD training program consists of three curriculum areas which are captioned for the hearing impaired and can be accessed in English or Spanish.

DVD: Sensory Perspectives, SKI-HI Institute, Utah State University, 2003. This set of two DVD’s is available from HOPE, Inc., 1856 North 1200 East, North Logan, UT 84321. Phone: 435-245-2888. E-mail: hope@hopepubl.com. Publisher’s web site: http://www.skihi.org/

Information taken from: DB-LINK: National Information Clearinghouse on Children Who Are Deaf-Blind, 1-800-438-9376, www.dblink.org, dblink@tr.wou.edu

Touch is an important means of communication and learning for children who are deaf-blind. Over the years, parents, teachers, and experts have used tactile strategies—strategies that use the sense of touch—to help children who are deaf-blind learn and experience the world. Ideas about learning through touch are often shared from person-to-person and individual strategies are included in articles and books, but until recently, comprehensive information about tactile strategies had not been gathered or thoroughly evaluated. Project SALUTE was created to address this need. The project looked at existing published materials, interviewed experts and family members, and conducted research with a small number of children. Through this process, it identified and evaluated a variety of tactile strategies and developed materials and guidelines to help families and teachers choose the best strategies for individual children. The focus of the project was on children who have very limited vision in addition to hearing loss and other disabilities.

Web Site: http://www.projectsalute.net

Information taken from: DB-LINK: National Information Clearinghouse on Children Who Are Deaf-Blind, 1-800-438-9376, www.dblink.org, dblink@tr.wou.edu
As children grow and develop, their skills and abilities increasingly allow them to become masters of their own domain. Grabbing for a favorite toy, finding a much loved book on the shelf, climbing up the slide or opening the box of cookies indicate a growing awareness of the world and the people and objects that occupy it. To develop fundamental communication and cognitive skills, children who are deaf-blind require environments that allow them to take in new information, respond to it and act on it appropriately. They require individualized instruction and families and professionals who understand their ability to learn. Learning to Learn brings together materials developed through a series of research projects to create an instructional model that identifies classroom activities and environments that simultaneously target the development of communication and cognitive skills. Easily understood inventories are used to assess these skills. Additional materials, including the Design to Learn inventory, assist in designing learning activities that target communication and cognitive development within environments that provide natural opportunities.

The Learning to Learn Model has four components:

- Assessing the Child
- Developing a Learning Plan
- Teaching & Learning
- Monitoring Performance to Promote Progress

The Learning to Learn model brings together a number of materials, all of which are available from the Design to Learn website: http://www.designtolearn.com/pages/D2Lpackage.html

Information taken from: DB-LINK: National Information Clearinghouse on Children Who Are Deaf-Blind, 1-800-438-9376, www.dblink.org, dblink@tr.wou.edu

NDSD STUDENTS HOPE TO ATTEND

Students, parents and Staff from the North Dakota School for the Deaf are participating in a fundraising project to raise money to attend the 16th Winter Games of the Deaf Olympics (Deaflympics) to be held in Salt Lake City, Utah, February 1-10, 2007.

This trip will be a once-in-a-lifetime experience for our students! 400+ Deaf and Hard of Hearing athletes from 22 countries around the world will be competing in 5 events-- hockey, curling, snowboarding, downhill, and cross-country skiing.

One of our own teachers, David Zimmerman, has been selected as an assistant coach to TEAM USA HOCKEY!

We are so excited for this opportunity. The funds raised will go toward covering expenses for food, lodging, transportation, and event tickets.

If you are able to help us to achieve this dream, please send your donation to:

Friends of Deaf Children Foundation
% NDSD
1401 College Drive N
Devils Lake, ND 58301.

All donations are tax deductible, and receipts will be provided.

**Please join us for our “Recipe for a Dream” Winter Gala, to be held on Thursday, December 7th from 5-9pm at NDSD.

We will have a Soup and Bread Dinner, a Holiday Bake Sale, a Silent Auction, a Gigantic Rummage Sale, and holiday sales from 15 local vendors—all in one BIG NIGHT!

THANK YOU FOR YOUR SUPPORT!
**NEW BOOKS IN THE NDDSP LENDING LIBRARY**

The library is currently being updated on the ND State Library ALEPH system. Soon, you will be able to visit the NDDSP website to view materials in the library. If you would like to check-out materials, or suggest resources to be added, please call NDDSP at 1-877-630-6214 or e-mail the coordinator at: sherri.nelson@sendit.nodak.edu.


  The ultimate goal of this book/DVD is to promote improved outcomes in children’s communication skills. The information contained may be used to assist family members and service providers in the development of a child’s Individualized Family Service Plan (IFSP) or Individualized Education Plan (IEP), particularly in relation to communication needs.


**JOB OPENINGS**

Outreach/Parent Infant Program Specialist located in Minot, North Dakota

For more information please visit our website @ http://www.nd.gov/ndsd/ or call 701-665-4400

Outreach Consultant- Services for the Visually Impaired position located in Riverton, Wyoming.

For more information or to apply online go to: http://statejobs.state.wy.us/JobSearchDetail.aspx?ID=10925

**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

**TACTILE COUNTING BOOK**

Sadie Can Count
Written & Illustrated by
Ann Cunningham

A full color, tactile counting book & a multi-sensory approach to early learning!

Print/Braille edition $25

In un-contracted Braille with full color tactile drawings for ages baby to Preschool.

Join Sadie as she explores her world and counts everyday treasures along the way. As Sadie moves along the floor, she finds 1 ball, 2 socks, 3 books, and so on, all the way up to 10 beads. Each object is represented in tactile format, so children can count the objects. Help your child take their critical first step toward literacy by introducing tactile and visual symbols that represent common objects like socks, keys and shells.

Read more about this book, or order it, at http://www.nbp.org/ic/nbp/SADIE.html
We are the SKI-HI Institute—a group of dedicated individuals whose goal it is to enhance the lives of young children with special needs, their families, and care givers. Our name is adapted from Sensory Impaired Home Intervention and is pronounced sky-high. “Sky high is, for us, a destination of hope and fulfillment, supporting the family unit as they strive to meet the challenges and expectations for their child of differing abilities.

Our training and services, begun in 1972, focus on early intervention and early childhood programming for infants and young children, ages birth to five, with hearing and vision impairments and other disabilities. We dedicate our work to encouraging discovery, learning, and the growth of self-esteem, thereby setting the stage for individuals with special needs to become able participants in society.

Below is a list of projects and their contact persons through Ski-Hi:

- **AHEAD** Developmental Delay, Early Intervention  
  Bess Dennison
- **CHILD TO CHILD** Materials for Classrooms K-4  
  Sue Watkins
- **DEAF MENTOR** Deaf Mentor Programming & Training (0-5)  
  Paula Pittman
- **FIPSE** Training Paraprofessionals to work with Deaf-Blind Children  
  Linda Alsop
- **HELP** Literacy Materials for Young Deaf Children  
  Sue Watkins
- **HERITAGE** Grandparents of Children with Special Needs  
  Bess Dennison
- **INSITE** Multi-disabled Sensory Impaired, 0-5  
  Bess Dennison
- **RIITE** Deaf/Blind Training Information  
  Linda Alsop
- **SKI-HI** Deaf/Hard of Hearing, Early Intervention  
  Paula Pittman
- **SPARKLE** Parents/Families of Children who are Deaf-Blind Supported by Access to Information & Training  
  Linda Alsop
- **VIISA** Blind/Visually Impaired, 0-5  
  Bess Dennison

82 Braille Books for $10.00?

It's true! Our Early Readers Series is a collection of 82 books for young readers—all in PortaBook format (electronic Braille) on a CD-Rom, ready for printing on an embosser, or read them with a refreshable Braille display. This collection includes books from these popular series: Amelia Bedelia, Arthur, Biscuit, Frog & Toad, and many, many others.

Each book is presented in four formats: single-spaced uncontracted Braille, single-spaced contracted, double-spaced uncontracted, and double-spaced contracted. You can print out whatever books you want and send them home with your students!

Please note that these books will only print out correctly if you are using a Braille embosser with the Duxbury embossing/printing software. Read the list of books on the Early Readers CD here: http://www.nbp.org/ic/nbp/EARLY.html

To order any books, send payment to:

NBP
88 St. Stephen Street
Boston, MA 02115-4302
800-548-7323 or 617-266-6160 ext. 20

Or order any of our books online at http://www.nbp.org/ic/nbp/publications/index.html
UPCOMING EVENTS

- The Helen Keller Birthplace Foundation is having a kick-off dinner on November 14, 2006 for the capital campaign to restore and maintain Helen Keller’s home in Tusculum, Alabama. Patty Duke is coming that night and will perform a part of “The Miracle Worker” in the amphitheatre at the home. If anyone is interested in coming to the event, please contact Mary Jean Sanspree at: sanspree@UAB.EDU. Seats for the dinner and evening events are $75. The nearest airport is Huntsville International. If you are a Southwest frequent flyer, Nashville is 3 hours and Birmingham is 1 1/2 hours. There are local hotels and a Marriott Hotel and Spa in the area.

- 11th Annual Lowenfeld-Akeson Early Years Symposium, "Just Tell Me What (S)he Sees: Issues in Low Vision for Young Children", February 3, 2007, 9 AM to 3 PM at the California School for the Blind, Fremont. For registration information, please contact Michael McFarland, BBF at 510-446-2229 or mcfarlandmike@blindbabies.org

- Addressing the Needs of Students Labeled Deaf & Low Functioning, Deaf-Blind or At-Risk Institute, March 28-30, 2007, Houston, Texas. An overwhelming majority of students who are deaf, hard of hearin, or deaf-blind do not transition to college. There are many factors that contribute to this—during childhood, as well as during and after transition from high school. This conference will provide opportunities to learn from national and state leaders about educational, rehabilitation, home, and job training strategies. For more information contact Theresa Johnson, Education Specialist, 7145 West Tidwell, Houston, TX 77092. Phone: 713-744-6391. E-mail: tjohnson@esco.net


- 14th Deaf-Blind International World Conference, September 25-30, 2007 in Perth, Australia. Exciting international and national speakers will form part of the conference program based around the theme, “Worldwide Connections: Breaking the Isolation.” An estimated 1000 delegates will attend from throughout the world. Participants will include international, national, and local health and disability professionals and service providers; recognized experts in deaf-blindness; and representatives from the international blind and deaf-blind communities. For more information contact Senses Foundation, Inc., PO Box 14, Maylands WA 6931, Australia. Phone: 61 8 9473 5400. TTY: 61 8 9473 5488. E-mail: conference@senses.asn.au. Web: http://www.dbiconference2007.asn.au.

- Helen Keller National Center National Training Team Seminars. The Helen Keller National Center National Training Team (NTT) was established to increase knowledge and support the development of skills specific to deaf-blindness in individuals working with consumers who are deaf-blind across the country. The NTT holds numerous seminars throughout the year. For more information, check the NTT web page at http://hknc.org/FieldServicesNTT.htm or contact Doris Plansker, NTT Administrative Assistant. Phone: 516-944-8900, ext. 233. TTY: 516-944-8637. E-mail: nttkhnc@aol.com

- New project recruiting for students for January 2007 term in Utah. Project SEIM, Sensory Impaired Early Intervention Masters Program has openings for new students interested in getting a masters degree in Early Intervention Deaf-blindness. Coursework will be done at Utah State University in Logan, Utah and is a three semester Masters program in the department of Communicative Disorders/Deaf Education. Program is designed to provide a unique experience for the individual desiring to work with infants and young children with sensory loss. Applicants who have a bachelors degree in special ed, early childhood ed, elementary ed, family and human development, education of the deaf, education of the blind or a related field are eligible to apply for this program. Student stipends are available that cover tuition and other expenses. Out of state students will receive in state tuition rates. All students accepted into the program are eligible for financial support. For further information, contact Linda Alsop at 435-797-5598 or E-mail: lalson@cc.usu.edu.

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 Maclver
Parent
Carol Lybeck
NDSD PIP/Outreach Coordinator
Connie Hovendick
Lake Region Special Ed
Vicky Whitcomb
SE KIDS Program
Nancy Lundon
Vocational Rehabilitation
Michael Marum
Developmental Disabilities
Pamilla Schauer
NDSD PIP/Outreach Coordinator
Anne Carlson Center
Nancy Skorheim
ND Public Instruction
Kari Chiasson
UND Vision Training Program
Melissa Elsperger
NDSD nurse
Lanna Slaby
Vision Outreach
Tami Iszler
Deaf Outreach
Ramona Gunderson
NE KIDS Program
Dr. Craig Bratvold
Optometrist
Linda Ehlers
Deaf Outreach
NEW NATIONAL CONSORTIUM ON 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 are delighted to announce the National Consortium on Deaf-Blindness, a new national technical assistance and dissemination center for children and youth who are deaf-blind. The consortium, which began on October 1, 2006, has received funding for 5 years from the U.S. Department of Education’s Office of Special Education Programs (OSEP). It will build on the technical assistance activities of NTAC and the information dissemination activities of DB-LINK and will add a third strand related to personnel training.

The goals and objectives of the consortium are based on requirements by OSEP, outlined in a December 2005 request for applications, for a national technical assistance and dissemination center for children and youth who are deaf-blind. Staff from TRI, HKNC, and Hilton/Perkins came together in January 2006 to conceptualize and write an application. The funding award was announced this past June.

The consortium will focus on two major purposes as required by OSEP. The first is to promote academic achievement and results for children and youth (from birth to age 26) who are deaf-blind, through technical assistance, model demonstration, and information dissemination activities that are supported by evidence-based practices. Activities will be directed toward families, service providers, state deaf-blind projects, state and local education agencies, and other organizations responsible for providing early intervention, education, and transition services. The second purpose is to assist in addressing state-identified needs for highly qualified personnel who have the necessary skills and knowledge to serve children and youth who are deaf-blind. Woven throughout the proposal are activities that meet OSEP goals for accountability, highly qualified service providers, positive child outcomes, results, collaboration, and the use of effective research (to name just a few).

The consortium will continue activities historically provided by NTAC and DB-LINK, and it will also strongly emphasize new activities that promote research-to-practice and practice-to-research. DB-LINK’s information services will continue, and the name DB-LINK will be used for the consortium’s information service activities. The following objectives provide an overview of our activities:

- Communicate, collaborate, and form partnerships as directed by OSEP and with agencies, organizations, and projects in order to improve results for children and youth and their families.
- Implement an ongoing, multilevel needs assessment to systematically identify the needs of children and youth, their families, and service providers, including personnel training, in order to adequately and appropriately address those needs.
- Provide national leadership in the implementation of evidence-based practices to address gaps in knowledge and to scale up current practices.
- Implement an array of technical assistance and personnel-training activities to build the capacity of state and local agencies to meet the needs of children and youth who are deaf-blind and their families.
- Utilize collaborative partnerships and facilitated efforts to build the capacity of youth who are deaf-blind and their families in order to promote self-advocacy, personal empowerment, and knowledge of deaf-blindness.
- Provide leadership in a coordinated national effort to promote personnel training on the implementation of IDEA and evidence-based practices in order to address the shortage of leadership and highly qualified personnel in the field of deaf-blindness.
The National Coalition on Deaf-blindness was formed in 1987 in response to a need to provide feedback to legislators and policy makers regarding the ongoing needs of children who are deaf-blind and the reauthorization of Individuals with Disabilities Education Act (IDEA). Founding members of the coalition include:

- American Association of the Deaf-Blind
- American Foundation for the Blind
- Association for the Education and Rehabilitation of the Blind & Visually Impaired
- Council of Schools for the Blind
- Helen Keller National Center
- National Association for Parents of the Visually Impaired
- National Family Association for the Deaf-Blind
- Perkins School for the Blind
- The Teaching Research Institute

Since that time, the National Coalition has maintained an active role on the Consortium for Citizens with Disabilities Education Task Force. Advocacy efforts on the part of the coalition have focused on legislation in education and rehabilitation, helping legislators to understand deaf-blindness as a unique and complex disability, and to appreciate the important role the federal government plays through its discretionary programs with regard to this low incidence disability.

Today, the National Coalition on Deaf-blindness is 2,000 member organization of parents, professionals, deaf-blind people and agencies serving the population who are deaf-blind. There have been many successes since the coalition began but in 2005 we find ourselves with a growing population and diminishing resources. Since the mid 1980s the number of children who are deaf-blind needing services has nearly tripled—increasing from roughly 4,000 to more than 10,000 today. At the same time the amount of federal funding for this group has remained level funded at $12.8 million.

In response to this crisis the National Coalition on Deaf-blindness has decided to launch the Children First Campaign (CFC). CFC is embarking on an authorization strategy beginning with FY2007 to strengthen support for children who are deaf-blind and their families. If the appropriation strategies is successful, appropriators may be able to help fill the gap between the needs of the growing population of children who are deaf-blind and the federal funding available to assist them.
HEAR SEE HOPE
CONNER MCKITTTRICK FOUNDATION FIGHTING USHER SYNDROME

ABOUT US
The idea to start the Hear See Hope foundation started in August 2004 when our oldest son, Connor (then 5) was diagnosed with Usher Syndrome Type I. We immediately began doing research on Usher Syndrome and all eye degenerative diseases. In this we found great hope that we could make a difference and that with funds there will be a cure for Usher Syndrome in Conner’s lifetime. We discovered many very helpful and knowledgeable doctors and researchers that are doing all they can to find a cure for Usher Syndrome.

We are a non-profit organization in search of funds to sustain the fight against Usher Syndrome. Please help us make a difference by supporting us in our fundraising efforts for preventing, treating and curing Usher Syndrome.

Thank you,
Todd and Lane McKittrick
Founders

MISSION
To generate financial resources to support Usher Syndrome projects. Through excellent focus, we can create, communicate and gain knowledge of this currently incurable disease. Our funds will be directly focused to Usher Syndrome research and by doing so we can target the needs of researchers and scientists. With our help the cure can be found.

HELEN KELLER NATIONAL CENTER

OUR MISSION
The mission of the Helen Keller National Center for Deaf-Blind Youths and Adults is to enable each person who is deaf-blind to live and work in his or her community of choice.

Authorized by an Act of Congress in 1967, the Helen Keller National Center for Deaf-Blind Youths and Adults (HKNC) is a national rehabilitation program serving youth and adults who are deaf-blind.

WHO WE SERVE
The Center provides services to youth and adults who are deaf-blind according to the definition of deaf-blindness in the Helen Keller Act.

WHERE WE ARE LOCATED
The Center operates a residential and training facility at our headquarters in Sands Point, NY

FOR MORE INFORMATION, CONTACT:
Information Services
E-Mail: hkncnod@aol.com
Phone: (516) 944-8900 Ext. 326 (Voice/TTY)
VP: (516) 944-8900
Website: http://www.hknc.org

THE CHARGE SYNDROME FOUNDATION

The mission of the CHARGE Syndrome Foundation is to provide support to individuals with CHARGE syndrome and their families; to gather, develop, maintain and distribute information about CHARGE syndrome; and to promote awareness and research regarding its identification, cause and management. For more information: CHARGE Syndrome Foundation, 409 Vandiver Dr Suite 5-104, Columbia, MO 65202, call 1-800-442-7604, e-mail to info@chargesyndrome.org, or visit our website @ http://www.charesyndrome.org/
NEW DEAF-BLIND INTERNATIONAL RUBELLA NETWORK

Deaf-blind International recently approved a new Rubella Network. Although the Centers for Disease Control and Prevention announced in 2005 that rubella had been eradicated from the United States, the World Health Organization estimates that annually, 100,000 children are born with congenital rubella syndrome (CRS) worldwide. CRS can cause deafness, blindness, heart problems, and a host of other health issues in babies born to mothers who contract rubella during the first trimester of pregnancy. Of grave concern, is the onset of additional health problems as these children age. The network will establish an international platform from which information and research about rubella and CRS can be shared. For more information, contact:

Nancy O'Donnell
Helen Keller National Center
141 Middle Neck Road
Sands Point, NY 11050
HKNCNOD@aol.com
516-944-6900, Ext. 326

NEW DEAF-BLIND INTERNATIONAL RUBELLA NETWORK

COCHLEAR IMPLANT STUDY  BY ELLA TAYLOR
THE TEACHING RESEARCH INSTITUTE
WESTERN OREGON UNIVERSITY

The Outcomes for Children Who Are Deaf-Blind after Cochlear Implantation (CIDB) Project is seeking approximately 250 children for participation in a study to determine the impact of cochlear implantation on auditory perception, language acquisition, and receptive and expressive communication. Currently, very little information is available about children who are deaf-blind and have cochlear implants. The primary goal of the study is to increase knowledge about this population. Children younger than 13 who currently use or are considering using a cochlear implant may be eligible to participate. At the beginning of the study, four assessment questionnaires are completed for each child: three by family members and one by a state deaf-blind project staff member based on interactions with the child. Follow-up assessments depend on how long a child has had an implant. Children who have not yet received a cochlear implant or who have recently received one will have subsequent assessments every 12 months for 3 years. Children who have had an implant for less than 7 years will be assessed one more time after 12 months. Children who have had an implant for more than 7 years undergo no further assessments. A small stipend is given to families of children who qualify for participation in the study. The CIDB Project is a joint effort by the Teaching Research Institute at Western Oregon University, the Beach Center on Disability at the University of Kansas, and the Midwest Ear Institute at St. Luke’s Hospital, in Kansas City, Missouri. Fifteen state deaf-blind projects are participating: California, Florida, Illinois, Indiana, Kansas, Kentucky, Maryland, Minnesota, Missouri, Nebraska, New Jersey, New York, Oregon, Pennsylvania, and Texas. This project (Grant #H327A050079) is funded by the U.S. Department of Education’s Office of Special Education Programs.

The Outcomes for Children Who Are Deaf-Blind after Cochlear Implantation (CIDB) Project is seeking approximately 250 children for participation in a study to determine the impact of cochlear implantation on auditory perception, language acquisition, and receptive and expressive communication. Currently, very little information is available about children who are deaf-blind and have cochlear implants. The primary goal of the study is to increase knowledge about this population. Children younger than 13 who currently use or are considering using a cochlear implant may be eligible to participate. At the beginning of the study, four assessment questionnaires are completed for each child: three by family members and one by a state deaf-blind project staff member based on interactions with the child. Follow-up assessments depend on how long a child has had an implant. Children who have not yet received a cochlear implant or who have recently received one will have subsequent assessments every 12 months for 3 years. Children who have had an implant for less than 7 years will be assessed one more time after 12 months. Children who have had an implant for more than 7 years undergo no further assessments. A small stipend is given to families of children who qualify for participation in the study. The CIDB Project is a joint effort by the Teaching Research Institute at Western Oregon University, the Beach Center on Disability at the University of Kansas, and the Midwest Ear Institute at St. Luke’s Hospital, in Kansas City, Missouri. Fifteen state deaf-blind projects are participating: California, Florida, Illinois, Indiana, Kansas, Kentucky, Maryland, Minnesota, Missouri, Nebraska, New Jersey, New York, Oregon, Pennsylvania, and Texas. This project (Grant #H327A050079) is funded by the U.S. Department of Education’s Office of Special Education Programs.
ASHA ANNOUNCES NEW EARLY INTERVENTION CAMPAIGN

Goal is To Treat Infants With Hearing Loss By The Time They Are Six Months Old

(Rockville, MD-May 5, 2006) The American Speech-Language-Hearing Association (ASHA) has announced a new five-year national effort to diagnose and provide early intervention services for 90% of children with hearing loss by the time they are six months old.

Hearing loss continues to be the most common birth defect in America. Nearly a decade ago, slightly more than 20% of U.S. hospitals screened newborns for the condition. In 2000, ASHA set a five-year goal to provide hearing loss screenings for at least 90% of newborns by the time they were one month old. That goal was achieved in 2005.

“The impact of delayed detection of hearing loss in newborns and intervention can last a lifetime,” ASHA President Alex Johnson, PhD, says. “When hearing loss is found early, intervention and treatment can produce dramatic improvements in a child’s speech and language development, and emerging literacy skills.

Some objectives of the five-year initiative include promoting:
• model eligibility criteria for the IDEA Part C program
• Expanded access to pediatric assistive technology
• Model coverage criteria for both public and private insurers.

The announcement of ASHA’s new campaign follows and complements the recent introduction of the Early Hearing Detection and Intervention (EHDI) Act of 2006 (HR 5250) by Representative James Walsh (R-NY) and 28 co-sponsors that would help further develop and promote early intervention services for children with hearing loss.

HR 5250 calls for:
• Improved follow-up for newborns who fail the hearing screening
• Access to appropriate and timely diagnosis and early interventions services

Formerly, Rep. Walsh introduced the Newborn Infant Hearing Screening and Intervention Act which was incorporated into Title VI of the Labor, HHS and Education Appropriations Act of 1999 and signed into law. The legislation was also part of the Children’s Health Act of 2000 (P.L. 106-310).

ASHA is the national professional, scientific, and credentialing association for more than 123,000 audiologists, speech-language pathologists, and speech, language, and hearing scientists. Audiologists specialize in preventing and assessing hearing disorders as well as providing audiological treatment including hearing aids. Speech-language pathologists identify, assess, and treat speech and language problems including swallowing disorders. For more information, go to www.asha.org or call 1-800-638-TALK.

PERKINS SCHOOL FOR THE BLIND

Defining a living institution is a challenge. Perkins School for the Blind is more than a campus. It’s more than a school. Perkins has been, and continues to be, a source of inspiration and opportunity for people who are blind, deaf-blind or with multiple disabilities across the nation and the world. True to its Mission, Perkins School for the Blind continues to grow and evolve with the needs, desires and dreams of its students and their families. The School fulfills, enriches and teaches. But ultimately, Perkins provides its students with the tools and knowledge to chart a course toward each individual’s maximum level of Independence, rich in experience and overflowing with potential. This commitment begins with the president, and radiates throughout the organization.

Contact Information
Perkins School for the Blind
175 North Beacon Street
Watertown, MA 02472
Fax: 617-926-2027
Phone: 617-924-3434
http://www.perkins.pvt.k12.ma.us

PERKINS SCHOOL FOR THE BLIND

NCLID
National Center on Low-Incidence Disabilities

Research Clearinghouse Community
By Nathan Lowell

NCLID is proud to announce the creation of the Research Clearinghouse and the Research Clearinghouse Community to facilitate the formation of a community of researchers in topics of interest to Special Education in general, and Low-Incidence Disabilities in particular.

Please join with us to help create new opportunities in research, collaboration, and mentorship.
ARTICLE REVIEW

Issues in the Management of Infants and Young Children Who Are Deaf-Blind—Lenore Holte, Jeanne Glidden Prickett, Don C. Van Dyke, Richard J. Olson, Pena Lubrica, Claudia L. Knutson, John F. Knutson, Susan Brennan, Wendy Berg. INFANTS AND YOUNG CHILDREN, Vol. 19, #4, pp. 323-337. (2006) Young children with major auditory and visual impairments are identified as “deaf-blind.” They have unique communication, developmental, emotional, and educational needs that require special knowledge, expertise, technology, and assistance. Having a child with this dual sensory impairment can create emotional and financial stress on a family. Programs that provide consultative training and technical assistance for families, education and service providers are key in meeting the needs of such children and their families. Behavior concerns, circadian rhythm disturbances, amplification, and special education needs all require expert and prompt attention. New research is adding to our knowledge of cochlear implants, cortical stimulators, and augmentative communication, which have the potential to improve the quality of life for the child who is deaf-blind. This article is intended to introduce professionals from a variety of disciplines to current practices and important considerations in intervention with infants and young children who are deaf-blind. It also includes discussion of the crucial role of family support in optimizing outcomes for these children. A companion article on evaluation of infants and young children who are suspected of or who are determined to be deaf-blind previously appeared in Infants Young Children, vol. 19, #3. (Author Abstract)

ND EHDI OVERVIEW BY WENDY THOMAS

ND EHDI stands for the North Dakota Early Hearing, Detection, and Intervention program. Our mission is to ensure that children with hearing loss achieve communication and social skills appropriate to their cognitive abilities. To do this, it is essential that infants with hearing loss be identified early, and appropriate intervention services are initiated. Hearing loss is the leading birth defect; outnumbering cleft lip/palate, Down Syndrome, Spina Bifida, and PKU (NCHAMS 2005). Without early identification and intervention, children with hearing loss may experience delays in developing language, cognitive, and social skills leading to poor academic and occupational outcomes.

The ND EHDI program has two grants housed at Minot State University supporting the above mission. The two grants are the ND First Sounds Project and Project Kaylyn. Both grants perform similar functions but have different areas of emphasis.

The ND First Sounds Project has been in operation since 2000, providing screening equipment to all birthing hospitals in ND and the necessary training to run this equipment. Their main emphasis has been to ensure that babies receive an initial newborn hearing screening and the results of this screening be tracked on a statewide data system called OZ Systems eSP. The ND First Sounds Project is funded through Maternal Child and Health Bureau.

Project Kaylyn was added to the ND EHDI program beginning July 1, 2005. This project focuses more on the follow-up phase of the screening process; ensuring that babies receive a second follow-up hearing screening or audiological assessment if needed, and be provided appropriate early intervention services as necessary. Project Kaylyn is funded through the Centers for Disease Control and Prevention.
USEFUL WEBSITES

- Alexander Graham Bell Association for the Deaf & Hard of Hearing:  www.agbell.org
- American Society for Deaf Children:  www.deafchildren.org
- American Speech-Language Hearing Association:  www.asha.org
- Laurent Clerc National Deaf Education Center:  http://clerccenter.gallaudet.edu/InfoToGo/index.html
- National Institute on Deafness & Other Communication Disorders Information Clearinghouse:  www.nidcd.nih.gov/
- Hearing Loss Association of America:  www.hearingloss.org
- American Council of the Blind:  www.acb.org
- American Foundation for the Blind:  www.afb.org
- Blind Children’s Center:  www.blindchildrenscenter.org
- National Association for Parents of the Visually Impaired, Inc.:  www.napvi.org
- National Association for Visually Handicapped:  www.navh.org
- National Eye Institute:  www.nei.nih.gov
- National Library Service for the Blind & Physically Handicapped:  www.loc.gov/nls
- Prevent Blindness America:  www.preventblindness.org
- The Foundation Fighting Blindness:  www.blindness.org
- National Dissemination Center for Children with Disabilities:  www.nichcy.org/index.html

NEW PERSONNEL PREPARATION PROJECT RECRUITING


Hunter College Master’s Degree Program in Severe Disabilities including Deaf-Blindness is recruiting for new full and part-time students. Applicants need a 2.8 GPA from an accredited undergraduate program and can enter with or without previous certifications. Graduates will be eligible for permanent certification in Childhood Education and Childhood Special Education with an annotation in severe disabilities. Tuition waivers and student stipends are available for students admitted into the program. The length of the program is between 1 1/2 and 2 1/2 years, depending on prior qualifications.

For further information, contact:
Dr. Rosanne K. Silberman
212-772-4740
rsilberm@hunter.cuny.edu
GRADUATE CERTIFICATE PROGRAM IN VISION

Applicants sought for Graduate Certificate Program in Vision. The RRTC on Blindness and Low Vision at Mississippi State University is seeking applicants for the Vision Specialist in Vocational Rehabilitation graduate certificate program being held March 26-May 25, 2007. The purpose of the program is to provide vocational rehabilitation counselors and graduate students in VR programs with the expertise to address issues specific to vision impairments. Students receive a stipend which includes tuition and fees, per diem for university housing and meals, and a travel allowance. The program consists of four courses for 12 graduate-level credit:

1. Rehabilitation for Persons who are Visually Impaired
2. Resources for Persons who are Visually Impaired
3. Computer Access Technology for Persons who are Visually Impaired
4. Special Project in Rehabilitation of Persons who are Visually Impaired

The registration deadline is December 15, 2006. Interested applicants can obtain additional information from our Web Site: http://www.blind.msstate.edu/Vspecialist1.html or by contacting:

Mr. BT Kimbrough, RRTC Training Director at (662) 325-7824
E-Mail: BKimbrough@colled.msstate.edu

FREE RESOURCE AVAILABLE

The CHARGE Syndrome Foundation announced that their manual, “CHARGE Syndrome: A Management Manual for Parents” version 2.1, is available as a free online resource. The manual is broken down into over 30 chapters that can be downloaded separately, or the entire 269 pages can be downloaded as one file. The manual can be found on the internet at www.chargesyndrome.org/resources-manual.asp.

JOIN THE NFADB LIST SERVE

The National Family Association for Deaf-Blind (NFADB) is a non-profit, volunteer-based family association. Their philosophy is that individuals who are deaf-blind are valued members of society and are entitled to the same opportunities and choices as other members of the community. NFADB is the largest national network of families focusing on issues surrounding deaf-blindness.

NFADB is sponsoring a list serve where you can share ideas, thoughts, questions, successes, etc. To join the list serve, send a blank e-mail to:

NFADB-SUBSCRIBE-REQUEST@TR.WOU.EDU.

Information taken from: Indiana Deaf-Blind Services Project’s News and Notes
The Individuals with Disabilities Education Act, IDEA, is the main federal program which ensures services to children with disabilities and their families. The IDEA was originally enacted by Congress in 1975 and has been reauthorized several times in past years.

On December 3, 2004, President Bush signed the Individuals with Disabilities Improvement Act, IDEA 2004, a major reauthorization and revision of IDEA. After passage of the IDEA 2004, the federal regulations were released August 3, 2006 and published in the Federal Register on August 14, 2006. These final regulations provide the guidance for implementation of IDEA 2004 in the United States.

To assist educators in the implementation of IDEA 2004 and its regulations, the ND Department of Public Instruction, NDDPI, has included a section on the NDDPI website that focuses on state and national resources relating to IDEA 2004. This website address is http://www.dpi.state.nd.us/speced/general/idea/index.shtm

Within the NDDPI website you will find several national IDEA 2004 resources. The website http://idea.ed.gov/ was developed by the U.S. Department of Education, Office of Special Education Programs. It is a “one-stop shop” for resources related to IDEA 2004. The site provides versions of IDEA and the regulations, access to cross-referenced content from other laws (e.g. the No Child Left Behind Act (NCLB), the Family Education Rights and Privacy Act (FERPA), etc.), video clips on selected topics, topic briefs on selected regulations, links to OSEP’s Technical Assistance and Dissemination (TA&D) Network and a Q & A corner where you can submit questions.

In addition to national IDEA 2004 resources, the NDDPI website provides links to ND resources relating to IDEA 2004 statutes and final regulations. You will find IDEA 2004 PowerPoint presentations as well as a Questions and Answer document that was developed to provide guidance to special and general educators providing services for families and students with disabilities in ND public schools.

The ND Office of Special Education will continue to provide updated guidance relating to IDEA 2004 on the NDDPI website. Please continue to check http://www.dpi.state.nd.us/speced/general/idea/index.shtm for the latest IDEA 2004 information.
I was asked to write about my journey through the wonder years of a deaf blind child. This story starts out with a princess...blonde hair, blue eyes, and all the drama that goes with the title of a princess. Her name is Eden. Like the garden, she is beautiful and rare and has the potential for greatness. This story is not so much about a journey, but rather, a life long road trip. I think of a journey as long, tedious, and painful. A road trip is more of an adventure. It is a fact-finding mission to seek out the unknown.

I will start at the beginning of this road trip so you can see how many miles have been traveled thus far. Eden was born January 11, 1999 by cesarean section. It was a normal pregnancy and delivery but something was wrong with her eyes. Her right eye wouldn’t open up all the way. When the nurses finally got it open, it looked a lot smaller than her left eye but nobody seemed too concerned about it. At her 2 week check-up she was referred to an Ophthalmologist in Fargo. The doctor checked her out and acted as though he didn’t really know what to make of it. He referred Eden to a Pediatric Ophthalmologist at the University of Minnesota.

So the road trip continues to Minneapolis. It was not a comforting feeling walking into a waiting room full of adults, children, doctors, and students. And waiting is what was done. Eden would go into some room and come back out to wait. This process would take several hours. What an exhausting experience with a newborn. She was finally given a diagnosis. She has microphthalmia (smaller) of the right eye. The optic nerve (optic nerve hypoplasia) in this eye is also considerably smaller. She has bilateral colobomas (involving the maculas). This means she has large blind spots that affect her central vision. Eden is near-sighted in one eye and far-sighted in the other. Her acuity has gotten better through the years but astigmatism continues to get worse. Leaving the parking ramp that day was a relief, I could handle a little vision problem. We just wanted to know why her eye was so small but we left with a lot of medical terms we couldn’t pronounce and a diagnosis we didn’t understand. As the months past by, I came to learn this little vision problem was quite a big deal.

With this diagnosis Eden was referred to a Geneticist. The Geneticist wanted to have her hearing tested because vision and hearing are closely related in the development of a fetus. Eden was bundled back into the car for another 5 hour road trip to Minneapolis. Of course, there was the usual process of waiting to see someone poke and prod this tiny little infant. A diagnosis was reached. There was no response. Well, clearly they didn’t do the test right. All infants can hear...right? After several more months of testing and a second opinion Eden was given the news. She is deaf in her left ear and has a moderate loss in her right ear. As several more months passed by she had an MRI and a CT Scan on both ears. Both the cochlea’s are significantly smaller and there was no sign of semicircular canals. The semicircular canals are used for maintaining balance. Right after her first birthday she was fitted for a hearing aid. Because of chronic ear infections and a new set of ear tubes, it would take several months to get full use out of this tiny, expensive, little instrument.

I was approached by a head start teacher in the town we lived in and she said she had heard about Eden. She asked what we were going to do. We didn’t know there was something to do. She asked if she could refer Eden to the infant development program. I will always remember her as a vital member of this road trip. The outreach staff started showing up in numbers. Eden started getting the royal princess treatment. A vision teacher, an occupational therapist, an audiologist, deaf blind support staff, a case manager, a physical therapist, and others came to the home for the initial assessment. For three years there was always a visitor. On one hand you feel so blessed that there are so many people willing to help make your child’s life more fulfilling but on the other hand you
FAMILY STORY: PRINCESS EDEN CONTINUED...

look forward to a cancellation. Early intervention was crucial for the success that Eden needed to be. Because of
these services she overcame her oral texture issues, she learned to walk before her second birthday, and she was
speaking. Not to mention the skills she attained to be a successful toddler.

Eden eventually left the toddler life behind. It was time to let the outreach staff go and become a student.
She attended a special education preschool but didn’t do so well. She was withdrawn, scared, and pretty confused
by all the commotion that goes along with a large preschool. After one year of preschool it was at a MN deaf blind
meeting that there was another option for her schooling. Would we consider a Deaf and Hard of Hearing preschool
program? Well, we are always up for an adventure. So she was off to her new preschool. She was pretty
apprehensive about the bus ride but learned to overcome her fears. Her new classroom consisted of two teachers
for the D/HH and 5 cute little boys. “Not bad for a princess”. It didn’t take long to get them eating out of her hands.
She has a personality that draws people in. Not to mention her classmates. The 5 little boys would soon become
her personal chauffeurs out at recess on the bikes and little tikes cars and were constantly vying for her attention.
She was very successful in her new school and her learning and communication skills were taking off. Throughout
her early preschool years social skills were a big concern. For someone who has a special look about her and her
lack of gracefulness and the fact that she doesn’t see and hear very well, a parent worries and wonders if there
child will eventually make some friends. Eden has several friends who accept her for who she is because she
accepts herself.

Eden would eventually become a successful Kindergartener and 1st grader. She was mainstreamed into her
classrooms with the public school system. She received para support mainly for her safety and continues to be
successful in the 2nd grade. She has been so blessed to have had so many wonderful educators help shape her
academic achievements.

Eden was diagnosed by a geneticist in 2003 with CHARGE syndrome. This syndrome is a combination of
many characteristics but she does not carry all of them. The letters in “charge” each mean something different. To
learn more about this syndrome you can link on to www.chargesyndrome.org. This diagnosis does not define who
Eden is. She has a remarkably high self-esteem and self-worth. Eden is an inspiration to everyone she encounters
because of her positive attitude and outgoing personality. Those qualities can not be taught. She was uniquely
blessed by a higher power for a special purpose. I pray that I am around to learn what that purpose is because I
know it will make me proud.

With advancements in technology throughout the years, there may be better ways for Eden to see and hear.
But if there aren’t, that’s okay. She is accepted for who she is. There are high expectations of Eden not only at
school but also at her house. She is always expected to try her best and never give up. There are no “what ifs” or
“why me’s?” but rather “why not me?” She has a 13 year-old brother and a 10 year-old sister. The rules apply
equally to all three children.

This is not the end of the road trip but merely a rest stop. Like I said before, Eden is beautiful, rare, and has
the potential for greatness. And I should know, I’m her mother.

Respectfully yours,

Jody Neva, mother to Eden
Please Help Update Our Mailing List

I would like my name added to the mailing list to receive future issues _____

I am no longer interested in receiving this newsletter, please delete my name from the mailing list _____

I have moved, please change my address: _____

I would like to receive the newsletter in:
Standard Print____ Large Print____ Braille ____

Name: _______________________________________
Agency: _____________________________________
Address: _____________________________________
______________________________________________

Mail to: ND Deaf-Blind Services Project
        1401 College Drive North
        Devils Lake, ND 58301-1596

---

The D-B Informer is a free newsletter published by the North Dakota Deaf-Blind Services Project.

The newsletter is produced and distributed through Grant #H326C030031 from the US Department of Education. Points of view and opinions do not necessarily reflect the position of the US Department of Education or the ND Deaf-Blind Project.

There are no copyright restrictions on this newsletter unless noted; however, please credit the source when using the material.

The North Dakota Deaf-Blind Services Project does not discriminate on the basis of race, color, national origin, sex, age, or disability in employment or the provision of services.

Carmen Grove Suminski, Project Director
ND Vision Services/School for the Blind
500 Stanford Road
Grand Forks, ND 58203

Sherri Nelson, Project Coordinator
ND Deaf-Blind Services Project
1401 College Drive N
Devils Lake, ND 58301-1596

Phone: 701-665-4401 or 877-630-6214
Fax: 701-665-4409
E-mail: sherri.nelson@sendit.nodak.edu
www.nd.gov/deafblind/

---

ND Department of Public Instruction
Dr. Wayne G. Sanstead, State Superintendent
North Dakota Deaf-Blind Services Project
1401 College Drive N
Devils Lake, ND 58301-1596

Presorted Standard
Non-Profit Organization
U.S. Postage Paid
Permit No. 18
Devils Lake, ND 58301