



# D - B I N F O R M E R

JANUARY 2011 WWW.ND.GOV/DEAFBLIND/ 1-701-231-6033

## Shaping Collective Wisdom in the Field of Deaf-Blindness

D. Jay Gense, Director  
National Consortium on Deaf-Blindness

Many readers may be aware that NCDB is working closely with the Department of Education's Office of Special Education Programs to implement a technology initiative to enhance and systematize the national deaf-blind project network and expand opportunities for technical assistance at state, local, and classroom levels. As this exciting initiative moves forward, I find myself reflecting on the current and future value of *Deaf-Blind Perspectives (DBP)*, as well as on ways that information about deaf-blindness and the broader field of special education can best be shared among families, consumers, educators, and other service providers within our field. That reflection leads me to a conclusion that a "dual reality" exists relative to information infrastructures that the deaf-blind network can and should exploit to make information and content available. While recognizing and very much supporting that information dissemination efforts are increasingly influenced by the technical, dynamic world of web-based information and resources, as well as by increasingly popular blogs and tweets that deliver "sound bites" of information, I believe it's important that we not lose sight of the inordinate value and purpose of more traditional publications like *Deaf-Blind Perspectives*.

DBP provides to its audience a dedicated mechanism to highlight current issues in and explore content about deaf-blind education. It focuses deeply on



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Dr. Wayne G. Sanstead  
State Superintendent



the specialized instructional strategies and methodologies required by students who are deaf-blind and provides families and schools a means to maximize this specialized knowledge by helping to integrate it with other information and resources within the broader field of special education. That's important. We should all offer our thanks for the significant time and dedication each contributing author gives to ensure that readers are provided with valuable information, and we should acknowledge and applaud the significant time and talent of DBP's editorial staff. It's extraordinary how much behind-the-scenes work is required to produce each issue in a way that meets consistently high standards. The high quality of content and the expert articulation of "message" are evident, and we are grateful.

All of us in the deaf-blind network should be cognizant of the opportunities that this publication provides and take advantage of them. To that end, I'd like to highlight the importance of DBP readers' direct participation in the published content. While most articles published in DBP address specific content from the field of deaf-blind education, some offer more personalized perspectives on service delivery models, theories, and approaches that may or may not be familiar to or supported by all readers. While readers all share a personal or professional focus on striving for improved outcomes for and achievement by infants, children, and youth who are deaf-blind, we also have different backgrounds and points of view and can increase our knowledge base by learning from each other. Exposure to and reflection on differing perspectives help to shape our own. Such reflection should be encouraged because the sharing of views and wisdom gained through experience strengthens the accumulated knowledge of our field.

As noted above, there are a variety of ways in which we can share our perspectives and experiential wisdom, and I challenge our readers to take advantage of them, whether in traditional publications like DBP or through newer technology-driven options such as discussion blogs or social media sites. This sharing of information is particularly important during these times in which the United States is engaged in significant educational reform efforts. For example, many readers are aware of pending efforts to reauthorize federal legislation, the Elementary and Secondary Education Act (or No Child Left Behind Act), and presumably to reauthorize the Individuals with Disabilities Education Act. Concurrently within the field of special education, a number of initiatives in the overall design and delivery of both general and special education services are becoming increasingly important, including Response to Intervention (RTI) and Universal Design for Learning (UDL). It is critical that we in the fields of deaf-blindness and other low-incidence disabilities engage actively in conversations about these and other

educational reform efforts to ensure that they reflect the needs of children who are deaf-blind and their families, as well as the systemic needs of the field of deaf-blindness. We each have a responsibility to help with the clear articulation of these interests.

In summary, I encourage you to recognize the value of *Deaf-Blind Perspectives* and take advantage of opportunities to contribute to the literature of the field. In the coming months, as NCDB moves forward with its technology initiative, other opportunities for active contribution will become available. Taking advantage of them will allow us to use the collective wisdom of professionals, families, and consumers to increase our knowledge base and our ability to serve infants, children, and youth who are deaf-blind.

Article from *Deaf-Blind Perspectives*, Volume 18, Issue 1.



## READING MATTERS: The Importance of Learning to Read by the End of Third Grade



ND KIDS COUNT—[www.ndkidscount.org](http://www.ndkidscount.org)

Reading proficiently by the end of the third grade can be a make-or-break benchmark in a child's educational development. Up until the end of the third grade, most children are **learning to read**. Beginning in the fourth grade, they are **reading to learn**, using their skills to gain more information in subjects such as math and science, to solve problems, and to think critically.

Three quarters of students who are poor readers in the third grade will remain poor readers in high school, according to Yale University researchers. And children who reach the fourth grade without learning to read proficiently are more likely to be on a path to dropping out of school.

Unfortunately, children from lower-income families are more likely to be poor readers. Disparities in developmental outcomes “emerge in infancy and widen in toddlerhood. By the time children from low-income families enter kindergarten, they are typically 12-14 months below national norms in language and pre-reading skills” (Council of Chief State School Officers, 2009).

### Current Reading Proficiency Levels in North Dakota

- The majority of North Dakota children are not learning to read proficiently by the end of grade 3
- 65% of North Dakota 4th graders score below proficiency level in reading

- 78% of North Dakota 4th graders from lower-income families score below proficiency level in reading

In North Dakota, we celebrate children's births. But, do we wait to see if they succeed in school before we pay attention to their strengths and needs?

We all are responsible for helping improve children's reading proficiency: Parents, policy makers, child advocates, educators, neighbors, libraries, early childhood caregivers, and community program organizers.

### **Some strategies for helping children to become better readers:**

**A is for ASSIST.** Help children prepare for entry into school through high-quality early care and education experiences. About half (49%) of North Dakota children ages 3-5 are not enrolled in nursery school, preschool, or kindergarten. This compares to 39% of U.S. children ages 3-5 who are not enrolled in nursery school, preschool, or kindergarten.

**B is for BOOKS.** Read to a child and cultivate a joy of learning. Some North Dakota children ages 1-5 (9%) are read to by family members less than 3 days a week. Young children whose parents read to them, tell stories, or sing songs tend to develop larger vocabularies.

**C is for CREATE.** Create language-rich summer learning opportunities. Children experience a decline in reading comprehension over the summer months. This reading comprehension loss is larger for children from lower-income families.

*This report is drawn from "early Warning! Why Reading by the End of Third Grade Matters," a 2010 KIDS COUNT Special Report from the Annie E. Casey Foundation, available at [www.kidscount.org](http://www.kidscount.org).*

## **National Family Association for Deaf-Blind (NFADB)**

The National Family Association for Deaf-Blind is the largest nonprofit national organization of families of individuals who are Deaf-Blind.

NFADB believes that individuals who are Deaf-Blind are valued members of society and are entitled to the same opportunities and choices as other members of their community.

NFADB exists to empower the voices of families of individuals who are Deaf-Blind and to advocate for their unique needs. All members automatically receive the NFADB newsletter, which is available by request in Braille, Large Print, or electronically.

For more information: NFADB 141 Middle Neck Road, Sands Point, NY 11050, #1-800-255-0411, email: [NFADB@aol.com](mailto:NFADB@aol.com) website: [www.NFADB.org](http://www.NFADB.org)

## HOW CAN YOU BE INVOLVED



Become an AADB member and receive *The Deaf-Blind American* magazine twice a year with in-depth coverage about important issues in the Deaf-Blind community. Individual membership is only \$15.00!!

The mission of AADB is to ensure that all Deaf-Blind persons achieve their maximum potential through increased independence, productivity, and integration into the community. They are involved in many projects to promote their mission in the national DB community : Advocacy & Outreach, National Conferences, National Task Force on DB Interpreting, Support Service Provider & Technology Summits, Information Clearinghouse, Deaf-Blind Count, and AADB Today.

We are a national consumer organization of, by, and for Deaf-Blind people and their supporters. Our membership consists of people with all types and degrees of vision and hearing loss, as well as family members, interpreters, professionals, and other interested people.

To learn more, go to [www.aadb.org](http://www.aadb.org)

**FACEBOOK:** Join AADB on Facebook and meet other teens and youth!!

Go to [www.facebook.com](http://www.facebook.com) and use the search engine to look for AADB.



There is a teen program at the national conferences. Teens can connect with each other and learn new skills. Check it out!!

**AADB**· 8630 Fenton St., Ste #121, Silver Spring, MD 20910

TTY/VP: 301-495-4402, VOICE: 301-495-4403, FAX: 301-495-4404

Email: [aadb-info@aad.org](mailto:aadb-info@aad.org)

Website: [www.aadb.org](http://www.aadb.org)



*"The best and most beautiful things in life cannot be seen or even touched. They must be felt within the heart."*

*-Helen Keller*

## HANDS & VOICES



Hands & Voices is a parent-driven organization that is dedicated to supporting families with children who are Deaf and Hard of Hearing without a bias towards communication mode or methodology. It also provides families with the resources, networks, and information they need to improve communication access and educational outcomes for their children. In addition, they have outreach activities, parent/professional collaboration, and advocacy efforts focused on enabling Deaf and Hard of Hearing children to reach their highest potential. For further information on the national organization go to: [www.handsandvoices.org](http://www.handsandvoices.org)

Currently we are working on starting a ND Chapter of Hands & Voices. On October 20, 2010, we received provisional chapter status and the authorization to use the name North Dakota Hands and Voices. If you are interested in being part of the “Start-up Team” or need more information, please contact Stephanie or Thomas Stiel at [handsandvoicesnd@midco.net](mailto:handsandvoicesnd@midco.net) or call them at #701-281-6098 or 701-866-6410 in Fargo.

We strongly encourage parents and professionals to join!

[www.handsandvoices.org/articles/education/popup/pop-index.html](http://www.handsandvoices.org/articles/education/popup/pop-index.html)

This is a product designed by Hands & Voices to help parents steer through IEP meetings. It is worth checking out!!

## FAMILY CONNECT

Every parent wonders, “Will I do a good job raising my child?” If your child is visually impaired, you’ll have the same question....and many more! FamilyConnect ([www.familyconnect.org](http://www.familyconnect.org)) has the answers. Whether your child was recently diagnosed, has been living with a visual impairment for years, or is multiply disabled, you’ll find the personal support, information, and resources you need to raise a child with vision loss from birth to adulthood. FamilyConnect offers you: vital links to families just like yours, customized information, events, and news based on your child’s age, eye condition, and location, and timely authoritative information. FamilyConnect is brought to you by the American Foundation for the Blind (AFB) and the National Association for Parents of Children with Visual Impairments (NAPVI). Visit today at [www.familyconnect.org](http://www.familyconnect.org) and find the support you need to raise your child!



**ND Dual Sensory Project  
Technical Assistance Team**

**ND School for the Deaf**

Carol Lybeck => Devils Lake  
Linda Ehlers => Fargo  
Denise Marback => Grand Forks  
Tami Iszler => Bismarck  
Nicole Swartwout => Minot



**ND Vision Services**

**School for the Blind**

Dianne Giessinger => Minot  
Linda Kraft => Fargo  
Lanna Slaby => Jamestown  
Cindy Williams => Grand Forks  
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  
Kathy Grzadzielewski => D. Lake  
Tracy Wicken => Grand Forks



Technical assistance request forms are located at [www.nd.gov/deafblind/](http://www.nd.gov/deafblind/) or call 1-800-421-1181

**National Association for Parents of Children with Visual Impairments  
(NAPVI)**

*For Parents.....By Parents*

NAPVI is a national, non-profit, independent organization that enables parents to find information and resources for their children who are blind or visually impaired, including those with additional disabilities.

NAPVI provides leadership, support, and training to assist parents in helping children reach their full potential.

NAPVI is dedicated to: Giving emotional support, Parent education; Initiating outreach programs, Networking, Advocating for the educational needs and welfare of children who are blind and visually impaired.

FOR MORE INFORMATION GO TO: [www.napvi.org](http://www.napvi.org)

NAPVI, PO Box 317, Watertown, MA 02471

National Toll-free Phone: #1-800-562-6265

Phone: 617-972-7441; Fax 617-972-7444

Email: [napvi@perkins.org](mailto:napvi@perkins.org)



**BLOGS relevant to Deaf-Blindness**

AERs Division Three Blog <http://divisionthree.org>

California Deaf-Blind Services <http://www.cadbs.org/staff-blog>

Deafblinddad.com <http://www.deafblinddad.com>

Kauffman Family Update <http://kauffmanlak.blogspot.com>

Kinnick and Carver Family Blog <http://kinnickandcarver.blogspot.com>

Life is a Patchwork Quilt-Deaf-blind category <http://lifeisapatchworkquilt.com/blog/?cat=128>

Tactile the World: Journey into Deaf-Blindness <http://tactiletheworld.wordpress.com>

The Deaf-Blind's Musing <http://thedeafblindsmusing.blogspot.com>



## PUBLICATIONS/PRODUCTS

### ***Practice Perspectives: Authentic Assessment***

This publication from the National Consortium for Deaf-Blindness describes an authentic approach to the assessment of communication and learning that emphasizes gathering information about children in their everyday environments during normal activities. For more information go to: [nationaldb.org/NCDBProducts.php?prodID=111](http://nationaldb.org/NCDBProducts.php?prodID=111) or call NCDB @ #1-800-438-9378

**CHARGE Syndrome by Timothy Hartshorne, Margaret Hefner, Sandra Davenport, & James Thelin. Plural Publishing, Inc., 2010, 381 pages.**

This book provides comprehensive information about the sensory, physical, and psychological challenges faced by children with CHARGE syndrome and ways to overcome these challenges. Available from the publisher ([www.pluralpublishing.com](http://www.pluralpublishing.com)) and through Amazon.com

**Child-Guided Strategies: The van Dijk Approach to Assessment (Guidebook and DVD) by Catherine Nelson, Jan van Dijk, Teresa Oster, & Andrea McDonnell. American Printing House for the Blind, 2009.**

This guidebook describes the assessment of children who are Deaf-Blind using an approach developed by Dr. Jan van Dijk. Assessment techniques and general intervention strategies are provided for a child's behavioral state, orienting response, learning channels, likes and dislikes, memory, social interactions, communication, and problem solving skills. Video clips of two children demonstrating the concepts described in the book are provided on the DVD. Available from the *American Printing House for the Blind*. [www.aph.org](http://www.aph.org) or call #1-800-223-1839

**Let's Talk Limbic: The Role of the Emotional Brain in the Well Being of Persons with Multiple Sensory Impairments (DVD) by Jan van Dijk, Catherine Nelson, Arno de Kort, Johannus Fellingner, & Rick van Dijk. 2010**

This DVD is for professionals and paraprofessionals who want to understand the deep emotional motives of a person with multiple sensory impairments. It describes the functioning of a major part of the human emotional brain, the limbic system, and illustrates how sensory deprivation affects emotional well-being. Available from Vision Associates: 295 NW Commons Loops, Suite 115-312, Lake City, FL 32055. #407-352-1200 or [www.visionkits.com](http://www.visionkits.com)

**Providing and Receiving Support Services: Comprehensive Training for Deaf-Blind Persons and Their Support Service Providers** by *Seattle Deaf-Blind Services Center, 2010.*

This curriculum is designed to be used to train support services providers (SSPs) to work with people who are Deaf-Blind and to train people who are Deaf-Blind to work with SSPs. Available free of charge at <http://seattledbsc.org/visualweb/SSPCurriculum.html>

**ONLINE MEDIA**

**New Perkins Webcasts!!**

[www.perkins.org/resources/webcasts](http://www.perkins.org/resources/webcasts)



Perkins School for the Blind has developed a variety of informative webcasts presented by experts in the field of visual impairment and Deaf-Blindness and more are planned for the future. Recently added include: “Reflections on Deaf-Blindness: Hands & Touch”, and “CHARGE Syndrome: Teaching Strategies for Students”. These can be viewed free of charge on the Perkins website.

**Who’s Who on My Child’s Team Videos**

[www.cadbs.org/videos](http://www.cadbs.org/videos)

California Deaf-Blind Services (CDBS) is developing a series of online videos that highlight the roles of specialists often included on educational teams for students who have both hearing and vision impairments. Currently two videos (“Teacher of the Deaf/Hard of Hearing”, and “Occupational Therapist”) have been completed. Six additional videos are planned.



**FACT:** Everyday in the United States, approximately 1 in 1,000 newborns (or 33 babies everyday) are born profoundly deaf with another 2-3 out of 1,000 babies born with partial hearing loss, making hearing loss the number one birth defect in America ([www.cdc.gov](http://www.cdc.gov)).

For North Dakota this equates to about 10 born profoundly deaf with another 20-30 infants born with some degree of hearing loss each year. In 2009, ND reported 13 cases of hearing loss. We have a long way to go!



## 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 Dual Sensory Project

Sherri Nelson, Project Coordinator  
701-231-6033

#### 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

The National Consortium on Deaf-Blindness completed their newest publication, *Authentic Assessment*. It is adapted from a manual called *Assessing Communication and Learning in Young Children Who Are Deaf-Blind or Who Have Multiple Disabilities*.

This is the sixth in a series of publications called *Practice Perspectives*, designed to increase the use of current information resources through the development of easily understandable products in accessible formats. This and previous publications are available at [www.nationaldb.org/NCDBProducts.php?prodID=111](http://www.nationaldb.org/NCDBProducts.php?prodID=111)

EHDI (Early Hearing Detection & Intervention) Programs are located in states and are designed to identify infants with hearing loss by universal screening. This allows identified infants to be enrolled in an early intervention program. These intervention programs are designed to help facilitate the development of visual and/or spoken language and the cognitive skills needed to succeed academically and socially. Check this out: [www.ndcpd.org/ehdi](http://www.ndcpd.org/ehdi)

## **THE MAGIC HAPPENS HERE**

### **10<sup>th</sup> International, CHARGE Syndrome Conference**

**July 28-31, 2011, Orlando, Florida**



The CHARGE Syndrome Conference is the largest worldwide gathering of individuals with CHARGE, their families, professionals, and experts on CHARGE. As parents learn and share, family members can attend day camp. With up to 5 or 6 concurrent presentations, the conference offers everyone a unique opportunity to learn from the experts and share experiences with other families.

While the learning is intense, so is the fun! Every evening is filled with opportunities to meet and mingle with other families. From Thursday's reception to Friday's conference Idol to Saturday's dinner party and silent auction- magic fills the air! Participation in a CHARGE conference is truly a life-changing experience.

It will be held at the Rosen Shingle Creek family resort nestled on a 230 acre site just off Universal Boulevard, ten minutes from the Orlando International Airport, Sea World, and Universal Orlando. Stay tuned for more information. On-line registration begins March 1, 2011. For more information go to: [www.chargesyndrome.org](http://www.chargesyndrome.org)



## Dual Sensory Advisory

### Board Members

#### **Carmen Grove Suminski**

Dual Sensory Project Director,  
ND Vision Services Supt, &  
ND School f/t Deaf Supt

#### **Sherri Nelson**

Dual Sensory Project Coordinator

#### **Joni Andre**

Teacher

#### **Jody Neva**

Parent

#### **Jodi Appelt**

Education of the Deaf

#### **Karalee MacIver**

Parent

#### **Carol Lybeck**

NDSD PIP/Outreach Coordinator

#### **Connie Hovendick**

Lake Region Special Ed

#### **Angie Villorreal**

SE KIDS Program

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Developmental Disabilities

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#### **Tami Iszler**

Deaf Outreach

#### **Ramona Gunderson**

NE KIDS Program

#### **Linda Ehlers**

Deaf Outreach

#### **Nicole Swartwout**

Deaf Outreach

# UPCOMING EVENTS

- ★ 2011 National EHDI Conference, Omni Hotel in Atlanta, Georgia, **February 21-22, 2011**
- ★ American Academy of Audiology Annual Conference, Chicago, Illinois, **April 6-9, 2011**
- ★ Council for Exceptional Children Convention (Expo), National Harbor, Maryland, **April 25-28, 2011**. <http://www.cec.sped.org>
- ★ American Association of the Deaf-Blind (AADB) National Symposium: The Future is in Our Hands, **June 19-23, 2011**, in Ft. Mitchell, KY. The symposium will be chock-full of activities for Deaf-Blind participants: workshops, exhibits, networking opportunities, special interest group meetings and more! For more info: <http://aadb.org/conference>
- ★ American Society for Deaf Children 2011 Biennial Conference: Parent Choices: Key To Your Child's Future, Maryland School for the Deaf, Frederick, Maryland, **June 22-26, 2011**. For more information call 301-360-2054
- ★ Helen Keller National Center Summer Seminar for High School Students Who Are Exploring Future Vocational and Educational Opportunities, Sands Point, NY, **July, 2011**. The Helen Keller National Center is offering a two-week seminar to high school students (juniors and seniors) who are Deaf-Blind and interested in learning about vocational rehabilitation services while meeting new friends. For registration materials or further information, contact Maureen McGowan, our HKNC regional rep at 303-934-9037 or [maureen.mcgowan@hknc.org](mailto:maureen.mcgowan@hknc.org) or [www.hknc.org](http://www.hknc.org)
- ★ International CHARGE Conference (10th), Orlando, Florida, **July 29-31, 2011**. <http://www.chargesyndrome.org>

## Training Opportunities

Tangible Symbol Systems and Pre-Symbolic Communication On-line Classes @ OHSU Design to Learn Projects. Both courses are offered as self-paced noncredit learning opportunities. You may register online at any time and go through the materials on your own timetable for two months. The cost is \$165. For more information: <http://www.ohsu.edu/oidd/d21/training>

### FUN FOR CHILDREN AND ADULTS!!

The Braille Bug is a fun and interactive website through the American Foundation of the Blind (AFB). Enjoy learning about Braille through games and riddles in addition to finding out more about Louis Braille and Helen Keller. Go to: <http://www.afb.org/braillebug>



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Dr. Wayne G. Sanstead, State Superintendent  
North Dakota Dual Sensory Project  
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## CHANGE SERVICE REQUESTED

**We are on the web!**  
[www.nd.gov/deafblind/](http://www.nd.gov/deafblind/)

### 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 Dual Sensory Project  
Sheri Hettwer, Admin. Asst.  
8687 53rd Street NE  
Devils Lake, ND 58301

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