

North Dakota
Deaf-Blind Services Project

D - B I N F O R M E R

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WWW.ND.GOV/DEAFBLIND/

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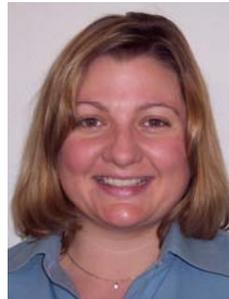
DEAF-BLIND PROJECT UPDATES

The North Dakota Deaf-Blind Services Project (NDDSP) is located in Devils Lake, ND, at the ND School for the Deaf. The NDDSP is a federally funded free resource designed to enhance the provision of services for children and young adults, birth through age 21, who are deaf-blind. The mission statement of the NDDSP is to improve the education and services for children with deaf-blindness and their families in North Dakota. This is accomplished through training, mentorship, resource dissemination, and technical assistance.

Carmen Grove-Suminski is the project director. Carmen is the superintendent of ND Vision Services/School for the Blind located in Grand Forks, ND. The project coordinator is Kristen Votava, who began working for the NDDSP in September of last year. The project support staff person is Sheri Hettwer, located at the School for the Deaf.



Carmen Grove Suminski



Kristen Votava



Sheri Hettwer



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

The NDDSP maintains a yearly census of children in the state who are deaf-blind and works to provide training to service providers and families. Outreach staff from ND Vision Services/School for the Blind and the ND School for the Deaf provide technical assistance to children, families, and service providers across the state. The NDDSP maintains a lending library of resources on the subject of deaf-blindness in Devils Lake, and the project website has useful information such as upcoming events, project brochures, and internet links.

We hope you enjoy this issue of the D-B Informer. The issue contains a variety of information on new books available in our lending library, useful websites, future training events, and Kaylyn's personal story. If you have any questions about the project, please call or e-mail Kristen Votava.

WHAT IS DEAF-BLINDNESS?

It may seem that deaf-blindness refers to a total inability to see or hear. However, in reality deaf-blindness is a condition in which the combination of hearing and visual losses in children cause "such severe communication and other developmental and educational needs that they cannot be accommodated in special education programs solely for children with deafness or children with blindness" (34 CFR 300.7 (c) (2), 1999) or multiple disabilities. Children who are called deaf-blind are singled out educationally because impairments of sight and hearing require thoughtful and unique educational approaches in order to ensure that children with this dis-

ability have the opportunity to reach their full potential. A person who is deaf-blind has a unique experience of the world. For people who can see and hear, the world extends outward as far as his or her eyes and ears can reach. For the young child who is deaf-blind, the world is initially much narrower. If the child is profoundly deaf and totally blind, his or her experience of the world extends only as far as the fingertips can reach. Such children are effectively alone if no one is touching them. Their concepts of the world depend upon what or whom they have had the opportunity to physically contact. If a child who is deaf-blind has some usable vision and/or hearing, as many do, her or

his world will be enlarged. Many children called deaf-blind have enough vision to be able to move about in their environments, recognize familiar people, see sign language at close distances, and perhaps read large print. Others have sufficient hearing to recognize familiar sounds, understand some speech, or develop speech themselves. The range of sensory impairments included in the term "deaf-blindness" is great.

Reprinted with permission from *Overview on Deaf-Blindness* by Barbara Miles. (Revised January 2005). Monmouth, OR: DB-LINK (The National Information Clearinghouse on Children Who Are Deaf-Blind), www.dblink.org.

NATIONAL COALITION ON DEAF-BLINDNESS

The National Coalition on Deaf-blindness has begun an advocacy campaign to increase the amount of federal monies allocated to services for children who are deaf-blind. We want to add \$2 million dollars over the President's budget in fiscal year 2007 to address the resource needs of children who are deaf-blind and their families. Approximately \$1.4 million of these monies would be allocated to the state projects, \$350,000 would support the activities of the National Deaf-blind Technical Assistance and Dissemination Center (the new merged NTAC/DB-LINK project) and \$250,000 would be earmarked to strengthen personnel preparation programs.

For several months, members of the Coalition have been meeting with key members of congress and their staffs to gather support for our initiative. We have also been work-

ing with families and professionals in a few states to inform their legislators about the critical need for greater support for children who are deaf-blind. We are gaining momentum. We are thrilled to announce that this request has been submitted in the Senate by Senator John Kerry and Senator Edward Kennedy. We are optimistic that the funding request and accompanying report language will also be submitted in the House.

Now we need your help! We need families and professionals concerned about services for children who are deafblind from all over the country to contact their legislators. Members of Congress and the Senate need to hear from their constituents. They need to understand how important their support for state and national deaf-blind projects is to you and your family and/or

the students with whom you work.

Federal support for the technical assistance and dissemination programs that support children who are deaf-blind and their families has remained stagnant for the past twenty years. At the same time, the population of children who are deaf-blind has more than doubled - increasing nationally from 4000 in the mid 1980s to nearly 10,000 today. We can not afford to let services continue to erode. We need the additional federal help now.

More detailed information about the funding request, the history of services to children who are deafblind, sample letters and links to help you contact your legislators are available at the Coalition's web site. <http://www.dbcoalition.org/>

ND Deaf-Blind Project Technical Assistance Team

ND School for the Deaf

Carol Lybeck => Devils Lake

Linda Ehlers => Fargo

Holly Pedersen => Minot

Tami Iszler => Bismarck

North Dakota



School for the Deaf

ND Vision Services

School for the Blind

Dianne Giessinger => Minot

Linda Kraft => Jamestown

Lanna Slaby => Jamestown

Marie Topp => Fargo

Mary Verlinde => Bismarck

Katrina Wendel => Grand Forks



Technical assistance request

forms are located at

www.nd.gov/deafblind/

or call 1-877-630-6214

EARLY CHILDHOOD SPECIAL EDUCATION UPDATES

BY NANCY SKORHEIM, DEPARTMENT OF PUBLIC INSTRUCTION

There are many new and exciting adventures happening nationally and statewide in the area of Early Childhood Special Education. Listed below are updates relating to three current ND projects.

EARLY CHILDHOOD TRANSITION GUIDELINES

Last school year, several ECSE professionals completed a survey for our Department that focused on the transition process from Part C services to Part B services. In response to the survey input and to needs expressed by parents and early childhood professionals, the Transition Guide-

lines Workgroup continues their work in the development of a comprehensive and useful Transition Guideline.

In March, the Workgroup met in Bismarck to review the final draft of the Transition Guidelines. Catherine Benitz from Mountain Plains

Regional Resource Center, MPRRC, is the main writer for this document. We are hopeful that once the Part C and Part B IDEA04 regulations are finalized, we will be able to complete the Guidelines and share this information through regional trainings across ND.



EARLY LEARNING GUIDELINES

Last spring, the Department of Human Services - Child Care, Part C and Head Start Collaboration Office and the Department of Public Instruction - Office of Special Education and Standards and Achievement, began the process of contracting skilled writers for the development of statewide Early Learning Guidelines, ELG. A draft of

the ELG has been developed by the ELG writers along with input from the ELG Committee comprised of individuals who provide services to young children, their families and preservice professionals working in early childhood education.

The ELG will provide guidance for all entities providing services for young children age's birth to five

years. The ELG embeds a set of developmental outcomes and benchmarks in early literacy, numeracy, motor, social/emotional, adaptive skills, communication and cognitive domains. The ELG Committee will be meeting in May to discuss input relating to the current draft and to determine long range training and distribution plans.

The ND Transition Steering Council announces the Interagency Transition Institute: "Collaborating for Successful Youth" October 2-4, 2006 in Mandan, ND

STATE PERFORMANCE PLAN

In December 2005, our Department submitted a six year state performance plan, SPP, to the Office of Special Education, OSEP. The SPP was a requirement of all states through the IDEA 2004 statutes. A copy of the ND SPP can be found at <http://www.dpi.state.nd.us/sped/general/perfplan.pdf>

One of the Indicators within the SPP, Indicator 7, focuses on the measurement of pre-

school outcomes in the areas of social-emotional skills, acquisition and use of knowledge in skills, and use of appropriate behaviors. The process to measure this Indicator is complex.

Our Department has begun work to develop a comprehensive plan to implement Indicator 7. We are working with the National Early Childhood Technical Assistance Center, NECTAC and a Work-

group of ND Early Childhood Special Education professionals to develop the ND plan.

The ND plan to implement Indicator 7 will begin with a pilot of the plan starting May 15th. Four locations have volunteered to participate as pilot sites for this plan.



UPCOMING EVENTS

- The **Fargo-Moorhead Monthly Social** is organized by local parents of children who are deaf or hard of hearing and the ND School for the Deaf. Socials will be held on Saturdays from 1:00 pm-3:00 pm at First Lutheran Church in Fargo. The social events are scheduled for Saturday, May 13, September 9, October 14, and November 11, 2006. If interested, please contact Linda Ehlers at 701-239-7116.
- The **Anne Carlson Center** is offering three educational opportunities: The Power of Positive Behavior Supports on June 1-2, 2006, Technocamp: Adapting the Arts Using Technology on July 9-14, 2006, Addressing Challenging Behaviors Using Visual Supports on August 14-15, 2006. For more details about these seminars or to register please visit: www.annecenter.org
- June 13-15, 2006 **North Dakota Family Connections Conference: When Children Have Special Needs is Building Community by Sharing Responsibility**. The conference creates opportunities for families with children who have delays, disabilities and chronic mental and physical health needs and the professionals who support those families to learn about best practice, and build welcoming ND communities by sharing responsibilities. Held at the Best Western Ramkota Hotel in Bismarck, North Dakota. For more information: www.conted.und.edu/connections/
- July 13-14, 2006 **Picture Exchange Communication System (PECS) Training**. Held at the Ramada Plaza Suites & Conference Center in Fargo, North Dakota. For more information: www.pecs.com
- July 13-15, 2006 **NTAC/NFADB National Family Workshop on Advocacy & Leadership**. Held in Tampa, Florida.
- July 24-28, 2006 **Nebraska Deaf-Blind Summer Institute**. Held at the University of Nebraska-Lincoln Barkley Center, East Campus. For more information call Teresa Coonts, Coordinator at 402-595-1810.
- July 27-29, 2006 **The Charge Syndrome Foundation** will host the 8th International CHARGE Conference in Costa Mesa, California. For more information: www.chargesyndrome.org or call 1-800-442-7604.
- August 9-10, 2006 The **Communities Collaborative Committee** will present northwest Minnesota's largest Brain Development Conference: "Working Together for Every Child." The conference will bring together Temple Grandin, Ph.D, Dr. Louis Rosetti, Dr. Zeynep Biringen, Monte Fox, Ron Glodoski, and Geoffrey Canada. Registration deadline is July 24, 2006 for the conference. The conference will be held at the Shooting Star Casino Hotel & Event Center in Mahanomen, Minnesota. For more information: www.whiteearthchildcare.com or call 218-983-3285 ext. 1407.
- September 19-20, 2006 **Cortical Vision Impairment Training** at the School for the Blind, sponsored by the North Dakota Deaf-Blind Services Project. Christine Roman, Ph.D., will present information about cortical vision impairment, assessment of children with CVI utilizing the CVI Range, IEP development, and intervention. Further information and registration will be out soon. Please call Kristen Votava, Deaf-Blind Project Coordinator, at 1-877-630-6214 for more information.

D-B Advisory

Board Members

Kristen Votava

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 Fogelson

ND School f/t Deaf Supt

Karalee MacIver

Parent

Carol Lybeck

NDSD PIP/Outreach Coordinator

Connie Hovendick

Lake Region Special Ed

Sherrie Nelson

Fargo Infant Development

Nancy Lundon

Vocational Rehabilitation

Michael Marum

Developmental Disabilities

Pamilla Schauer

Anne Carlson Center

Nancy Skorheim

ND Public Instruction

Kari Chiasson

UND Vision Training Program

Darlene Schoenfish

NDSD nurse

Lanna Slaby

Vision Outreach

Tami Iszler

Deaf Outreach

Ramona Gunderson

KIDS Program

Dr. Craig Bratvold

Optometrist

Linda Ehlers

Deaf Outreach

ASSISTIVE TECHNOLOGY

NO, NOT “SPECIAL”...THEY ARE ORDINARY NEEDS

REVOLUTIONARY COMMON SENSE BY KATHIE SNOW

To create this article, I needed a computer with the software that meets my needs. To learn to write and read, my son, Benjamin, has also needed a computer with the right software since the age of four.

To get to work every day, Richard needs a good set of wheels on his car. Holly also needs a good set of wheels to get from class to class on campus.

Miranda needs a clip-on wireless microphone before she can successfully deliver her keynote presentations. Jose needs a communication device before he can successfully express himself at home, at school, and in other environments.

Daniel, a doctor, needs voice recognition (VR) computer software to effectively dictate his daily notes. Samantha, an eight-year-old, needs VR software so she can write stories and book reports in third grade.

Kate spends 50+ hours at her desk, but couldn't do so without her ergonomic chair and curved desk that holds her multiple terminals. Amelia also needs a desk that meets her work needs—a height-adjustable, curved desk with desktop cubbys so everything is within arm's reach.

Acme Widget Company has risen to the top of its field because the individual differences—including some behavioral eccentricities—of all employees are supported and valued. Mrs. Dahl's classroom is viewed as a model of success and all students are learning, because she's created a caring environment where all students—including those with significant differences and needs—are valued and supported.

Tyrone is a great “honey-do” hubby at home. But he can't do everything for himself, so he occasionally hires a plumber or an electrician. Oscar is thrilled to have his own apartment, but he can't do everything for himself—including getting dressed and undressed—so his family and neighbors pitch in and he pays for other assistance.

Maria cannot sit through the Sunday morning sermon without rhythmically shaking her right leg as it's crossed over her left, and she also doodles on the Sunday program. Tony cannot sit through church without occasionally flapping his arms and rocking back and forth in the pew.

To be successful at home, school, work, and in other environments, to achieve our hopes and dreams, and-or to simply get through each day, *everyone* needs assistive technology (AT), accommodations, and supports. The examples above describe these *ordinary needs* of a variety of different people. And as you might have figured out by now, the second example in each description involves people with disabilities.

Too often, however, we say children and adults with disabilities have “special needs.” In another article (*The Case Against “Special Needs”* available at www.disabilityisnatural.com), I describe the dangers of using this term to describe individuals with disabilities, as in, “She has special needs.” This descriptor generates pity, segregation, and worse.

But we need to take an even closer look at the consequences of the “special needs” mentality. For it seems that

identifying the needs of a person with a disability as “special” and *using the term* “special needs” leads to the perception that these needs are different, extraordinary, expensive, and/or abnormal. This perception, in turn, results in these needs *not* being met, and the negative chain of events ends with exclusion and segregation, loss of opportunities, the presumption of incompetence, and more!

For example, Julia, a child with a disability, is not talking and cannot write with a pencil. Based on formal assessments, she's said to have an IQ of 50 (and is presumed incompetent). As a result, her teachers and parents believe she must be in the special ed room where her “special needs” can be met. Speech and occupational therapists will attempt to help Julia learn to talk and write. Based on her IQ, it's believed she can't learn academics, so she'll be taught life-skills. (But are we sure the assessment is correct? If one doesn't talk or write, how can a traditional assessment provide an accurate picture of the one's abilities?)

Would Julia's parents and teachers go without *their* computers for writing, along with their cell phones which they use to *communicate* with others? Then why should they deny these tools to Julia?

It's time to recognize that the needs of children and adults with disabilities are ordinary—just as ordinary as the needs of people *without* disabilities. Furthermore, AT, supports, and accommodations *are the pillars upon which inclusion and success are built!*

ASSISTIVE TECHNOLOGY CONTINUED. . .

NO, NOT "SPECIAL"...THEY ARE ORDINARY NEEDS CONTINUED...

Because when Julia is provided with a speech output device and a computer for writing, she can demonstrate her competence and abilities; be included in an age-appropriate general ed classroom, as well as in typical community activities; make friends; and live a self-determined life of her dreams.

Stephen had been denied opportunities to get a real job because of "inappropriate behavior." But when he was provided with behavior supports and the environment was modified to meet his needs, his "inappropriate behavior" magically disappeared. There are certain work activities Stephen performs best with a co-worker, and others he does best alone. He needs the freedom to take frequent short breaks when stress builds up, and he needs only one "go-to" person when he needs help, instead of the multiple layers of staff used by co-workers. His employer is willing to do what it takes to ensure *all* his employees are successful—for that's what makes *his company* successful. Similarly, teachers in inclusive classrooms are doing the same for students who need behavior supports and other accommodations.

Assistive technology devices can be defined as anything that makes life easier or better—and they come in all shapes and sizes, and are used by everyone. A carpenter needs a good hammer; a busier carpenter needs a high-tech nail gun. A doctor needs the best and newest equipment—or would

you prefer one who diagnoses with just a stethoscope? Look around your home and office. Could you get by without *your* computer, printer, cell phone, microwave oven, garage door opener, and . . . Make a list to see how dependent *you are* on all the AT devices in *your life!*

Supports—including behavior supports—come in many forms. Tobacco, caffeine, chocolate, shopping, daydreaming, whisker-pulling, crotch-rubbing, sports betting, hugs, sex, a comforting word, exercise, calling in sick when you're not, and many, many, many other things or activities help us get through the daily grind. Which of *your supports* would you be willing to go without? And haven't most of *us* exhibited "inappropriate behavior" when *our needs* weren't met?

Accommodations also come in a variety of shapes and sizes, including flex-time, a personalized workspace, music playing softly at bedtime, a boss or teacher who really listens and cares, an atmosphere that supports creativity, and much, much more. What type and how many accommodations do *you* use at home, work, or in other environments? And which would *you* be willing to go without?

Examine your own life with regard to needs that are ordinary, but *crucial to your success*. Now look at the individuals with disabilities in your life. Are inclusion and success in any en-

vironment being denied to them because their needs aren't being met? Can we continue to put the burden of failure on *their* shoulders? Isn't it time *we* took responsibility for our beliefs and actions, and our refusal to recognize that their needs are just as ordinary and important as ours?

It's time for swift and positive change to ensure children and adults with disabilities have the same *opportunities and experiences* most of us take for granted. And this will happen when their ordinary needs for assistive technology, supports, and accommodations are met. Can we afford to do anything less?

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WWW.DISABILITYISNATURAL.COM



WHAT IS ASSISTIVE TECHNOLOGY?

Assistive technology is any kind of technology that can be used to enhance the functional independence of a person with a disability. Often, for people with disabilities, accomplishing daily tasks such as talking with friends, going to school and work, or participating in recreational activities is a challenge. Assistive Technology (AT) devices are tools to help to overcome those challenges and enable people living with disabilities to enhance their quality of life and lead more independent lives.

Assistive technology can be anything from a simple (low-tech) device such as a magnifying glass, to a complex (high-tech) device, such as a computerized communication system. It can be big — an automated van lift for a wheelchair — or small — a grip attached to a pen or fork by Velcro. Assistive technology can also be a substitute — such as an augmentative communication device that provides vocal output for a child who cannot communicate with her voice.

Reproduced from the Family Center on Technology and Disability website at <http://www.fctd.info/resources/tech101.php>.



“THE SOUND OF COLORS: A JOURNEY OF THE IMAGINATION”

BY JIMMY LIAO

A story about a young girl who has lost her sight and navigates the subway, imagining and describing her adventures as she gets off at each stop. She has her cane with her in every picture and talks a lot about all of her senses. Like every good children’s book, it has a deeper meaning for adults, too.

USEFUL WEBSITES

- **DB-Link** is the National Information Clearinghouse on Children Who Are Deaf-Blind. Their website contains information to help nurture, empower, and instruct children who are deaf-blind. Their website is: www.dblink.org or call 1-800-438-9376.
- Big.com—a new search engine developed to deliver search results to users in a large, easy to read format—the **Big.com Web Magnifier** is available immediately. Available from <http://www.big.com/toolbar> as a free, downloadable toolbar for use with Internet Explorer web browsers, Web Magnifier provides users with the ability to enlarge the text and graphics of any HTML web page for easier reading and navigation. The trend of decreasing font sizes in web design has made navigating the web an increasingly difficult task for many Internet users.
- **National Family Association for Deaf-Blind (NFADB)** has added a listserv for families and professionals to share ideas, thoughts, questions, and successes. Send a blank e-mail to NFADB-SUBSCRIBE-REQUEST@TR.WOU.EDU to join.
- Do you have a child under the age of 3 who uses Assistive Technology? **Tot’s-N-Tech** is conducting a survey of AT use and training. Please consider completing the online parent survey. Go to the Tots-N-Tech website: <http://tnt.asu.edu> and click on “parent survey.”
- **The Family Center on Technology and Disability** can be found at www.fctd.info. The site has online discussions, links, and free information. You can receive a free ‘Family Information Guide to Assistive Technology’ and CD-ROM titled ‘2005 Assistive Technology Resources.’ In August, a free ‘Family Transition Information Guide’ will become available.

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
Kristen Votava, Project Coordinator
701-662-9001 or 877-630-6214

North Dakota School for the Deaf
Outreach teachers 701-662-9000 or 800-887-2980

ND Vision Services/ School for the Blind
Outreach teachers 701-795-2700 or 800-421-1181

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:

kristen.votava@sendit.nodak.edu.

- Teaching Social Skills to Students with Visual Impairments
- The Young Deaf or Hard of Hearing Child
- 2006 AccessWorld Guide to Assistive Technology Products
- School Professionals Working with Children with Cochlear Implants
- Tactile Strategies for Children Who Have Visual Impairments and Multiple Disabilities
- Working with Young Children Who Are Blind or Visually Impaired and Their Families, 2nd Edition
- Teaching Orientation and Mobility in the Schools
- Young Children with Disabilities in Natural Environments
- Vision Skills in the Natural Environment
- CVI Perspectives

REGISTER FOR A FREE BRAILLE BOOK

Seedlings Braille Books for Children would like to present the new and improved "Anna's Book Angel Program!" Thanks to several generous donations from Anna's friends, family, and the W.H.O. Foundation, now every child can receive one free Braille book per year! In loving memory of Anna Kirstina Bonde, hundreds of Braille books are being made in her name and given away free to children around the world. How does it work? Just register online at: <http://www.seedlings.org/bkangel.html> or use the form on page 40 of the 2006 Seedlings catalog or call Seedlings at (800) 777-8552.

PARENT'S COLUMN

TOYS

Three websites with some ideas for toys for kids with disabilities:

The AblePlay Rating System can be found at www.ableplay.org. The system provides a snapshot of the toy's appropriateness for children with special needs. At the heart of the AblePlay Rating System are the comprehensive AblePlay Toy Reviews. These reviews detail the "hows and whys" of each product, specifically for children with disabilities.

Toys R Us puts out a catalogue at Christmas time geared towards children with disabilities. The catalogue is called "guide for Differently Abled Kids!" The pictures are of children with special needs and the descriptions tell you if it is good for hearing, vision, ambulatory, balance, etc. Search the internet for Toys R Us or click on www.amazon.com.

The National Lekotek Center, a nonprofit dedicated to using toys and play as a way to fully include children into family and community life, has a list of questions that their expert's use in choosing toys. They ask about such things as multisensory appeal, safety and durability, self-expression, and potential for interaction. Their web site is www.lekotek.org.

Taken from the "CHARGE Accounts," a newsletter for families and friends of kids with CHARGE syndrome.

WHAT IS ROP?

Retinopathy of prematurity (ROP) is a potentially blinding eye disorder that primarily affects premature infants weighing about 2¾ pounds (1250 grams) or less that are born before 31 weeks of gestation (A full-term pregnancy has a gestation of 38–42 weeks). The smaller a baby is at birth, the more likely that baby is to develop ROP. This disorder—which usually develops in both eyes—is one of the most common causes of visual loss in childhood and can lead to life-long vision impairment and blindness. ROP was first diagnosed in 1942.

Using Routines and Functional Activities to Enhance Communication

What are they?

Caregiving routines and functional activities such as bathing, eating, and socializing are events that happen frequently in our lives. There are many opportunities to teach and enhance communication within routines that happen everyday in the home and community. Routines can be daily caregiving activities (dressing, eating, etc.), play interactions with friends and family, or community outings.

Why are they important?

Teaching communication within routines and functional activities is important because it provides a meaningful and repetitive structure for children to learn and practice communication. Routines and activities give children and adults something to talk about and provide the basis for development of concepts such as time and sequence. They also provide a child with a sense of control over events. The steps of a simple routine or daily activity can serve to cue the child about the next step in the activity. Children can focus more attention on learning communication within the context of routines that are predictable and safe (Klein, Chen, & Haney, 2000).

Teaching communication within the context of routines enhances development and generalization. Daily routines and functional activities also provide an age-appropriate teaching environment that can promote interactions with family, siblings, and peers.

The sequence of a routine

Caregiving routines and functional activities typically have a beginning, a middle, and an end. It is important for a child to know when an activity is going to start and when it will be finished. This contributes to the development of concepts of time and sequence.

The nature and type of a routine or activity that is chosen and the specific targets on the child's IFSP/IEP will determine which forms and functions of receptive/expressive communication will be used within the routine. Opportunities for using receptive and expressive communication should be embedded into the routine or activity, and opportunities for reinforcing motor, vision, hearing, and cognitive skills should also be built into the routine.

- The *beginning* of a routine or activity should clue the child into what is going to happen next. There should be a consistent form of communication (object cue, picture, sign, spoken word or a combination) that tells the child what activity is to follow (example: an object cue, sign, word, or picture that represents "it's time to eat.") Make sure that the child is ready for the routine (glasses are on, hearing aids in, positioning is correct, etc.) so that optimal learning can take place.
- The *middle* includes all of the steps that happen as part of the routine or activity. During the activity, the sign, object, picture, or word chosen should be reinforced so that the child connects the activity to the communication attempt. The process should be simple and consistent. The child should be encouraged to participate in all aspects of the routine. Opportunities for communications should be provided.

The *end* of the routine or activity should indicate that the activity is finished for now. The word "finish" or a finish box for object/picture cues may be used. Transitions into new routines may serve as the end of the old routine.

Examples of Routines and Activities

Routines:

- Eating/feeding
- Dressing/undressing
- Social interaction games with young children
- Toileting

Activities:

- Going to the store
- Going to the park
- Cooking
- Visiting a friend

Important Points to Remember

- When developing a routine, choose a word, sign, object cue, or picture that the child will easily associate with the activity to introduce and repeat during the activity.
 - Be consistent with the use of signs, pictures, and objects.
 - Encourage the child to participate in all aspects of the routine and use partial participation when appropriate.
 - Include peers and siblings in daily routines.
 - Make the routine simple so that the child does not get frustrated.
 - Place materials and communication symbols where the child can access them.
 - Allow for some flexibility; it is important that children learn to deal with change.
 - Choose routines that other children of the same age are doing.
- Provide opportunities for communication.

Parent Tip

Label items in your home environment with your child's favored communication (sign, symbols, or words) so that everyone can use the same language.

Reprinted with permission from Communication Fact Sheets for Parents. (2002). Monmouth, OR: NTAC (The National Technical Assistance Consortium on Children and Young Adults Who Are Deaf-Blind), <http://www.tr.wou.edu/ntac>.

FAMILY STORY: KAYLYN

BY KARALEE MACIVER

To really understand our family and what a miracle life is you need to hear our story. In February 2004, when we discovered we were going to have a baby, excitement filled the air around us. Our friends and family were almost as excited as we were. Kaylyn surprised us by entering the world 15 ½ weeks prematurely. She was born on June 5th weighing only 1 pound, 9 ounces, and measuring 12 inches long. Neither Cory nor I had a chance to get a close look at Kaylyn, as the minute she was born the doctors and nurses whisked her away to the Neonatal Intensive Care Unit (NICU) with the hopes of keeping her alive. We heard a soft “meowing cry,” and we saw tiny little fingers up in the air as they rolled her away. We were convinced she was waving to us, assuring us she was going to be alright. Two hours later, we were allowed into the NICU to see our small miracle.

The following month was a roller coaster of ups and downs keeping her breathing stable, infection free, and tests, tests, tests! We sat beside Kaylyn’s open bed and sang songs, read books, and held her hand. Other times she was too worn out for us to even talk to her, so we sat and watched her while the nurses were hard at work. On July 3, almost a month after Kaylyn was born, I was asked if I wanted to hold her for the first time. She was a little over 2 pounds at this time. It was very, very scary as she was so sensitive and small, but it was also one of the best feelings in the world! She spent close to thirty minutes on my chest and then was ready to go back to her open bed and rest. The next night Cory had the opportunity to hold her as well. She handled it just as well and enjoyed snuggling with Daddy.

The next week, Kaylyn was respirator free and breathing on her own with the help of a steady flow of oxygen. She struggled for quite a while and would have many apnea spells, but she never needed to be reintubated. July and August offered reasons for celebration as Kaylyn was moved to an isolette. We were taught how to bathe her, gavage (tube) feed her, and we changed many, many diapers. We were anxious for September as most premature babies are ready to go home by their original due date. Kaylyn’s date was September 18th.

Kaylyn was finally stable enough to see Dr. Johnson for her first eye check. We knew that retinopathy of prematurity (ROP) was a risk factor with any preemie but even more so when born between 23 and 25 weeks gestation. Kaylyn’s initial diagnosis was Stage 1 ROP (see

article on ROP next page.) When Dr. Johnson saw her in the middle of August, Kaylyn’s ROP had advanced to Stage 3 in which she would need laser surgery ASAP to stop advancement of detachment of the retina in both eyes. We traveled from Trinity’s NICU in Minot to Merit-care’s NICU in Fargo by ambulance. It was quite an adventure for us as Kaylyn had never left her isolette except to take a bath a few feet away. The report after surgery was that it looked to be successful, but reevaluation was needed in a few weeks. We were sent back to Trinity with many doses of eye drops to give!



The week of Labor Day in September brought Kaylyn’s re-evaluation by Dr. Kindey. The news was not good. Kaylyn’s ROP had advanced to Stage 4a in her right eye and Stage 4b in her left eye. She needed to have major eye surgery done to both eyes if she was to have any vision at all. This condition can advance so quickly that we needed to have surgery as soon as plans could be made for travel. Kaylyn was flown by air ambulance to Royal Oak, Michigan, for *Vitrectomy surgery*. Vitrectomy involves removing the vitreous and replacing it with a saline solution. After the vitreous has been removed, the scar tissue on the retina can be peeled back or cut away, allowing the retina to relax and lay back down against the eye wall. We flew into Michigan on; Kaylyn’s right eye was worked on Wednesday. By Friday, they felt Kaylyn was strong enough to have surgery on her left eye. The best scenario the doctor’s hoped for was Kaylyn seeing large print with the worst-case scenario having only light perception. We felt we could handle this and hoped for the best!

Kaylyn had to spend the twenty-four hours after surgery face down. When I was not there to hold her face down on my lap, she was strapped to a board, almost like a small ironing board, so she would not disturb the work that had been done. She also was patched for the entire time we were in Michigan. We were sent home the following Saturday.

When we returned to Trinity hospital, Kaylyn struggled to eat bottle after bottle and was losing weight. At first we thought it was the stress of the trip, but then realized she was suffering from reflux issues. We took another step backwards as she was given gavage feedings again and only taking a bottle a couple of times per day. She also spent the hour after her feedings propped up in a bouncy chair to help the digestion process.

FAMILY STORY: KAYLYN CONTINUED... BY KARALEE MACIVER

A few days later it appeared she was close to being ready to go home. Kaylyn was given her newborn hearing screening. She did not pass. Dr. Carver, our neonatologist and Dr. Klein, our audiologist, had ordered more intensive testing to see what the problem was. An auditory brainstem response (ABR) test was ordered, which Kaylyn again failed. Dr. Klein came over the following day to explain what was happening as a follow up ABR was ran to test multiple frequencies. It was discovered that Kaylyn had moderate to moderately severe hearing loss in both ears. We were devastated and full of questions. We also knew that this was a fact and that we needed to know what to do to help Kaylyn.

Kaylyn was discharged from the NICU October 7. She spent her first 122 days of life at Trinity hospital. It was hard to say goodbye and leave with this tiny (5 pound, 5 ounce) baby. We were lucky to have such wonderful nurses in the NICU to train us to care for this little bundle of joy and were unsure if we would survive life without them as they had become a constant in all our lives. I was lucky enough to have been given a year's leave of absence from my teaching position so I could be home with Kaylyn.

In November, we began receiving home visits from Kathy Lee, Minot Infant Development Program; Holly Pedersen, North Dakota School for the Deaf Parent Infant Program; and Linda Kraft, North Dakota Vision Services/School for the Blind Vision Outreach Teacher. The three individuals we have worked with have been the best we could have ever asked for. We learned more and more information about the future for Kaylyn and what we could do at home to make sure she made the best use of the equipment we were given and the useful vision and hearing she did have.

By the end of January 2005 Kaylyn was fitted for hearing aids and wearing them for brief amounts of time during the day. We have also been using sign language with her since we brought her home. Kaylyn has done very well with her hearing aids over the past year and is wearing them most of the day. As a true toddler, she has decided that if she is told 'no' by mommy or daddy, they are the first thing to go! If she does not have her hearing aids in and wants to watch TV or listen to something, she signs for her aids. She

is trying to spit out words and says, "Yeah!" and "Dada!" When asked to say, "Mommy!" she signs, 'no'!

Kaylyn also went to Minneapolis to see a pediatric ophthalmologist in early April of 2005 for a better reading on what to expect with her vision. The trip was a stressful one. Kaylyn took part in several different tests and was given drops to dilate her pupils bringing painful reminders of the work that had been done to her tiny eyes already. We were given an approximated acuity of L-20/360 and R-20/540. Kaylyn was also given a prescription for lenses to be filled in Minot. We finally found a perfect fit the first week of May. Kaylyn had beautiful pink glasses to match her pale pink hearing aids. Kaylyn generally wore her glasses when her hearing aids were in and seemed to see much better with them on. It also helped to straighten out her left eye as it is a lazy eye.

When we were back to see the ophthalmologist in November of 2005, Kaylyn's prescription had made a significant change for the worse. He had expected this in her first year. However, we did not. We again had many questions such as, "Will her eyes continue to get worse until she has no usable vision left?" We filled Kaylyn's new prescription, and she began wearing her glasses most of the day as well!

We have been blessed with wonderful people to work with and assist in Kaylyn's health and well-being. We would love to connect with other families and hear your stories as well! Kaylyn does have a web page if you would like to keep track of her progress that journals the past 2 years of her life at www.geocities.com/kaylynraemaciver/kaylynrae.html.

Cory and I are also part of a NDCPD (North Dakota Center for Persons with Disabilities) project called Project Kaylyn that is working in conjunction with the First Sounds Project to promote awareness of the importance of newborn, infant, and toddler hearing screenings. It also takes a look at the importance of all support programs working together with a family to create positive results. For more information about this project contact the NDCPD office at Minot State University.

STAGES OF RETINOPATHY OF PREMATURITY

Stage I — Mildly abnormal blood vessel growth. Many children who develop stage I improve with no treatment and eventually develop normal vision. The disease resolves on its own without further progression.

Stage II — Moderately abnormal blood vessel growth. Many children who develop stage II improve with no treatment and eventually develop normal vision. The disease resolves on its own without further progression.

Stage III — Severely abnormal blood vessel growth. The abnormal blood vessels grow toward the center of the eye instead of following their normal growth pattern along the surface of the retina. Some infants who develop stage III improve with no treatment and eventually develop normal vision. However, when infants have a certain degree of Stage III and "plus disease" develops, treatment is considered. "Plus disease" means that the blood vessels of the retina have become enlarged and twisted, indicating a worsening of the disease. Treatment at this point has a good chance of preventing retinal detachment.

Stage IV — Partially detached retina. Traction from the scar produced by bleeding, abnormal vessels pulls the retina away from the wall of the eye.

Stage V — Completely detached retina and the end stage of the disease. If the eye is left alone at this stage, the baby can have severe visual impairment and even blindness.



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

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

Phone: 701-662-9001 or 877-630-6214
Fax: 701-662-9009
E-mail: kristen.votava@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

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