



"together for independence"

Editor: Peggy Fogarty

January, 2007

2007 PRC Parent Weekend February 23-25, 2007



Once again Project Reach/Philip Rock Center/IADB will be holding the annual Parent Weekend on **February 23-25, 2007** at the Double Tree Suites in Downers Grove. Friday night, February 23, 2007 there will be an informal reception to kick off the weekend.

Presentation topics include:

Saturday, February 24th

- "Tools for Building Communication Programs for the Learner with Sensory and Additional Disabilities" (Tanni Anthony)

Tanni Anthony, will be the keynote speaker on Saturday from 10:00 – 3:00 p.m. Tanni works at the Colorado Department of Education as State Consultant on Visual Impairment and Project Director of the Colorado Services for Children with Combined Vision and Hearing Loss Project. Prior to 1992, she worked in Alaska for nine years as a Parent/Infant Specialist and as an Early Childhood Consultant in St. Paul, Minnesota. In November of 2002, she completed her PH.D. from

the University of Denver. In 1983, Tanni completed her ED.S. degree from the University of Northern Colorado in the area of educating learners with visual impairment with a focus on students with significant support needs and a certification in O & M. Tanni's undergraduate degree is from the University of North Dakota in elementary and special education (VI endorsed).

Sunday, February 25th

- "From NTAC to NCDB: What It Means for Families" (Barbara Purvis)
- IADB – Parent Organization

Barbara Purvis, Technical Assistance Specialist has taught both general and special education, with an emphasis on early intervention (birth to 3 yrs. old). As part of the NTAC/NCDB staff she has provided training and resources to a variety of groups and individuals and is always excited for the opportunity to present to families.

"From NTAC to NCDB: What it Means for Families" - With change comes opportunity! The federally funded project formerly known as NTAC is now the National Consortium on Deaf-Blindness, but our commitment to families hasn't changed. During this session we will explore opportunities for new ways to share resources and build skills, drawing on ideas from other states and developing our own.

• **Watch for registration information!**



RESEARCH PROJECT ON COCHLEAR IMPLANTS FOR CHILDREN

The Teaching Research Institute (Western Oregon University), the Beach Center on Disabilities (University of Kansas), and the Mid-West Ear Institute have received a Federal grant to study the outcomes of children who have dual sensory impairments after cochlear implantation. Fourteen state deaf-blind projects are participating in this national project including: California, Illinois, Kansas, Minnesota, Nebraska, New York, Pennsylvania, Florida, Indiana, Kentucky, Missouri, New Jersey, Oregon, and Texas.

This project will determine the different ways that children who have both vision and hearing difficulties will be helped by having a cochlear implant. This project is funded by the Federal Office of Special Education Programs (OSEP).

Families may struggle when deciding whether or not to get a cochlear implant for their child with both vision and hearing difficulties. Very little research-based information exists on the benefits or challenges of a cochlear implant for children with these impairments. The information that is collected from the participants will be vitally important in assisting other families make informed decisions.

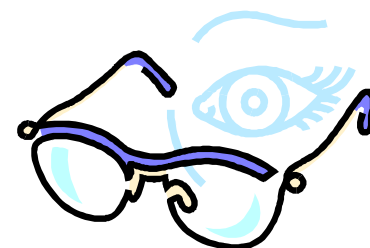
We are seeking two groups of children: those for whom an implant is being seriously considered and those who already have an implant. Children must be between the ages of 9 months to 13 years. Children who have other disabilities, in addition to hearing and vision loss, are eligible. The resources of a child's state deaf-blind project to conduct the assessments required for the study is also a factor in the selection process.

A variety of assessments and questionnaires will be used to evaluate a child's listening, talking, and communication skills. None of the assessments are medical procedures. State deaf-blind project personnel will conduct the assessments in your home, over the phone, at your child's school, or at any location in your community. Most of the assessments are simple observations and parent reports. One assessment requires that your child respond to specific tasks. Some of the observations and questions may be conducted in the classroom rather than in the home. The results of your child's assessments will be shared with you upon your request. All information will be confidential.

If your child is chosen for participation in this grant and parent consent for participation is obtained, you will receive \$100 for completing the first assessments. You will receive another \$100 after subsequent assessments have been completed.

If you would like to be considered for participation in our study, please contact:

Tina Lechnick or Peggy Fogarty
Project Reach Illinois Deaf-Blind Services
(630) 790-2474
PRC@aol.com





Tips for Developing “Good” Communication

(Excerpts from “Early Interactions With Children Who are Deaf-Blind,” by Deborah Gleason Reprinted with permission from the National Clearing house on Children Who are Deaf-Blind. The entire DB-LINK fact sheet “Early Interactions With Children Who are Deaf-Blind” available in its entirety in both English and Spanish at <http://www.tr.wou.edu/dblink/lib/early.htm>.)

Early communication development is based on four ideas:

- Developing a close and trusting relationship with your child
- Using consistent daily routines in which your child is fully involved
- Providing your child with cues so he or she can learn to anticipate what is going to happen
- Giving your child opportunities to have some control over his or her environment.

You, as the parent, take the all important beginning steps by developing a close and trusting relationship with your child. One of the most important things you can do to develop a sense of bonding and security is to hold your baby in your arms.

As you join your child in play, you demonstrate that you share your child’s interests. You play simple turn-taking games together, which, through daily repetition, a child may learn to recognize. You interact in ways that encourage your child to tolerate touch and handling, and in which he or she can begin to demonstrate enjoyment during interactions.

The following suggestions may be helpful as you and your child learn to communicate together:

- **“Hello. It’s me. Let’s play.”**
- **Establish predictable routines with clear beginnings and ends.**
- **Involve your child in the whole activity**
- **Provide opportunities to make choices**
- **Remember to offer pauses**
- **Watch for cues**
- **Invent your own games**
- **Explore the world together (“hand under hand”).**
- **Join your child in her play**
- **Encourage use of all sensory information**
- **Adapt the environment**
- **Monitor levels of stimulation**
- **Use appropriate cues**
- **Expose your child to language**
- **Help your child interact with others**

Summary:

The term “deaf-blind” can be confusing. We know that very few children are totally deaf and totally blind, and when the term is used, it refers to a child who has a combination of vision loss and hearing loss. Most young children who are deaf-blind have some usable vision and/or some usable hearing. The combined effects of both losses, however, are far greater than either loss would be by itself. Your child will require special methods of communication and special education services that will surpass what may be required for a child who experiences either vision loss or hearing loss.

It is you, however, the parents and family members, who will have the greatest influence on your child’s development. Seek our help from others but be assured that your loving response to your child, coupled with ideas gleaned from professionals and those who have “been there,” will make the biggest difference. Just as other parents do, you will discover your child’s unique personality and celebrate your child’s achievements. **VVV**



**PROJECT REACH:
Illinois Deaf-Blind Services
Changes.....**

Project Reach has made some changes to the deaf-blind specialist regions:

Michelle Clyne covers the Chicago and Northeast part of Illinois. Michelle can be reached at the Philip Rock Center (630)790-2474 or email: michelleclyne@sbcglobal.net.

Carla Beck covers the Southern section south of McDonough and Vermillion Counties. Carla can be reached by calling (618)483-3062 or email: carlabeck@frontiernet.net.

Karen Windy covers the Northwest/Central section of Illinois. Karen can be reached by calling (815)223-2037 or email: windy61@sbcglobal.net.

Peggy Fogarty is working on the Cochlear Implant Grant and you can reach her by calling PRC at (630)790-2474 or email: peggy-fogarty@sbcglobal.net.

The specialists will be collecting information to complete the Illinois Deaf-Blind Census, as required by the federal law. This census is used to determine the number of youth in Illinois eligible for our grant-supported deaf-blind services. We would like to thank, in advance, all the family members and professionals who will be helping us in this process.



The 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 for NTAC and the information dissemination activities of DB-LINK and will add a third strand related to personnel training.

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. Kat Stremel is the director, and John Reiman and Kathy McNulty are the associate directors. DB-LINK's information services will continue, and the name DB-LINK will be used for the consortium's information service activities.





Upcoming Conferences!

February 21-23, 2007

IAER (Illinois Association for the Education and Rehabilitation of the Blind and Visually Impaired) Conference, Holiday Inn Select, Naperville, IL.
<http://il.aerbvi.org>.

March 2-3, 2007

Illinois Teachers of Hard of Hearing/Deaf Individuals (ITHI), "Reaching New Heights." Indian Lakes Resort in Bloomingdale, IL.
www.ithi.org.

October 17-19, 2007

10th Biennial Sharing a Vision Conference: "Many Hands, One Vision", Crown Plaza Hotel, Springfield, IL sharingavision@aol.com.

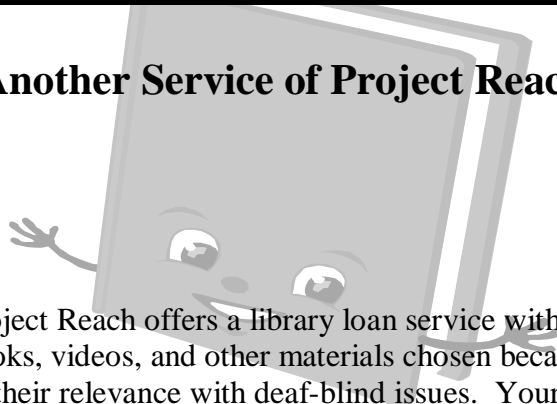
HEALTHCARE AND FAMILY SERVICES

Outreach for persons with developmental disabilities

The Department of Human Services, through the Division of Developmental Disabilities, is required to collect and maintain information on the need for services by Illinois citizens with developmental disabilities. This information is gathered through the Prioritization of Urgency of Need for Services (PUNS) form. Children and adults with developmental disabilities who are seeking services from the state system are encouraged to complete a PUNS form through any of the 18 local coordination agencies across the state. For more information, please contact www.dd.illinois.gov or 1-888-337-5267.

OUR RESOURCE LIBRARY

Another Service of Project Reach



Project Reach offers a library loan service with books, videos, and other materials chosen because of their relevance with deaf-blind issues. Your only cost is the postage required to return the materials to us, and the time it takes to fill out the survey card that comes with each material loaned.

NEW ITEMS:

"Autism Spectrum Disorders and Visual Impairment: Meeting Students' Learning Needs" By D. Jay Genese, Ed.S., Marily H. Genese, M.A. - This book gives a comprehensive look at how autism spectrum disorders interact with visual impairments.

"Vision Program: Vision Skills in the Natural Environment" by Utah School for the Deaf-Blind - This book and CD Rom is a curriculum designed for teachers of young children with visual impairments. It's set up with a series of lesson plans and activities that parents can do with their children during daily activities. It covers areas such as: vision, daily living skills, and cognitive skills.

"Teaching Language Arts, Math, & Science to Students with Significant Cognitive Disabilities" by Diane M. Browder & Fred Spooner - To help students with severe disabilities make progress on state academic content standards. The first major research-to-practice resource on this critical topic, this text goes beyond functional and access skills and shows educators how to make the general curriculum accessible to students of all ages with significant cognitive disabilities.



Project Reach Mentor Program

We are very happy to announce that Project Reach now has two more volunteer deaf-blind mentors!

Kim Liddell (Hard of Hearing) and Mindy Joy Mayer (Deaf/Sign), both completed the Project Reach Mentor training in September. They are eager to work with teens and families to help them find answers to questions about how to move into adult life. If you would like to contact either mentor, please call or email **Michelle Clyne at 630-790-2474 or email: michelleclyne@sbcglobal.net**. You will find their brief autobiographies below. We hope you enjoy getting to know them as much as we have?

Mindy Joy Mayer, Deaf-Blind Community Outreach Specialist. She is a Chicago native, who is deaf with Usher Syndrome. She graduated from Illinois School for the Deaf in Jacksonville, IL.

In 1995, Mindy moved to Seattle, Washington having accepted a job at Seattle Lighthouse for the Blind and to gain experience living among a large deaf-blind community. Mindy lived in Seattle for 9 years and worked at Seattle Lighthouse for the Blind where her job responsibility was a part of the Boeing Department as a Set-Up machinist to make parts to build airplanes.

Mindy moved back to Chicago, IL in 2004 with the idea to bring back with her what she experienced from Seattle which may help strengthen and reach out to Chicago's deaf-blind community. Ever since, she has been involved with the Helen Keller National Center (HKNC). Mindy does presentations with HKNC about deaf-blindness. At this time she is very active with LeCOBDA (The Club of Blind Deaf Adults) at Chicago Lighthouse as well as with SSP

(Support Service Provider) Task Force. She has taught Columbia College interpreting students how to become a SSP.

The things that bring Mindy pleasure are being with family, enjoying her cats, being on the computer playing games and reading emails, reading a Harry Potter book, knitting, swimming, traveling by car and Amtrak, and chatting on her blackberry. She also enjoys spending time with her 11 year old niece and step grandchildren.

Kim Liddell lives in Joliet, Illinois. She has gotten network support from the Will/Grundy Center for Independent Living and is now working at the DuPage Center for Independent Living in Glen Ellyn, IL.

Kim's work involves providing information and referral services, advocacy, peer mentoring and independent living skills development. She believes that individuals that she serves have the right to be as independently involved in their community as they want to be. Her main goal is to help deaf-blind consumers find a personal assistant(s) who is looking for employment. On one hand, she is listening to the deaf-blind consumer and assessing their needs. On the other hand, she recruits personal assistants and puts them on a referral list that is given to the deaf-blind consumers. Her work deals with helping deaf-blind consumers become good bosses and manage their personal assistant. The deaf-blind consumers' work involves interviewing, hiring, and maintaining their personal assistant.

Kim's hobbies include: meditation, spirituality, listening to mysteries, web designs, and outdoor activities and sports.



Free Resource Available on CHARGE Syndrome

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.UU

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 deafblindness.

NFADB is sponsoring a list serve where you can share ideas, thoughts, questions, successes, etc. To join the list serve, send a blank email to NFADB-SUBSCRIBE-REQUEST@TR.WOU.EDU.



DID YOU KNOW....



Sorenson VRS is a free service that allows anyone to conduct video relay calls through a certified ASL interpreter.

Sorenson Video Relay Service (VRS), a free service provided by Sorenson Communications, enables deaf and hard-of-hearing individuals to conduct video relay calls with family, friends, and business associates through a certified sign language interpreter, Sorenson videophone, TV, and a high-speed Internet connection. The deaf user sees an interpreter on their TV and signs to the interpreter, who then contacts the hearing user via a standard phone line and relays the conversation between the two parties. Hearing customers can also place video relay calls by simply dialing the toll free number 1-866-FAST-VRS. Sorenson VRS is available 24-hours a day – 365 days a year. For more information, visit www.sorensonvrs.com.

To apply for a free Sorenson VP-100 Videophone go to <http://www.sorensonvrs.com/apply/> VVV

Please return the following information to: **Philip J. Rock Center and School**

- Please make no changes to my address and keep me on your mailing list
- Please take my name off the mailing list.
- Please make the following changes on my mailing address label.
- Please add my name to the newsletter mailing list.
- Please mail me a large print edition of the newsletter.
- Please mail me a Braille edition of the newsletter.

Name: _____

Parent/Job Title/Organization: _____

Address: _____

Telephone: _____

Comments:

Thank you!

***Philip J. Rock Center and School
818 DuPage Blvd.
Glen Ellyn, IL 60137***



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