

Deafblind Focus

Volume 11, No. 3

Fall/Winter 2000



Project News and Notes ...

Indiana Deafblind Services Project Family Scholarships

The Indiana Deafblind Services Project provides scholarship funds to families of children and youth who are deafblind and to consumers. Scholarships are used to reimburse families for expenses incurred while attending a training on deafblindness or a closely related topic which supports the direction of the Indiana Deafblind Services Project. These scholarship funds may consist of a reimbursement of gas mileage for a family attending a workshop, paying for conference fees, or even paying for a hotel overnight. However, scholarships are currently limited to \$300.00 per family, based on the available funding. Family members who are interested in applying for a family scholarship should contact project staff at 1-800-622-3035 for an application form.

Families who receive scholarships must submit a reimbursement form, receipts and an action plan after attending the event. The action plan must indicate how they plan to use the information they learned as it relates to their child's or family's educational needs. In addition, in return for the project's support to attend these conferences and workshops, the families are asked to share the information they gained with others.

This newsletter focuses on reports from Indiana families and consumers on the workshops and conferences they attended through the scholarship program. It is hoped that by sharing the experiences and knowledge gained through this newsletter that others will benefit from what these family members learned.

Indiana Deafblind Services Project



Under the Magnifying Glass: Parents Share Conference Experiences

Creating Strategies for Cortical Visually Impaired Children

Attending the *Cortical Visual Impairment: Linking Information & Strategies* Conference was very informative. Many families, therapists, and caregivers were there to learn what Cortical Visual Impairment (CVI) means and how to build strategies to cope with it. Dr. Deborah Chen, Ph.D., Dr. Brent R. Bailey, Ph.D., and Dr. Georgia Hambrecht, Ph.D. made presentations. Strategies were created for each family to implement with instructions to record over a three-month period.

What is CVI? Most of us were asking that question. The simplest definition is that CVI can be a temporary or permanent visual impairment caused by the disturbance of the posterior visual pathways and/or damage to the occipital lobe of the brain. The degree of vision impairment can range from minimal vision loss to total blindness. The degree of neurological damage depends on the time of onset, the location and intensity of the insult. CVI is a condition where the brain does not consistently understand or interpret what the eyes see. The presence of CVI is not an indicator of a child's cognitive ability.

We learned that some children have CVI along with vision problems. A child could be nearsighted or have cataracts, for example. Corrective glasses can be prescribed for the child. For a child with CVI, the glasses will only help correct the acuity problem, for example, not the processing difficulties. Having multiple vision problems plus having CVI can create a bigger learning challenge. Our children must learn to work with the vision they have and use it to their fullest potential. Some children learn to compensate for the vision loss by using their other senses, like hearing or feeling.

After learning many strategies for working with children who have CVI, we broke into focus groups consisting of

(Continued on page 2)

Under the Magnifying Glass: Parents Share Conference Experiences

(Continued from page 1)

parents, therapists and caregivers of individual children. We learned how to take a strategy and make it into a goal or objective for our own child's special needs. We also learned how to keep data, which is a good idea to measure progress when working on a specific objective.

At the end of the conference, Dr. Chen conducted a question and answer session. Families were encouraged to share their own experiences. The group shared and learned from Dr. Chen and from one another. How to advocate for children with CVI and other disabilities continued to be a central theme. This "Parents Only" session reflected concerns about families not having enough time, resources or information. Parents agreed that there are times that medical personnel are difficult to deal with. Many parents shared ideas such as taking a note taker to the Dr.'s appointment, insisting that your list of pre-written questions be answered, and asserting yourself while advocating for your child. If your child has CVI, he/she may qualify for a C.H.O.I.C.E award or Medicaid waiver. Either waiver would allow some assistance so the family has time to regroup, rest, or run errands.

Enrolling your child with CVI in school is always a hot topic. No matter where you place your child, there will always be some issues to deal with. Teachers and therapists may not know all that your child needs. Communication is the key to getting the best education for your child. Our children need to be around other children as they learn from them and love to socialize. Don't be afraid to place your kids in the school system allowing them to live as "normal" a life as possible. The parents are the best advocates and will need to get and give the most information. These tips along with the strategies will give the families a lot to work on.

We wish all of the families, therapists, and caregivers the best of luck.

by Denise Shipley
Parent of a deafblind child

Successful Transitioning

At the conference we discussed many issues regarding the transitioning process for all ages of deafblind children. One meeting that we found particularly useful dealt with the Individual Education Plan (IEP). We were given a handbook from the SKI-HI Institute that included a "child profile". We have decided to fill out the "child profile" for our son, Nate. We have also given the "child profile" to his therapists for them to fill out. We will then combine the

information on one "child profile" and give it to the preschool so they can better understand Nate. Nate's IEP will be more in depth and will help the preschool know our wants for Nate before he enters school. We had a wonderful time at this conference. The NTAC and NFADB staffs were great. All of the networking we did will be used. Thank you for sending us the invitation for the conference. Thanks!

by Kimberly and Chuck Witmer
Parents

Foundation Fighting Blindness Conference

The following information is a brief outline of the information presented during the different sessions at the conference.

Session I

Current Treatments for Retinitis Pigmentosa

- 1. Retinal Cell Transplantation**
Can new, healthy cells replace the cells of the diseased retina?
- 2. Restoring Sight through Implantable Chips**
Implantable microelectrode chips, also called visual prosthetic devices are being developed to restore lost vision.
- 3. New trends in Nutrition**
Dr. David Birch and Dr. Barbara Underwood reviewed the importance of nutrition for genetic eye diseases. They also presented information about clinical trials utilizing nutrients for treatment of RP.
- 4. Pharmaceutical Therapies for Retinal Degeneration**
The development of new chemical compounds that can prevent or slow inherited retinal degenerative diseases is the basis of pharmaceutical therapy.
- 5. Gene Therapy**
This session addressed unique methods that scientists have developed to repair or treat inherited retinal degenerative diseases.

Session II

Usher Syndrome (all types) Dr. William Kimberling

- Usher I:** Born profoundly deaf
Born with a balance problem
Retinitis Pigmentosa
They have currently found 6 genes that cause Usher I.
- Usher II:** Deafness progressive (more verbal)
No balance problem
Retinitis Pigmentosa
They have currently found 4 genes that cause Usher II.

Usher III: Progressive Hearing Loss
Progressive balance loss
Retinitis Pigmentosa

**Session III
Driving with RP
Dr. Gerald Fishman**

Currently, 33 states can test for peripheral vision when renewing a license. Only 19 states actually do. Seventy percent of persons with RP pass the vision test required for a drivers license. Dr. Fishman stated that the current peripheral tests are not accurate for RP patients.

There was much discussion in the session on whether to drive or not. Many felt that it is an individual decision.

I also facilitated a networking session for parents of children over 12 with RP.

Thank you.

**by Linda Lechner
Parent**

Help Keep Us Up To Date!

We need your help to make sure that we are reaching everyone who wants to get information from the *Deafblind Focus* and our project. If you or someone you know needs to change their address or would like to be added or removed from our mailing list, please fill out the form below and return it to the Indiana Deafblind Service Project, Blumberg Center, School of Education, Room 502, Indiana State University, Terre Haute, IN 47809. In addition, if you prefer to receive information and newsletters through electronic media please indicate that and provide us with your e-mail address. Thank you!

- Add me to your *Deafblind Focus* mailing list
- Remove me from your mailing list
- My info has changed. Please update your records.

Name: _____

Address: _____

City: _____ **State:** _____ **Zip:** _____

Phone: () _____

Parent **Service Provider**

I would prefer information via e-mail.

E-Mail Address: _____



Happy Holidays!

from the Indiana Deafblind Services Project Staff



Communication at Home

and in the Community: Helpful Strategies and Suggestions from Parents and Families with a Child who is Deafblind

The information contained in this booklet covers communication in both the home and community environments. It specifically focuses on the answers to the following questions:

- How can we facilitate and promote a child's individualized mode of communication?
- How can we increase the number of people who can effectively communicate with our children?
- How can we encourage others to respect our children and feel more comfortable interacting with them?
- How can parents support and promote communication when personal time and energy are limited?

The answers to these questions were drawn from over one hundred parents and family members of children who are deafblind who attended the 1998 and 1999 National Technical Assistance Consortium for Children and Young Adults Who Are Deaf-Blind (NTAC)/The National Family Association for Deaf-Blind (NFADB) national parent workshops. These family members identified what they thought were the most important practices needed to effectively promote communication with children who are deafblind. Then they worked to identify strategies to put the practices into action. The information was collected and published in this booklet. It is an excellent collection of strategies, advice and suggestions from "parent experts."

For more information on this resource, including how to obtain a copy of it, please contact:

The Indiana Deafblind Services Project
 Blumberg Center
 School of Education, Room 502
 Indiana State University
 Terre Haute, IN 47809
 (812) 237-2830
 (800) 622-3035
 e-mail: soebryan@befac.indstate.edu

Family Chat Rooms and "Ask the Expert" Internet Chats

The Indiana Deafblind Services Project is pleased to announce our new on-line Internet Chat rooms. The

project has available on its web site, chat rooms for individuals with deafblindness, their siblings, and their parents or other adult family members. Family chat rooms are available all of the time for family members to arrange their own chat times. Feel free to use these rooms to contact other persons with deafblindness and their families to discuss concerns, provide each other with new ideas, or just have fun!

In addition, a chat room is available for scheduled real time "chats" or discussions with experts in various fields related to deafblind issues. We try to pick topics that are frequently of concern to families of children who are deafblind. A new schedule with topics, dates, and times will be mailed in January, 2001 for the spring and summer chat dates. You are encouraged to join us to ask whatever questions you may have on a particular topic.

If you have questions about the chat rooms or "Ask the Expert" chats, call Lisa Poff at 1-800-622-3035.



New Items in the Resource Library

The following are new items in the Indiana Deafblind Services Project's Materials Resource Library. If you are interested in checking any of these out, please contact the project at 1-800-622-3035.

Beukelman, D. & Mirenda, P. (1998). *Augmentative and Alternative Communication: Management of Severe Communication Disorders in Children and Young Adults*. Baltimore, MD: Paul H. Brookes Publishing Co.

Binger, C. & Light, J. (1998). *Building Communicative Competence with Individuals who use Augmentative and Alternative Communication*. Baltimore, MD: Paul H. Brookes Publishing Co.

Downing, J. (1999). *Teaching Communication Skills to Students with Severe Disabilities*. Baltimore, MD: Paul H. Brookes Publishing Co.

Hussey-Gardner, B. (1999). *Best Beginnings: Helping Parents Make a Difference*. Palo Alto, CA: Vort Corporation.

Schleien, S., Ray, M. & Green. (1997) *Community Recreation and People with Disabilities, 2nd Edition*. Baltimore, MD: Paul H. Brookes Publishing Co.

(Continued on page 6)

Thank you from a Consumer!

Words can never express adequately the wonderful experience I had at the American Association of the Deaf-Blind 25th Anniversary Conference in Columbus, Ohio. I will use imagination to sketch what a profound impact my first AADB Conference was to me. First, imagine being in a world, where at times, you feel immensely alone in dealing with the frustrations of every day life, only with a bit MORE frustration, trying so hard to be as independent as a perfectly normal person is so others will never label you as "incompetent." Imagine having to practically scream to make your voice and your meaning heard by "normals." Imagine feeling all your energy drained almost completely explaining to people that you are very capable, sometimes even more so than a person who never has to face what you do as a disabled person.

Now imagine being in a world where the consciousness of having disabilities, primarily deaf/blindness seem miraculously to disappear in the knowledge that you are with those that see first and foremost the person and not what might be different in the way of physical being. Imagine never needing to explain and explain AND explain 'til you become so ultra sensitive to your disabilities that you feel as if your are only half a person. Imagine the pure JOY of being very much a participant in the wonderful, exhilarating FUN, the magical tingling of laughter, and all the challenges, sharing of thoughts and ideas without feeling one bit excluded. Imagine how WONDERFUL it feels when you know your thoughts and decisions are IMPORTANT and RESPECTED. Imagine being given ALL the options and choices so that you can make the BEST decision for yourself instead of others making them for you because it happens to be easier for them. Imagine feeling so much POWER and JOY within yourself, because you realize the only difference is who you are as a person, a unique human being.

I know this all sounds like some kind of fantasy dream we cherish and hope for. Yes, I had to keep pinching myself to make sure this was all for REAL and not some deep, wonderful dream I never wanted to wake up from. AADB was one of the most wonderful things that have ever happened to me. I never felt so much alive and devoid of the EXTRA frustrations that I deal with almost on a daily basis. To be honest, it is wonderful to have extraordinary challenges that help you grow tremendously as a person but when your disabilities are overrated in how people look at you can ultimately cause extraordinary frustrations. So, imagine how ultra wonderful it is when those EXTRA frustrations seem to just melt away, like M&M's in your mouth, and you are first and

foremost a PERSON with unique talents, abilities, sensitivities, and wonderful strengths. Suddenly, you can RELAX, be yourself, and enjoy the atmosphere and the people who are being themselves too. This was truly a time when disabled are transformed into ENABLED.

There were so many things going on at AADB Conference, so many, many wonderful, compassionate, FUN people, so many choices to make, never a dull moment, in fact, quite the opposite! It is impossible to share EVERYTHING that touched me to the core. If I did, I am sure this would become a book, a novel, instead of an article. What I learned and experienced at AADB is PRICELESS. I'll never in a thousand lifetimes forget my experiences at AADB. It has helped me grow into a much stronger person. I now know for certain that my disabilities are only secondary to who and what I am as a person, even if the majority of human beings do not see it that way, I know inside with all my heart, my disability is not a priority. It's just part of the thread that helps to make the WHOLE fabric of who I as an unique human being. If I did not have my disabilities, I would be a completely different person. Being disabled has given me insights, compassion, understanding, empathy for others, and a real funny bone for life's little quirks. I believe very strongly, that when one or more senses are taken away, God gives us an extra helping of other senses that we otherwise may never have had. AADB made me realize how PROUD I was to be a deaf/blind person, and prouder yet to be part of the Deaf/Blind community of the world. And now, I am totally and hopelessly addicted to AADB for life! As long as I can help it, I will never miss another AADB Conference!

Marcia McDermott

**"Imagine how
WONDERFUL it feels
when you know your
thoughts and decisions
are IMPORTANT and
RESPECTED."**



Upcoming Events

Where Do You Go From Here? Weekend Seminar

The Indiana School for the Blind, the Division of Aging and Rehabilitative Services, Blind and Visually Impaired Section, and the Department of Education are sponsoring a weekend seminar on transition from school to work for visually impaired students and their parents on February 23, 24, 25, 2001. This seminar will be held at the St. Vincent Marten House at 1801 W. 86th St., Indianapolis, IN 46260.

The program, which is offered at no expense to the family, provides an opportunity for students and their parents to find out how a visually impaired person prepares for moving from school to work. Sessions will include a job readiness assessment, an expectation discussion and a hands-on technology session. The families will develop a plan for their own use during the last session on Sunday morning. The goal is to provide families with opportunities to learn from the experiences of others, as well as hear from teachers and counselors who work with children and adults who are visually impaired.

The application deadline is January 12, 2001. Participants will be selected on a first come basis. For more information contact:

Ms. Judy White
Assistant Superintendent of Outreach
Indiana School for the Blind
7725 N. College Ave.
Indianapolis, IN 46240-2504

New Items in the Resource Library

(Continued from page 4)

Downing, J. (1996). *Including Students with Severe and Multiple Disabilities in Typical Classrooms: Practical Strategies for Teachers*. Baltimore, MD: Paul H. Brookes Publishing Co.

Batshaw, M. (1997). *Children with Disabilities, 4th Edition*. Baltimore, MD: Paul H. Brookes Publishing Co.

Pugh, G.S. & Erin, J. (1999). *Blind and Visually Impaired Students: Educational Service Guidelines*. Watertown, MA: Perkins School for the Blind.

Koegel, Doegel, & Dunlap. (1996). *Positive Behavioral Support: Including People with Difficult Behavior in the Community*. Baltimore, MD: Paul H. Brookes Publishing Co.

Indiana Deafblind Services Project Deafblind Focus Vol. 11, No. 3

Editors:

Karen S. Goehl, Project Director
Lisa Poff, Program Coordinator
Sharon Bryan, Office Assistant
Dr. William R. Littlejohn
Director of the Blumberg Center

The Indiana Deafblind Services Project grants permission for individuals, groups, and agencies to reprint articles from our newsletter. We request that you document the article with the author's name, date, and *Deafblind Focus*.

This publication is made available by the Indiana Deafblind Services Project, through the Blumberg Center for Interdisciplinary Studies in Special Education, located at Indiana State University, with support from the U.S. Department of Education, Office of Special Education Programs under grant award #H326C990009 and the Indiana Department of Education, Division of Special Education. The views expressed in this newsletter do not necessarily reflect the opinions of either the U.S. Department of Education or the Indiana Department of Education and no official endorsement should be inferred.

FD0E68

The Indiana Deafblind Services Project
BLUMBERG CENTER for Interdisciplinary
Studies in Special Education
School of Education 502
Indiana State University
Terre Haute, IN 47809

Indiana State
University



Non-Profit
Organization
U.S. Postage
PAID
Permit No. 48
Terre Haute, IN