

Deafblind Focus

Volume 16, No. 1

Summer 2005

NTAC/NFADB Parent/Family Workshop

Keeping It All Together?!? Strategies for Managing Family Life when a Member is Deaf-Blind

This workshop was sponsored by The National Technical Assistance Consortium for Children and Young Adults who are Deaf-Blind (NTAC) and The National Family Association for Deaf-Blind (NFADB). It was held in Salt Lake City, Utah in August.

The workshop focused on teaching families how to:

- understand the impact of having a child with deaf-blindness on the family,
- support the well-being of siblings,
- use individual and family strengths to address family needs,
- use positive problem solving to address day to day demands,
- apply techniques that reduce stress, guilt and isolation, and
- become more comfortable and confident in building positive relationships with extended family members and professionals.

The presenter was Marlyn Minkin. She is a counselor/therapist with over

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Under the Magnifying Glass: The 7th International CHARGE Syndrome Conference

The following article was written by Marilyn Ogan. She is the parent of a child with deafblindness who used a Family Scholarship from the project to assist with the cost of attending the workshop.

I wanted to take this time to thank the Indiana Deafblind Services Project. Without funding from your agency it would be difficult for my family to connect with the numerous individuals, parents, and professionals who live or work with CHARGE Syndrome. It is such a rare disorder, and having the opportunity to interact with adult individuals with CHARGE Syndrome and see that my daughter will really be "OK" when she grows up; the opportunity to discuss common struggles the parents of children with CHARGE Syndrome experience; the true understanding from professionals who "get It" and really have devoted their lives to helping individuals and families with CHARGE Syndrome - it is in one word "awesome"!

I have learned so much from this conference about **transition** to the community, what to look for, and where I can turn for resources and information. The transition presentation by NTAC (National Technical Assistance Consortium) was very informative. DB-LINK gave great information about resources for deafblind individuals. Joe McNulty (Executive Director, Helen Keller National Center) discussed IDEIA 2004 and Transition Services as they are

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Under the Magnifying Glass: The 7th International CHARGE Syndrome Conference

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currently being implemented. The presentation by Amy Parker (Regional Representative, Helen Keller National Center) about community supports was really exceptional for creative ways to find and use resources. She also talked about teams collaborating effectively.



Children at Conference Making Flamingos

The **Teaching Strategies** session by Martha Majors and Sharon Stelzer from Perkins School for the Blind was amazing! Their approach is truly inspired by the individual, and the curriculum is really geared to that person. They do not try to “fit” the individual to the program; they tailor the program to the individual. Just the statement made about setting up the curriculum for “flexibility” and using whatever communication works makes so much sense it is scary. Many schools, unfortunately, do not use that approach or philosophy.

We’ve learned we need to have a DEXA (bone density) scan to check bone density for Kristin, since many of these individuals are becoming osteoporotic at early ages (adolescence). We also learned that we will probably need to force puberty, as a high percentage of individuals with CHARGE do not enter puberty on their own. These are concerns that will need fairly quick attention as Kristin is moving into the age range for these problems.

This conference marked the historic explanation of the recent discovery of a genetic mutation (CHD7) that results in CHARGE Syndrome. To have been involved in the collection of triad blood samples (affected individual and parents) for research purposes back in 1999 at the Houston conference, and to know that we have contributed to helping find one gene responsible for CHARGE Syndrome...well, there is great satisfaction in knowing you have helped in even a small manner. And the genetic sessions were fascinating! We also received official confirmation that Kristin has the genetic mutation on CHD7. That also gives us concrete information regarding her chance of “passing” that gene on to offspring, and of Ken’s (sibling) chances of passing it on. It is as much as 50% for Kristin; 1-2% for Ken. It has eased Ken’s thoughts about future children a great deal.

I attended the session for siblings presented by staff from the Tennessee School for the Deaf. And, although our son, Ken, has attended Sibling Workshops at the Indiana School for the Deaf, it was nice to attend a session for parents that really explained not only the model of **SibShops** (on which ISD bases its workshops), but the unusual concerns and opportunities faced by siblings. In attending this workshop, I could identify those concerns/opportunities already experienced by Ken and see how they have shaped him, and will continue to do so in the future. I also discovered there are things that need to be clarified about the future with Ken

and Kristin. (Example: We neither expect, nor plan, for Ken to “take care of” Kristen when Rick and I are deceased. Ken and Kristin both need to know we are planning for Kristin’s future once we are gone. If Ken wants to be a part of that, that is fine. But he should not be forced into responsibility for Kristin).



Panel of Young Adults with CHARGE

The highlight of the conference – for everyone – was when the young adult and adults with CHARGE Syndrome spoke in a panel presentation. To see them was to see our younger children “all grown up.” And how encouraging to see and hear these individuals presenting, enlightening, and advocating for themselves! I already see much that our daughter does at 13 years old, that some of these young adults have had to wait to learn, or else got a late start. Rick and I were both so amazed at the level of self-advocacy evidenced by Kristen already. And she was so thrilled to be able to meet adults that are affected the same way she is. Previously, she has only met individuals who are her age or younger with CHARGE Syndrome. Now she has seen that she will grown up and have opportunities like the older individuals have – or, hopefully, even more and better opportunities.

The off-session times and reception was terrific for comparing “war stories” of the difficulties our families have encountered.

Rick appreciated hashing through insurance issues with other fathers. I appreciated swapping therapy and appointment experiences with others. The “connections” made between families and professionals are incredible and lasting. I met David Brown, a deafblind educator, in 1996 at a conference (in Australia) and have maintained a great relationship with him since. He has valuable experience that is nationally and internationally recognized in his contributions to deafblind behaviors and communication. David is always a favorite at conferences and he makes himself so available during networking times. What a wonderful man, and an indefatigable resource for our families!

Our family – all of us – cannot thank you enough for the continued funding made available for individuals to attend conferences that provide us with invaluable information found nowhere else. We will be disseminating the information we learned through various parent support groups, ISD, ISB, and other agencies like the Indiana Governor’s Planning Council for People with Disabilities. Feel free to contact us for any needs you encounter. We are more than willing to forward information to your agency, or through any other avenues you deem appropriate. And if you have contact from parents or professionals needing information specific to CHARGE Syndrome. You can contact us by email at oganm@insightbb.com.



Macarena at the Saturday Night Carnival

Tips for Funding Hearing Aids

The following article has been reprinted with the permission from the News From Advocates for Deaf-Blind newsletter:

The following tips for funding hearing aids were posted on the Intervener listerv, an email listserv for families with children who are deaf-blind and professionals working in the field. Shannon Butulla, Family Specialist for the Nebraska Deaf-Blind Project compiled this list and shared on the listserv.

1. The Lions Affordable Hearing Aid Project (AHAP) developed a low cost, high quality hearing aid for a little over \$100 a piece. It has proven to perform as well as aids that sell for \$2,000. This aid is available through Lions Clubs in partnership with local audiologists. Whereas these partnerships exist worldwide, so does the AHAP program. Read more about this program at their new website: www.lionsear.org - or call them at 630-571-5466, ext 615.
2. HEAR NOW - - part of Starkey Hearing Foundation - accepts DONATED USED hearing aids which are sold to a repair lab. The money generates funds for the "So the World May Hear" Program which allows persons with low income to purchase a hearing aid for the cost of the application process (\$100 for one and \$200 for two). Complete instructions and application are available on the Starkey website: www.sotheworldmayhear.org. Click on 'HEAR NOW' and follow the link to the application. If you have questions or do not have access to the Internet, call 800-648-4327 and a Starkey staff member will return your call.

LEGISLATIVE UPDATES:

TAX CREDIT FOR PURCHASE OF HEARING AIDS: Last year, HR 3103 was pending approval in Congress. The bill hasn't died, but is still pending. It now has over 50 sponsors and, if passed, the Hearing Aid Assistance Tax Credit Act will provide up to a \$500 tax credit per device toward the purchase of hearing aids. It can be used on any type of hearing aid with any professional provider by an individual over the age of 55 or a parent purchasing an aid for a dependent child. Check the Self Help for Hard of Hearing (SHHH) website for the latest information at www.shhh.org.

THE ASSISTIVE TECHNOLOGY ACT OF 2004 was signed into law in October. This reauthorization provides funds, improves access and fosters better program administration. It ensures that technology will be available where people need it... in schools, at work and in the community. It also requires states to focus on two populations: (1) students with disabilities receiving transition services, and (2) adults with disabilities maintaining or transitioning to community living. For more information, contact the Assistive Technology Project in your state.

TAX EXEMPTION FOR BLINDNESS: Individuals who are legally blind (and/or spouses filing jointly) should check the box indicating so and attach a letter from his/her physician documenting the fact. If this statement certifies that the condition is unlikely to improve, a new certification is not required in subsequent years. For 2004, the additional standard deduction is \$950 (for married taxpayers and surviving spouses) and \$1200 for single taxpayers. For more information, contact your tax preparer or check the IRS website for standard deduction tables.

Posted by Shannon Butulla, On the SPARKLE Listserv

Call for Art Exhibit Entries

VSA arts of Indiana is now accepting entries for an exhibit at the IN*SOURCE Annual Conference which will be held on October 21-22, 2005, in West Lafayette, Indiana. This exhibit will showcase artwork created by artists with disabilities from around the state of Indiana.

Whether you are a parent, student, adult, professional artist, teacher, department chair, or a principal - please feel free to take advantage of this opportunity. VSA arts of Indiana (VSAI) and IN*SOURCE feel that this is a very exciting opportunity to gather from across the state of Indiana and celebrate the work of artists with disabilities and give those artists of all abilities the chance to exhibit their artwork. The **deadline for entries is September 28, 2005.**

For more information, contact:

- Linda Wisler at (317) 974-4123 or lwisler@vsai.org
- Emily Compton at (317) 874-4123 or eyoung@vsai.org
- www.insource.org

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thirty years experience working with individuals who are deaf-blind and their families. Marlyn has conducted national trainings for family specialists on state deaf-blind projects and is a popular and sought after presenter at deaf-blind family weekends across the country.

The Indiana Deafblind Services Project provided support for three Indiana families to attend the workshop through the Family Scholarship program.



Medicaid Reference Desk



The Medicaid Reference Desk is an online resource at <http://www.TheDesk.info> that explains Medicaid in basic terms, state by state. It gives people with cognitive disabilities, family members and advocates information about what is available through their State Medicaid Plans and waivers. The site also gives information on where to apply for services.

The resource explains each Medicaid service in ordinary language. People can see and hear the information rather than read it. So far, there are about 3,000 recordings on the site.

Family Scholarship Program

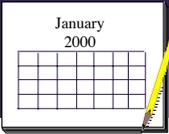
Family scholarships are offered to parents and family members of children with deafblindness that have current certification status on the Indiana Deafblind Census. Family scholarships are to be used to reimburse families for expenses incurred while attending training on deafblindness or a closely related topic which supports the direction of the Indiana Deafblind Services Project.

Scholarships must be requested in advance and may cover the costs of conference registration fees, mileage, airfare, hotel, and child care. They are currently limited to \$300 per family, based on available funding.

More details about the program can be found on the project's website at

<http://www.indstate.edu/soe/blumberg/dbfam.html>

or you can reach us by telephone at 1-800-622-3035.



Upcoming Events

November 16-17, 2005:

PATINS 2005 Collaborative State Conference, Indiana Convention Center, Indianapolis, IN

AIM: Accessible Instructional Materials

Today's classrooms house an increasingly diverse student population, including not only students with widely different social, economic, cultural and language backgrounds, but also students with a wide range of physical, cognitive, and sensory disabilities. The *No Child Left Behind Act of 2001* and the *Individuals with Disabilities Education Improvement Act (IDEIA) of 2004* mandate increased expectations and accountability for this diverse range of students to access, participate, and progress in the general curriculum. The conference will focus on new assistive and accessible technologies that will enhance and facilitate learning for all students.

Who Should Attend?

- Special Education Teachers
- Regular Education Teachers
- Regular Education Administrators
- Special Education Administrators
- Teachers of the Visually Impaired
- Teachers of the Deaf & Hard of Hearing
- Speech-Language Pathologists
- Related Service Personnel
- Assistive Technology Specialists
- Parents
- School Instructional Technology Specialists

Collaborating sponsors: PATINS, Project Vision, & the IEP Project at BSU. For more information, contact PATINS by phone at (317) 227-8501.

Family Learning Weekend

The Indiana Deafblind Services Project is sponsoring a Family Learning Weekend at Bradford Woods on October 21-23, 2005. The focus of the weekend will be Person Centered Planning. The guest speakers will be Barb Purvis from NTAC & Larry Schaaf from the Indiana Institute for Disability and Community. As always, several activities are being planned for the children.

For more information about the weekend, contact Lisa Poff at lpoff@indstate.edu or at 1-800-622-3035.

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