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News From Advocates for Deaf-Blind

A Publication of the National Family Association for Deaf-Blind

NFADB UPDATES

Linda Syler, President, NFADB



2008-2009 was a busy year for NFADB. Our **project with Oregon Health and Science University** was completed with the publication of *"Assessing Communication and Learning in Young Children Who are Deaf-blind or Have Multiple Disabilities."* We are in the process of making this available to our members. The final draft of our Transition Study is completed and the National Issues committee is now in the process of creating a PowerPoint presentation.

Board members attended the **Topical Meeting in June, Project Directors' Meeting in July, and a forum on Parent Leadership in September.** Read more about these activities in the newsletter.

The big activity of the year was the **international conference "Families Connecting with Families."** This was a collaborative effort between NFADB and the National Association for Parents of Children with Visual Impairments (NAPVI) **held in Costa Mesa, CA, July 17-19th.** Our assessment pamphlet was distributed and Dr. Deborah Chen led a discussion on the assessment process. Board members were active participants on various panels including: *What is Deaf-blindness?*; *Raising a Child with Multiple Disabilities*; *What is NFADB?* We were able to add the deaf-blind perspective to many discussion topics.


NFADB sponsored the attendance of our state affiliates to the conference. Friday morning, the Board and affiliates took part in a training ses-

sion led by Paddi Davies and John Killoran of the **National Consortium on Deaf-Blindness (NCDB).**

The **Board welcomed a new board member – Kelli Sabin from Michigan.** NFADB thanked **Cora Holloway** for her past work on the Board. She will continue to help us with our fund raising activities. **Special thanks to the Hilton-Perkins Foundation and to Helen Keller National Center for their continued support. Last but by no means least, THANKS to our Special Advisors for all their help and support.** NFADB would not exist without the support of all of these people.



Wanted

Volunteers 
to serve on the NFADB Board

Would you like to have an impact on the lives of individuals who are deaf-blind? Do you have free time that you would be willing to spend serving on the NFADB board? If so, please request a board member application packet. For more information and a packet please email Sheri Stanger at SheriMEd@aol.com.

THE NATIONAL FAMILY ASSOCIATION FOR DEAF-BLIND (NFADB) SUPPORTING PERSONS WHO ARE DEAF-BLIND AND THEIR FAMILIES. A non-profit national family organization established in 1994. The philosophy of the Association 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."

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CHILDREN'S DAY — April 19, 2009



Submitted by Blanche Stetler,
NFADB Board of Directors

The National Family Association for Deaf-Blind of Puerto Rico had the opportunity to participate in *The Children's Day's* activities held on April 19, 2009, in the Bayamon's Central Park for Children in Puerto Rico. The topic of the day was "Ask Me?" During this event, the Association had the opportunity to provide resources to the parents who assisted as well as the students, teachers and various professionals who gathered at the park. This event helped to develop links and create awareness about deaf-blindness throughout the Island. The day was a great success in achieving our goal.♥

NFADB MEMBERSHIP DRIVE

The NFADB annual membership drive has begun! Our membership year is from January 1 thru December 31. Current members – check the mail for your renewal packet. New members may join by submitting the form on the back of the newsletter. A new lifetime membership category is available which includes all family members residing at one address.

1 year membership - \$15

3 year membership - \$30

**Lifetime (individual/family)
membership - \$100**

PPDB Update

submitted by Gordon Boe,
President, PPDB



Since our last update a year ago, the Pennsylvania Partnership for the Deafblind (PPDB) has been active in a number of areas. PPDB is an affiliate of NFADB.

First, we established the "Annual PPDB Helen Keller Award", to be given to an individual who has made significant contributions to the deaf-blind community in Pennsylvania. The **first recipient** of this award was **Rich McGann**, who is deaf-blind. Rich has worked for over 30 years in the field of deaf-blindness, and has been not only a strong advocate for those who are deaf-blind, but also a great mentor to young people. Rich serves on the PA Deafblind Project's Advisory Council and is a life member of PPDB.

NCDB/OSEP DEAF-BLIND PROJECT DIRECTORS MEETING

NFADB was represented at the NCDB/OSEP (Office of Special Education Projects) Deaf-Blind Project Directors' meeting for state deaf-blind projects July 19, 2009 in Washington DC. The theme for the day was "Culturally Responsive Partnerships." The main speakers were Beth Harry, Professor Of Special Education, University of Miami and Djenne Morris, Family Specialist, North Carolina Project for Children and Youth Who Are Deaf-Blind. Dr. Harry gave an overview of cultural reciprocity while Ms. Morris led participants in a self-reflection activity. There was also a panel discussion on cultural reciprocity facilitated by Anne Smith of OSEP and John Reiman of NCDB. John Killoran, Director, Teaching Research Institute, gave a presentation on "Data Informed Thinking on Culture and Race." One of the most interesting parts for me was the discussion on cultural definitions of disability. Every culture does not define disability in the same way. It really made me do some self-reflection on how I interact with parents from different cultures in regard to their children with disabilities.

Debbie Ethridge, Vice President NFADB

AFFILIATIONS COMMITTEE

*Submitted by Blanche Stetler, NFADB Board Member
Chair of the Affiliations Committee*

NFADB now has affiliates in five states — New York, California, Pennsylvania, Wisconsin and Puerto Rico. We hope to add several more states to this growing list. One of the benefits of being an affiliate is participation in workshops. We were fortunate to be able to invite our affiliates to the NAPVI conference this past July. Paddi Davies of NCDB and John Killoran of Teaching Research Institute at Western Oregon University facilitated a training for our board and affiliates to reflect on ways to improve family organizations at the local and national level. The issues identified at this training will help us to move forward and become even more productive and successful in supporting our families.

Having the opportunity to get together is

always a good thing and working together makes it even better. Our goal is to be able to provide regular opportunities in the future for our affiliates to get together and for all of us to continue to learn and grow. We are so grateful to Paddi, John and all of our affiliates and board members for their enthusiastic participation and hard work.

The members of the Affiliations Committee are Blanche Stetler, Janette Peracchio and Susan Green. There is a formal process in becoming an affiliate of NFADB and we are always looking to identify successful parent groups to join us. If your group is interested in becoming an affiliate of NFADB, please contact Blanche, Janette or Susan. Their contact information is on page 2. ♥

PPDB....continued from page 2

Second, **PPDB completed its website**. The address is **www.papdb.org**. We are now in the process of learning how to keep the site updated with new information, so that it stays relevant and current.

Third, we are in the **final stages of our grant with the PA Developmental Disabilities Council**. This project focuses on providing parents of those who are deaf-blind with the tools to successfully transition their children from high school to adulthood. We presented our findings at the Pennsylvania Community on Transition Conference in July. The parents guide will be published early next year.

Fourth, the **PPDB Board** has been really busy. We have had **six face-to-face meetings** and **numerous conference calls** during the last 12 months. The **Board is developing policies in three areas: (1)** using PPDB to facilitate the donation of equipment, toys, medical devices, etc., from members who don't need them any longer to members who do; **(2)** developing the means to sponsor members in attending trainings, conferences and meetings; and **(3)** creating a PPDB "Rainy Day Fund" to assist members who face emergency situations. At the PPDB Annual Meeting in June, the membership elected two new members to the Board: Susan Shaffer and Lori Velnovich, both of whom are parents of children with deaf-blindness.

Our **priorities for the coming year are to expand our funding** (our two current grants will end in January), **to continue our focus on providing services to our members, and to maximize the involvement of all our members in the partnership.**

Assessing Communication and Learning in Young Children Who are Deaf-Blind or Who Have Multiple Disabilities

By Sheri Stanger, NFADB Past President



We all need to be informed on best practices and included as contributing members on our child's educational team. How often have we heard that our children are "difficult to test?" How do we go about finding quality assessments that lead to good educational decisions for our children? The goals of this project were to identify instruments used for assessment of children that are deaf-blind, to conduct validation studies on these instruments and to produce final products that summarize this data and make assessment recommendations. To help families and practitioners provide better educational opportunities for our children that are deaf-blind, NFADB was asked to participate in a 5-year research grant funded through the US Department of Education with 4 other project investigators. These project investigators are Dr. Deborah Chen from the University of California—Northridge, Dr. Harvey Mar from Teachers College, Columbia University, Dr. Charity Rowland from Oregon Health & Science University and Dr. Robert Stillman from the University of Texas at Dallas. The booklet is edited by Dr. Charity Rowland. This collaborative effort examined best practices for assessing communication and cognitive skills in young children (2-8 years of age) who are born deaf-blind and who have additional impairments. NFADB participated on the advisory committee and identified family members to participate in the study.

While this booklet is intended for professionals, it can be extremely useful for the family. It is a wonderful resource for the educational team that is looking to improve interventions through a practical approach to assessment based on current best practices. It also helps the family to understand their important role in the assessment process. Professionals from various fields were surveyed to see what tools were commonly used to assess children who are deaf-blind. Families were surveyed about their children's needs and tools used to assess them. The result is a user friendly booklet organized into 3 main sections: 1) Getting Started 2) Gathering Information 3) Interpreting and Applying Results. Throughout the booklet the text is broken up by questions that parents often ask, general questions that the team might ask about the child, pictures and summaries of each section. There are also checklists for families and professionals. In addition, there is a specific illustration of a child who is deaf-blind. This vignette shows how to apply the strategies described in the 3 sections to "see how it's done." Later in the booklet, twelve tools that are used to assess children who are deaf-blind are listed, described and assessed on their strengths and weaknesses. Also included are notes to families and practitioners

such as special educators, speech-language pathologists and psychologists to explain the relevance of the guide to their particular field.

While this narrative is just a brief overview of the assessment booklet, the booklet itself is quite comprehensive. To view the project's abstract and download materials, please go to: http://www.ohsu.edu/oidd/d2l/com_pro/db_assess_ab.cfm A print copy of this booklet can be requested by contacting DB-LINK at the National Consortium on Deaf-Blindness at info@nationaldb.org or by calling 1-800-438-9376 voice; 1-800-854-7013 TTY. NFADB encourages families of young children to obtain this information. We believe families need to play an informed and active role in their child's education. This assessment booklet will be extremely helpful in that endeavor. ♥



NFADB ATTENDS the FORUM ON COLLABORATIVE FAMILY LEADERSHIP IN WASHINGTON, DC

On May 13, 2009 I attended a brainstorming meeting held at the Topical Conference in Cincinnati, Ohio. The reason for the meeting was Anne Smith, from OSEP, and Katie Shepherd, from University of Vermont, had something to offer each other but they were not sure what that was. Anne works for the Office of Special Education Programs and Katie had a grant. What a great match! The purpose of the federally funded grant is to support parents of children with disabilities to develop their skills and experiences in leadership and collaboration.

A group of individuals, many of us from NFADB, were asked to give input on what is needed for the deaf blind population. After the quick brainstorming meeting, we went home and waited to hear what the next step was. What transpired next was a much larger meeting, Forum on Collaborative Family Leadership. This was held September 11-13 in Washington, DC. Representatives from NFADB and our state affiliates were among the many organizations and groups that attended.

The Forum provided opportunities for discussion and networking, as well as a series of team activities related to family support and leadership, collaboration and resource mapping. After several group activities and discussions three topics of great concern were chosen to expand on, Transition / Post School, Family Leadership, and Interveners. We realized these issues were a bit overwhelming so a PATH was developed for each group to help us begin our process. It was interesting to see who chose which group and for what reason. Listservs, meetings, and phone calls were among the many tools put in place to keep the momentum going after the Forum. This is just the early stages of what hopes to bring better opportunities, changes and services for individuals with disabilities. ♥

Submitted by Susan Green



Learning about Lorenzo

By Veronica Castillo, Lorenzo's Grandmother

My name is Veronica Castillo and I am the paternal grandmother of a toddler named Lorenzo who is deaf-blind. For the first nine months of his life, Lorenzo went without occupational, physical or speech therapy, as well as early intervention. When our teenage son received custody of Lorenzo 16 months ago, our grandson came to live in our home. This enabled us to finally access services that Lorenzo desperately needed. We were able to get his vision and hearing impairments documented and, most importantly, he received the diagnosis of "deaf-blind." Once the dual diagnosis was made (confirmed at 18 months of age), we were able to get him the services he needed.

While Lorenzo was receiving services through the Arizona School for the Deaf and Blind, I was put in touch with NFADB president Linda Syler. Linda asked if I would like to attend the 2009 *Families Connecting with Families International Conference* in Costa Mesa, California, this past July. I was quite honored to be invited to participate in a conference that would give me a better understanding of Lorenzo's world. Attending the conference gave me the opportunity to meet and be around other families who have dealt with, or are dealing with, the same issues we are. We compared our lives and shared ideas and solutions with one another. I truly felt like I belonged.

I started the conference by attending the NFADB Affiliations Representative dinner and board planning meetings, and getting to know many wonderful people throughout the United States and Puerto Rico. The first day of the conference, I roamed the exhibit halls, which featured the many vendors that were showcased at the conference. I was able to buy Lorenzo

his first two braille books! Saturday morning, Dr. Bill Takeshita shared his thoughts on how parents, doctors, teachers and therapists working together can create a formula for success. His story was especially inspirational in that "Dr. Bill" lost his own vision after having spent several years working with persons with various degrees of vision loss. His personal experience gave him a very unique perspective on his own work with individuals who were visually impaired as well as the work of professionals in the field.

Other sessions I attended included one on eye conditions, where I received information on one of Lorenzo's many diagnoses - "CVI - Cortical Vision Impairments"; the "ABC's of Negotiating"; "Braille Literacy within Daily Routines"; and my favorite session on "The Forgotten Senses of Pressure and Balance." Speaker David Brown talked about how deaf-blindness affects vestibular and proprioceptive senses. So much of what Mr. Brown was saying were things that I could see Lorenzo exhibiting in his behavior - pulling his teeth and lower jaw downwards, grinding his teeth, banging on his face or head, clapping or flapping his hands, kicking heavy objects like furniture or doors, poor temperature, and adopting specific postures such as lying flat on his back with both of his legs bent and one ankle resting on the other knee. His behaviors finally began to make sense. They were tied to his dual sensory impairment!

Through this conference, I gained a better understanding of Lorenzo's needs and the way he lives within *his* world. I also met many people who I hope to remain in contact with - people who understand what family members and persons who are deaf-blind are going through.

NFADB Survey and Position Paper on Transition

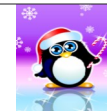
Janette Peracchio and Blanche Stetler
National Issues Committee

Students who are deaf-blind and in school systems in the US are required by law to have programs that meet their individual needs (Free Appropriate Public Education-FAPE). There is a process in place to recognize what those needs are, to provide the proper services, and to provide remedies when that is not accomplished. When these students reach high school, parents report that the transition planning process to adult services does not always meet the unique needs of this group of students.

NFADB conducted a transition survey in 2007 of families who have completed or are in the process of transitioning their sons and daughters to the adult service agencies. The results of this survey has led NFADB to creating a Position Paper on the issue of Transition to Adult Services. The Board of Directors would like members of NFADB and their Affiliates to use this Position Paper to discuss the needs of people who are deaf-blind with their local, state and national legislative members. Please use your family stories to help legislators to understand and fix the transition system nationally.



Transition and Post-School Life Survey - 2007 Position Paper



The National Family Association for Deaf-Blind (NFADB) is a non-profit organization dedicated to assuring that all individuals who are deaf-blind are valued members of society and receive the same opportunities as other members of their communities. Individuals who are deaf-blind have unique, life-long needs and require specialized services and accommodations in order to gain equal access to their communities and achieve optimal independence. NFADB exists to provide a national voice for the promotion and support of services and policies that benefit individuals who are deaf-blind and their families.

NFADB has identified transition to adult life as a critical area of concern for young adults who are deaf-blind. Research conducted in the late 1990s (Petroff, 1999) indicated that after leaving school many youth with deaf-blindness were unemployed, had limited access to their communities, did not live independently, and lacked social networks. Since that time, families from across the country have continued to report to the leadership of NFADB that transition outcomes have not significantly improved. To gain insight into factors that may lead to these poor outcomes, NFADB conducted a survey in 2007 of families of youth with deaf-blindness who were still in school and in the process of transitioning to adult life (age 12 to 21) or who no longer attended school (age 22 and older). Although not a comprehensive study, the survey gathered information that NFADB can now use to recommend specific practices and policies.

The survey targeted the following areas:

- 1) Aspects of post-school life that are most important to families.
- 2) Challenges and barriers to achieving a meaningful adult life for individuals who are deaf-blind.
- 3) Employment and living situation.

Survey Results

The survey, consisting of a series of closed-ended questions, was mailed to 500 families throughout the United States. Completed surveys were returned by 146 family members, all but five of whom were parents of individuals with deaf-blindness. The individuals with deaf-blindness ranged in age from 12 to 58 (6 were deceased at the time of the survey). Fifty-five percent were between the ages of 20 and 39. Of these, 50% did not graduate with a high school diploma. This may be an artifact of individual state policies as many states do not award regular diplomas to students with individualized education programs (special education students).

Aspects of Post-School Life that are Most Important to Families

An overwhelming majority of parent respondents (90%) identified the physical and emotional safety and quality of life of their adult children once they, the parents, had died, as extremely important. Respondents also rated the following as extremely important for their children: a place to live (62%); healthy relationships, including relationships with siblings (60%); continued life-long learning (64%); and financial security (70%). Overall, responses to this question indicate that parents want their sons and daughters to lead happy and contented lives.

Challenges and Barriers to Achieving a Meaningful Adult Life

Respondents were asked to identify challenges and barriers to achieving a meaningful life for their adult children by selecting all that applied from the following list. They were also asked whether the list captured the greatest challenges and barriers.

Funding for appropriate services

Access to appropriate services

Availability of qualified personnel (school and adult services)

Family's knowledge of available agency and community resources

Access to effective transition planning

The majority of respondents (66%) reported that the list captured the greatest challenges to achieving a meaningful adult life. The availability of qualified personnel was selected as a challenge or barrier by 80% of respondents, followed by funding for appropriate services (76%), and access to appropriate services (70%). Approximately 20% of the respondents indicated that all of the listed factors were relevant challenges or barriers.

Respondents were also asked to indicate in which of the following areas they had received training: adult services options, benefits, guardianship, and person-centered planning. A majority had received training on guardianship (69%) and person-centered planning (61%). Nearly half had received training on adult service options (54%) and benefits (47%).

Sixty-seven percent of the respondents reported that their sons or daughters had a transition plan while in

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school. However, the survey did not elicit data about the effectiveness or quality of these plans. When asked if the barriers and challenges identified above were addressed within their child's transition plan, 37% responded "yes," and 43% responded "no." The majority of families reported that their child's IEP was modified as a result of the transition planning process (52%).

The survey asked several questions about the role of adult service agencies during transition planning. Responses indicated that an adult lead agency was identified during the transition planning process for 56% of the respondents' children and participated in transition planning meetings for 54%. Those who reported that an adult service agency had participated in meetings were asked whether they believed the adult agency had enough funding for the specialized services necessary to implement their child's transition plan. Of the 54% who reported that a lead agency participated in meetings, 33% responded "yes," the agency did have sufficient funds and 36% responded "no."

Employment and Living Situation



Thirty percent of the respondents' adult children were employed and being paid, which is a higher rate than has been reported in an earlier study (Petroff, 1999).

With respect to living situation, the survey found that 57% of adult children still live at home, 19% live in group homes, 11% live independently, and 3% are in residential school programs.

Survey Implications

Survey results indicate that a significant number of individuals who are deaf-blind have not received appropriate transition services and have not successfully transitioned to adult life. Parents and other family members need access to accurate and timely information in order to advocate for services that promote successful post-secondary outcomes. This is particularly true for families with a child or family member who is deaf-blind. Specific outreach strategies and services must be in place at state and local levels to ensure that parents and families are well-informed and deeply involved in the transition process. NFADB is committed to promoting equal partnerships between parents and service providers throughout the transition process.

A large number of families with an adult member who is deaf-blind are not receiving adequate adult services. NFADB's leadership recognizes a need to heighten the organization's advocacy efforts in order to obtain increased funding for the types of supports that make it

possible for each individual who is deaf-blind to live and work in the community of his or her choice. In addition, the increasing use of interveners and support service providers (SSPs) who provide one-to-one support to individuals with deaf-blindness in education and community settings indicate a need to develop national and state policies on the provision of individualized supports to persons who are deaf-blind. NFADB will advocate for federal and state policies to ensure funding for these services.

Deaf-blindness can severely limit employment opportunities, housing options, connections with other people, and access to community services. To overcome these limitations, individuals who are deaf-blind must receive services from trained personnel, but the survey results indicate that there is a serious shortage of trained personnel. NFADB advocacy efforts will include collaboration with institutes of higher education to address personnel preparation issues, and with education agencies and adult service agencies to expand state and local professional development opportunities related to deaf-blindness.

The very nature of a low-incidence disability such as deaf-blindness makes federal and state support for parent and family leadership training imperative. Families consistently report that they experience feelings of isolation and frustration as they attempt to obtain appropriate services for their children who are deaf-blind. Although small in number, parents and families with a member who is deaf-blind, need to work together to create a strong and effective voice to ensure funding for leadership training programs and to increase public awareness of the unique needs of the deaf-blind population. NFADB will seek federal and state funding to support leadership training for NFADB members throughout the country.

Conclusion

NFADB recognizes that there is critical need for parents and families with a member who is deaf-blind to join forces within their states and at the national level to advocate for appropriate transition services for individuals who are deaf-blind. Achieving successful outcomes for young adults who are deaf-blind will remain a major focus of NFADB's advocacy efforts.

Reference

Petroff, J.G. (1999) *A national transition follow-up study of youth identified as deafblind: "Parent perspectives"* (Doctoral dissertation. Temple University).

2009 Janette Peracchio, Blanche Stetler and Kathy McNulty



Deaf-Blind Connections

Rhonda Jacobs

October 2009

Submitted by Pearl Veesart

The following article is an edited version which appeared in the Registry of Interpreters for the Deaf "RID Views" Fall 2009 publication and is reprinted here with permission from RID. Please note that in referring to curriculum, faculty, and IEPs this article is talking about college Interpreter Education Programs, not Individualized Education Programs -Pearl Veesart

The National Task Force on Deaf-Blind Interpreting (NTFDBI) had its second face-to-face meeting on July 31-August 1. The purpose of this meeting was to identify goals and activities for the coming year. The following six items were determined to be the most salient and suitable to this group's mission and scope of work:

1) Infusion vs. specialized training - 'infusion' refers to having deaf-blind people included as part of the spectrum of consumers (along with deaf, hard-of-hearing and hearing people) in *every* course in the curriculum (such as ASL to English classes, English to ASL classes, as models in the stimulus material, etc.) instead of a special class/training on deaf-blind interpreting. The group discussing this topic felt that both approaches were necessary in order for the topic to be covered in sufficient depth.

2) Faculty not having expertise - faculty/staff not possessing the knowledge and skills needed in order to infuse the necessary strategies throughout the curriculum, thus continuing the pattern of minimal exposure to students in interpreter education programs.

3) Outdated resources - many materials that are presently being used are outdated. There is a wealth of current materials (articles, curricula, videos, etc.) that are available but are not known to instructors and administrators in interpreting programs. Of note, the National Curriculum for Training Interpreters Working with People who are Deaf-Blind, completed in 2001, was listed on the survey by only four educators and approximately nine administrators. Since this curriculum was a nationally funded project and is available as a free download, there are questions as to why it is not being used more than it is. It is speculated that it may be due to lack of awareness of the curriculum and lack of understanding of the content and how to infuse it into current curricula.

4) Where are interpreters coming from? - how are current interpreters who work with deaf-blind people becoming trained/educated? Are they mainly from interpreter education programs or from the community? This information will be helpful to gather so that we learn where the attitudinal barriers are created and why they exist. One issue that was raised in regard to interpreters being trained to work with deaf-blind people was that often students get a one-time *exposure* to "deaf-blind interpreting" in their interpreting program as a "special topic/setting" so they therefore are considered *trained*.

5) Deaf-Blind interpreting as a 'setting' - the paradigm that currently exists is that deaf-blind interpreting is viewed as a 'special topic' or a 'setting' just as educational, legal or theatrical interpreting. This paradigm does not accurately represent the fact that deaf-blind people are *people* who are consumers of interpreting services in *all* settings.

6) Further training of faculty/staff/instructors – how can the Task Force increase the knowledge and skills of current faculty/staff/instructors within interpreter education programs?

To further the prioritization process the group then divided into small work groups. This allowed for in-depth discussion on each of these issues in terms of ideals, resources, obstacles and how the Task Force could assist in bridging the gap between theoretical belief and practical application. Each group reported out so that the members could vote on the top three issues the Task Force could realistically address over the course of a year. From this, the top issues we will be working on this year and courses of action are:



(Deaf-Blind Connections - continued on page 9)

(Deaf-Blind Connections continued from page 8)



1. Increasing faculty expertise – The goal of this work group is to have a face-to-face train-the-trainers workshop by the summer of 2010, and possibly online training. Teams have been assigned to work on logistics and curriculum development.

2. Deaf-Blind interpreting as a setting – The goal of this work group is to alter the perspective of interpreters, emphasizing that deaf-blind interpreting is not a 'setting', but represents a spectrum of consumers who utilize interpreting services in any and all settings. Members will be focusing on educational efforts, both in face-to-face settings and in print.

3. Where do interpreters come from (in regard to both attitude and training) – This work group is working from the theory that interpreters begin working with deaf-blind people via personal recruitment and contact, which allows for the development of trust. The goal of this group is to confirm (or deny) this theory via surveys and focus groups and identify attitudinal barriers that may exist and the cause of such barriers. Ideally, action steps will be identified that will assist in altering the perspective of all interpreters entering the field.

In addition to these focus areas, one issue that received much discussion was the necessity for a presence on the Internet to make available the materials we have already developed, and to be a central place where people can go to find information and resources on deaf-blind interpreting. There are a number of challenges to making this a reality, but it is something that all agreed would be beneficial. There was also discussion on our status as a task force and whether we should become a more permanent entity. Is there a time when our 'task' will be completed or will this be an on-going effort?

The Task Force's work thus far has been accomplished due to the generous support of the National Consortium of Interpreter Education Centers (NCIEC), with additional funding from RID and donations to the American Association of the Deaf-Blind (AADB). As NCIEC funding has now ended, the efforts outlined above were conceived with the understanding of needing to develop a realistic agenda for the coming year that could further our mission and purpose with the limited funds available. The members also discussed possible new funding streams

NTFDBI members:

Aimee Chappelow Bader – Deaf-Blind community member;
 Ashley Benton - Deaf-Blind community member;
 Jennifer Byrnes – RID Deaf Members in Leadership Committee;
 Janice Cagan-Teuber – Massachusetts Commission for the Deaf and Hard-of-Hearing;
 Jane Hecker Cain – Conference of Interpreter Trainers;
 Richelle Frantz – community interpreter;
 Jill Gaus – AADB Board representative;
 Rhonda Jacobs – NTFDBI Co-chair, AADB representative;
 Richard Laurion – National Consortium of Interpreter Education Centers;
 Michelle Moore – National Alliance of Black Interpreters;
 Susanne Morgan Morrow – NTFDBI Co-chair, RID representative;
 Pearl Veasart – National Family Association for Deaf-Blind;
 Jeannette Ocampo Welch – RID Cultural Diversity in Leadership Committee.

The NTFDBI has recently set up an E-mail distribution list to announce training/learning opportunities and conferences. If you would like to be added to this list, or if you have training announcements you would like us to distribute, please send your E-mail address and/or announcement to NTFDBI@gmail.com.

The NTFDBI is made possible with funding support from the NCIEC, which is funded through the Dept. of Education, Rehabilitation Services Administration, the Registry of Interpreters for the Deaf and the American Association of the Deaf-Blind.♥



CHARGE. . .And All That Jazz

By Sheri Stanger

All I can say is, **WOW!** 756 people representing this challenging syndrome descended upon Chicago with exuberance. This 9th International CHARGE Syndrome Conference in Bloomington, IL, at the Indian Lakes Resort from July 24-26, 2009 was our biggest gathering. Parents, grandparents, siblings, individuals with CHARGE, caregivers and professionals from all medical, educational and therapeutic backgrounds representing 37 states and 10 countries made for one incredible learning experience. The atmosphere was similar to a huge family reunion but, despite our size, felt very intimate. The Foundation's board members and crew of volunteers worked incredibly hard to put this conference together and their efforts were rewarded with an immensely successful event.

Most people don't know about the hard work and planning that goes into making an event such as this one take place. From the outside it looks like the process moves along with ease. This takes diligent planning for over 2 years with much fundraising and many meetings. The success of this conference was due to the hard work and dedication of the board members, the conference chairperson, Brownie Shott, the local family, David (who is also a board member) and Jody Wolfe, as well as the board advisors. Collaborations with HKNC, NCDB and Perkins School for the Blind, as well as sponsors also made this conference possible.

This was a year of firsts. It was the first time the Foundation held a **conference for professionals**. It was a full day for professionals to gather, present their work and research and share information the day before the conference began. It was also the 1st Annual CHARGE Syndrome "Conference Idol" Talent Extravaganza held at the end of the first day of the conference. What a turn out! There was amazing talent from kids of all ages which included singers, dancers, comedians, musicians and actors. A panel of 4 wonderful judges, 2 emcees, technical staff, interpreters, helpers that carried signs announcing the next act and drum rolls rounded out the entertainment. All participants received a trophy for their efforts and talent with the grand prize going to pianist Sean Timberland. A surprise musical performance of "I've Got You Babe" from panel judges Joe McNulty and Dave Brown brought down the house with applause. The **tears of joy,**



laughter and love in that room made this event a highlight of the weekend.

As always, the weekend was jam packed with information and "all that jazz." General sessions, break-out sessions, sib shops, a grandparents' meeting, a father's forum, gatherings for young adults with CHARGE, a pre-conference reception for families and professionals, opportunities to participate in research studies, time to talk with professionals, a poster session and a vendor fair were all part of this weekend. And parents would not be able to attend all these sessions if it were not for the wonderful **child care through Camp Discovery and Camp Explorer** that

kept all of our children busy with many activities. We had the added bonus of Kenny and Cheryl Moretz from Maryland running **Uncle Kenny's Corner** - a woodworking station for the kids.

Dr. Bryan Hall started the conference with the history of this syndrome. From there we learned about the various medical, educational and therapeutic aspects of CHARGE. There was not a dry eye in the room when new board member, **Cynthia Antaya** gave a special presentation on her unique experiences of having CHARGE syndrome and being the mother of a child with CHARGE. There was also a **heartfelt tribute** to the **Foundation's founder, Marion Norbury**, on her retirement from the board.

Our conference cannot be complete without **our traditional silent auction, dinner, carnival and dance held on Saturday night**. What a celebration! There were so many smiles in that room and many friends made.

We were entertained by **Rachel Coleman** of "Signing Time," sponsored by the Texas CHARGErs. It was incredibly interactive, fun and appealed to people of all ages.

This conference was truly a celebration of our wonderful children and those that love them. It was educational, supportive and most of all inspirational. I look forward to seeing everyone again **July 28-31, 2011 at the 10th International CHARGE Syndrome Conference in Orlando, FL**.

For more information on CHARGE Syndrome go to www.chargesyndrome.org. ♥



Commit to an NFADB Committee!



NFADB has several committees working behind the scenes all year. We welcome your participation on any of the following committees. Please contact the committee chairs, as indicated, or our main office at 800-255-0411, if you would like more information about the committees' activities and/or are interested in lending a helping hand.

COMMITTEES & EXECUTIVE COMMITTEE (EC) LIAISONS:

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Affiliates: Blanche Stetler e-mail: JTMommy@aol.com, ph: 732-822-3423; **EC:** Janette Peracchio e-mail: jbperacchio@gmail.com, ph: 860-558-7648.

Newsletter Coordinator: Vacant

Fundraising Coordinator: Cora Holloway e-mail: mcdh765037@aol.com, ph: 608-332-5186; **EC:** Cynthia Jackson-Glenn e-mail: Cynthia.jackson-glenn@rsc.state.oh.us, ph: 513-504-8597.

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Board Recruitment & Development: Sheri Stanger e-mail: SheriME@aol.com, ph: 914-478-7248; **EC:** Debbie Ethridge e-mail: debbieethridge@yahoo.com, ph 479-619-8383.

International Coordinator: Clara Berg email: ClaraB428@hotmail.com, ph: 718-428-1591; **EC:** Janette Peracchio e-mail: jbperacchio@gmail.com, ph: 860-558-7648.

Conference Coordinator: Linda Syler e-mail: l.syler@cox.net.

Web Site Coordinator: Debbie Ethridge e-mail: debbieethridge@yahoo.com.

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- ☐ **One Year** \$15 ☐ **Three Years** \$35

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Regular members are eligible to serve on the NFADB Board of Directors.

All members automatically receive our NFADB newsletter which is also available by request in BRAILLE, LARGE PRINT or electronically. Indicate preference on application.

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