

in touch



Winter 2003

The Newsletter of the New England Center Deafblind Project
175 North Beacon Street • Watertown, Massachusetts 02472 • tel: 617-972-7515
and we are online at www.necdbp.org

Greetings from NEC!

Here's to peace, happiness, and good health in the new year! As we plan and conduct upcoming events in 2003, NEC staff also will be writing a new grant. With this new proposal and the current grant, we strive to provide consultation and workshop trainings that are child and family-focused. Our survey information continues to highlight that many parents want consultation and technical assistance activities that relate directly to their child's classroom situation and learning needs. We will make every effort to develop a new proposal with this focus in mind.



This project is supported by the U.S. Department of Education, Office of Special Education Programs (OSEP). Opinions expressed herein are those of the authors and do not necessarily represent the position of the U.S. Department of Education.

In addition, the federal government is encouraging more local responsibility and accountability relative to quality educational programs for children who are deafblind. Therefore, in the next grant proposal NEC will seek even more local support and collaboration when conducting technical assistance/training activities. Also, we need your continued advocacy and support at the local level to convey the importance of the educational needs of children who are deafblind, particularly in the areas of communication and environmental access. Some examples of advocacy are: (a) advocating for your child's educational needs within the IEP process; (b) educating other parents in your local school about how your child can interact with peers; (c) suggesting that your local recreation department include your child in their summer planning; (d) calling your state legislators and explaining the importance of their support for ongoing funding for deafblind consumers upon transition from school; or (e) suggesting that fellow team members attend a NEC sponsored training about deafblind issues. Remember, your voice makes a difference in so many ways!

Dear New Hampshire and Massachusetts Families:

WE NEED YOUR HELP!! In order to provide technical assistance and training in your state, NEC is mandated to maintain updated vision and hearing reports on all children on the registry. If you have an updated report (evaluation conducted within the last year) please send us a copy. Your assistance is greatly appreciated.

Mail to:

New England Center Deafblind Project, 175 N. Beacon St., Watertown, MA 02472

NTAC Parent Training Conference on Self-Determination Held in Kansas City, MO

by Janette Peracchio
CT Family Specialist

I was fortunate to attend the parent training workshop on self-determination titled "Being Self-Determined: What Does it Take? Skills + Knowledge + Attitude + Opportunity" which was held in Kansas City, MO on August 1-3 this past summer. It was sponsored by the National Technical Assistance Consortium for Children and Young Adults who are Deafblind (NTAC) and National Family Association for Deafblind (NFADB).

The keynote speaker was Dr. Brian Abery, Project Director at the University of MN Institute on Community Integration. One of the main messages Dr. Abery conveyed was the fact that all individuals have the potential to express self-determination, regardless of severity or type of disability. I realized that it is my job as a parent to increase choices for my daughter, starting in infancy and continuing throughout her life. The choices do not have to be major in the beginning - let your child choose the socks or shirt they will wear for the day; the type of snack or beverage to take to school. These self-determination skills exist along a continuum of little choices when the child is young, which increase as the child grows. This will help with the child's development of his sense of control over his life, power to show personal preferences and the freedom to develop a vision for his future. When a child is raised this way, he will have improved learning, greater community participation, increased personal responsibility, and higher self-awareness and self-esteem.

As a parent of a child with multihandicaps, it was comforting to hear that being self-determined does not mean that a person becomes completely independent. It is just as important to be

interdependent, and self-determination is definitely a "family affair."

Another inspiring workshop was given on Assistive Technology and presented by Jack McCauley from the Boston Public Schools. Assistive Technology is a critical link to Self-Determination because it helps students to overcome barriers in their environment. Some tools are considered "No Tech," such as body positioning and gestures; others are "Low Tech" such as a magnifying glass or object communication system; some are "Mid Tech" tools such as headphones, tape recorders, and voice-output communication aids. Finally, there are "High Tech" tools such as calculators and Braille printers. The workshop gave us a format to use when choosing Assistive Technology tools for students, which are related to their IEP goals and objectives. This format titled "Student Access Map" or SAM enables the school team to devise a plan which enables our students to participate and be successful in completing activities with their peers.

...all individuals have the right to express self-determination, regardless of severity or type of disability.

One of the most enjoyable parts of the conference was meeting other families and professionals; sharing experiences and information with each other. That has always been a highlight of NTAC's parent-training workshops. There is so much knowledge to share and learn. Together we do make a difference in our children's lives.

The Third Mid-Atlantic CHARGE Syndrome Conference: Aberdeen, Maryland

by Andrea Garewski
CT Deafblind Family Specialist

The Third Mid-Atlantic CHARGE Syndrome Conference was held on June 21, 22, and 23 at the four points Hotel in Aberdeen, Maryland. The conference was cosponsored by Connections Beyond Sight and Sound (the Maryland Deafblind Project) and the Havre de Grace Lions Club.

Many thanks go out to organizers Bruce and Susan Appell for their dedication in supporting families and children who have CHARGE Association. My husband Jeff, daughter Katie and I attended this fun and extremely informative conference. It was wonderful to come together with our families and share experiences.

Guest speakers included Dr. James Thelin, Associate Professor of Audiology, University of Tennessee who spoke about Understanding the Hearing Loss in CHARGE Syndrome and its Consequences. Dr. Thelin also discussed promising research on cochlear implant technology for children with CHARGE. Many conference participants participated in a study exploring the characteristics of children with CHARGE and their impact on communication development. Good luck to Jill Fussner, graduate student at the University of Tennessee, in completing this important and relevant research. We look forward to reading the findings and recommendations from this study.

It was wonderful to come together with our families and share experiences.

Kat Stremel, Director of the National Technical Consortium for Children and Young Adults Who are Deafblind (NTAC), discussed the critical components of communication and how families can enhance their child's communication intervention program as changes take place over time.

We also had the privilege of participating in workshops led by skilled and knowledgeable staff from Perkins School for the Blind, Deafblind Program. Ms. Martha Majors, Assistant Supervisor, Deafblind Program, discussed overall programming needs for children who have CHARGE Syndrome. Teachers Sharon Stelzer and Kimberly O'Donnell shared strategies for planning meaningful instruction for our children.

Conference speakers' insight into the needs of our children was immediately apparent. Based on what I heard, parents came away with valuable strategies and unique and innovative ideas to share with their own child's educational team.

**Tell me and I'll forget.
Show me, and I may not remember.
Involve me, and I'll understand.**
Author unknown

A Family Trip to the CHARGE Syndrome Conference

by Janet Murray
MA Parent

The Murray family left for Aberdeen, Maryland on Thursday night June 20, 2002. It was a real close call, as the Weymouth Public Schools did not get out until June 20th! We travel at night. Spending time away as a family is enjoyable. We've also met a number of families who have children with CHARGE syndrome. Obtaining more information about CHARGE is a very important part of the experience.

Traveling at night is easier on Joshua, Justin, and Julianne as they get to sleep through the entire trip. It is hard on us because in the morning the kids are ready to go and we want to sleep. Generally we leave about midnight. That is exciting for the kids as they get to stay up very late and help to prepare for the trip by packing clothes in their bags and deciding what they want to bring for toys. It is a learning experience for them since they have to make decisions based on where we are going, what we will be doing, and what the weather is predicted to be. Debi, who is 18, also prefers to travel at night.

[A] benefit of meeting these families is that we get to see their interactions as a family and realize that we are not alone. Many times families without children with disabilities do not understand the dynamics of our family.

Traveling together as a family gives up plenty of time to talk about lots of different topics. We talked about the end of the school year, what else we wanted to do for the summer, and where we were headed. Usually the kids fall asleep quickly on the

drive there. When we get to the hotel room, we need to scope out the place to decide who is going to sleep where and with whom. Since we do daycare and foster care and usually have lots of kids at the house, it is a nice time to be a family.

Attending the conference are other families who have children with CHARGE Association. We have gotten to know many families from around the country: New York, Indiana, Florida, California, Maryland, Virginia, New Jersey. It has been a geography lesson as we have a giant map of the USA and the World to talk about where these new friends live. Another benefit of meeting these families is that we get to see their interactions as a family and realize that we are not alone. Many times families without children with disabilities do not understand the dynamics of our family.

And last, but certainly not least, is the conference itself. The Maryland Mid Atlantic Conference is a regional conference held in the year in between the International CHARGE Syndrome Conference. The conference is made possible by the hard work of Bruce and Susan Apell who put in many long hours putting the conference together and finding sponsors since the regional conferences are not run by the international organization.

Janet and Matt went to seminars on "Hearing in CHARGE" which were given by Dr. Jim Thelin. Also there were several professionals from Perkins School for the Blind in Watertown, MA and from NTAC in Oregon. The main topic of their seminar was behaviors and how to work with our children for successful outcomes.

The hearing seminars talked about the effects of hearing loss in CHARGE children. Dr. Thelin also introduced his graduate student, Jill, who will be

doing her graduate research project on hearing loss and associated behaviors in CHARGE children. Dr. Thelin spoke about the different types of hearing loss and how it affects a child's ability to function.

The discussions on behavior were very interesting. The speakers spoke about how we can set our children up for success or failure. Also we discussed how the child's vision and hearing play into their communication abilities. One speaker had a chart that detailed the various ways a child can "talk" to us.

It was such a learning experience for us and it also showed that when you really want to communicate with someone, you will find a way.

The kids headed off to childcare. One of the activities was Uncle Kenney's Corner. Uncle Kenney brings woodwork projects for the older kids to work on. Joshua absolutely loved this and was Uncle Kenney's helper for the weekend. Justin was feeling the effects of the humid weather and felt very comfortable in the air-conditioned childcare room, planted in front of the television. Although Julie, who is only 5, can have a hard time separating from us, she usually settles right in. The childcare staff has many toys for the kids to play with and crafts for the older kids to do. The hotel had a pool and it was certainly hot enough for all of us to enjoy it.

Debi generally spends time in the daycare rooms helping out with the kids. She has picked up quite a bit of ASL and she really enjoys the experience. She has connected with a 10-year old girl with CHARGE from New York who calls Debi "her" teenager. Debi wasn't feeling well so she didn't spend as much time with the kids as she usually does. She has helped in the past at the Mid Atlantic

CHARGE Conference in July 2000, the Indianapolis conference in August 2001, and the New England Center Family Weekend in October 2001.

Meals are provided as part of the conference costs and are served buffet style. Even though we are a family of 5 and usually need a whole table just for ourselves, we did get the chance to eat with other families. At one meal, we had the pleasure of the company of an almost 10-year old girl with CHARGE who only signs. Although we know a few signs, when Justin was 3 years old we chose the verbal route. It was such a learning experience for us and it also showed that when you really want to communicate with someone, you will find a way.

As we were eating lunch she wanted more applesauce; she was signing the word "apple" which is signed by putting the knuckle of your pointer finger into your cheek and twisting your knuckle just a little. It took me a bit to figure out what she wanted because she was also pointing at the table that the applesauce was on and there was a huge cake right next to it. She is only able to eat foods of soft consistency so I was signing to her "no." Finally she pointed to the applesauce on her plate and signed apple again. It was then that I understood.

We left for home on Sunday afternoon and were quickly reminded of why traveling at night is so much easier. The 7-hour drive was made longer by almost 2 hours due to Jersey Shore traffic and a very long delay going around New York City. Overall the family time together, the catching up with old friends from previous conferences, making new friends, and learning new information about CHARGE Syndrome make attending the conference very much worthwhile.

Advocacy Tips....

...In Preparing for the IEP Meeting

1. Decide if you need more information. Do you know your child's present level of performance? Have you received progress reports? Are you aware of testing that may need to be done? Is it time for a three-year reevaluation?
2. Get answers to your questions. Observe your child in the present program or visit some of the classrooms that will be available next year. If possible, visit the classroom more than once at different times in the day. Meet with teachers and other staff to find out what they think about the child's needs and the types of programs which would be appropriate. (Do not limit your options to programs which are currently available.) Read your child's records.
3. Find out who will attend the IEP meeting. Make plans for your own support. When you are notified of the meeting time and place, ask who else has been invited to attend, and if you believe someone providing services to your child has not been included in the meeting, ask that they be invited. Ask if a draft IEP has been developed. If it has, then request a copy prior to the meeting. It would be helpful to invite someone for moral support, to take notes for you, or to present additional information. Let the school know who you are asking to come with you.
4. Make sure enough time has been scheduled for the meeting. Ask how much time has been scheduled for the meeting. If you feel the time scheduled for the IEP meeting is too short, ask to meet at another time or begin work with everyone agreeing to a future meeting should every issue not be discussed. Make sure you have enough time to ask questions and share your opinions.
5. Be ready to support your ideas and requests. Find information in the records, progress reports,

evaluation results and elsewhere to support your ideas or requests. Know WHY you are making requests or suggestions. Have a "back-up" plan or suggestions that can be part of "give and take" to negotiate with school staff.

6. Plan for the meeting.
 - a) ORGANIZE your materials. (Reports, letters, etc.)
 - b) WRITE DOWN your questions.
 - c) KNOW what you want to say.
 - d) REVIEW Assertive Communication Skills.
 - e) PRACTICE communicating assertively.
7. Be positive. Assume that you and school system personnel can work together effectively to develop an appropriate program for your child. Get anger and frustration out before the meeting.

...For Participating in the IEP Meeting

1. Participate in all meetings regarding your child to demonstrate your desire to be an active participant on the team.
2. Follow up on timelines to ensure the IEP is completed on time.
3. Take notes about decisions made, activities for follow-up and timelines.
4. Bring a friend, relative, or advocate to the meeting.
5. Take time to review fully the final draft of the IEP before signing off on it. Before you sign the proposed IEP, take it home and highlight any questions or concerns so you can later get clarification from the team and can feel comfortable that the IEP is meeting your child's needs. Remember, the only time your signature is required is for the first IEP that is developed for your child.
6. Where appropriate, have the student participate

in the meeting.

7. View any document presented at the beginning of the IEP meeting as a “working document” as opposed to a final IEP. Do not accept a document that has been fully developed prior to the meeting without your consideration or input.

8. Know who in your school district is responsible for decision making regarding related services (for example, the Director of Special/Pupil Services, Assistant Superintendent, etc.)

9. Remember that the IEP can always be revised at any time during the school year, should you think changes are required. You should ask your case manager for a meeting to discuss the changes.

Adapted from Equals in Partnership by Pamela Crane, Diana Cuthbertson, Kay Alicyn Ferrell, and Hazel Scherb.

Maine Events

INSITE Training (Part 1) will be held in Augusta, ME on January 24 and 25, 2003. The training is for people who are working with young children (birth to five) with sensory impairments and additional disabilities. Call Charlotte Cushman at (207) 596-6209 for more information.

There will be an **introductory training for teachers and service providers working with children with deafblindness and multiple disabilities** in late May/early June in Portland and Orono. For more information, call Charlotte Cushman at (207) 596-6209.

An Open House will be held at the **Adaptive Design Center** in Bangor on January 9 from 1 -7 PM (snow date: January 16). Come and see the new center and learn about how you can make low cost materials and adaptive devices from cardboard, plastics, foam, fabric. Projects may include positioning equipment, communications systems, adapted toys, and more. The Adaptive Design Center is at UCP of Maine, 700 Mount Hope Ave., Suite 320, Bangor. Call (207) 941-2952 ext. 227 for more information.

Are there any parents in Maine who would like to learn more about what it means to be a “**family specialist**”? Call Charlotte Cushman at (207) 596-6209 for more information.

AER Division 3

As many of you are aware, there are very few organizations that provide useful information and support in the area of multiple disabilities and deafblindness. The Association for the Education and Rehabilitation for the Blind and Visually Impaired (AERBVI) has an active division on multiple disabilities and deafblindness. AER has a bi-annual conference. The next conference will be at Disney World in Orlando, FL in July, 2004. Please check their website for further information about this conference and membership. Their address is www.AERBVI.org.

-Marianne Riggio, Chair, Division 3

Workshops on Cortical Vision Impairment Held in Maine, Massachusetts, and New Hampshire

From October 28th to November 6th, 2002, Dr. Christine Roman of Marshall University presented a series of workshops on Cortical Vision Impairment (CVI) in Maine, Massachusetts, and New Hampshire. Dr. Roman, who had come to Massachusetts for a workshop on assessment and CVI last spring, presented a follow-up workshop at Perkins School for the Blind on November 1st and 2nd entitled, "Creating Appropriate Learning Environments for Children with Cortical Vision Impairment." For those in other states who were not able to attend the previous conference last spring, Dr. Roman presented a similar workshop, "Assessing Functional Vision in Children with Cortical Visual Impairment," at the Somerset Hotel in Rockland, ME on October 29th and 30th and at the Highlander in Manchester, NH on November 5th and 6th.

At each workshop, Dr. Roman discussed several issues related to working with children who have CVI. This included the use of a multi-element scale to assess a child's level of vision beyond the typical tests of visual acuity and with an emphasis on measuring a child's responses to color, motion, and position. At the workshop held at Perkins, several teachers of children who are deafblind presented case

studies in order for Dr. Roman to review and provide feedback specific to proper assessment and recommendations for future learning environments.

These workshops were organized by a collaborative effort of the New England Center Deafblind Project, the M.I.C.E. Program in New Hampshire, Catholic Charities in Maine, UMASS/Boston and Perkins School for the Blind in Massachusetts. Special thanks to Charlotte Cushman (ME), Jean Small (ME), Jan Halley (NH); and, from Perkins School for the Blind, Martha Majors, Veronika Bernstein, Liz Pike, Tom Collins, Anita Patel, Barbara Birge, Patti Bastiani, Liz Breadon, Nicole Laffan, and Kim O'Donnell.



Dr. Christine Roman presenting at Perkins School for the Blind on November 1, 2002.

For Your Information!

The materials in the NEC Library are moving to DB-LINK, located in the Howe Building of Perkins School for the Blind. Please direct all requests for materials to Lisa Jacobs at DB-LINK at (617) 972-7540 or Lisa.Jacobs@Perkins.org.

Massachusetts Parent to Parent News

Is your child 16 or older? If yes, it is time to start thinking about your child's transition to adult services. In these times of economic troubles, state funded services also have had budget cuts. It is now more difficult to acquire the funds needed for the group of adults "turning 22" each year. Last year's budget for Deabind services was cut drastically. Word was spread through our parent organization, the Massachusetts Deafblind Family Alliance, and phone calls were made by parents and friends asking state legislators to fully restore the budget under the Mass. Commission for the Blind. **Our efforts paid off!** The budget was restored to 80% of what the Commission was looking for which was enough to maintain services that were in danger of being lost and to include the new "turning 22" group of young adults. This year's budget will undoubtedly be cut during debates and will again require parents involved in advocacy. The best advocates for our children will always be parents and immediate family members. We urge all of you who have children 18



Commissioner David Govostes from Massachusetts Commission for the Blind addressing attendees at the October 3rd, 2002 Legislative Breakfast. Sign Language Interpretation was provided by Christine Lebert.

Upcoming Meetings of the MA Deafblind Family Alliance

Meetings at 6:30PM, Hilton Bldg., Perkins

Jan. 21 - Students to Adulthood, Rep.

Kaufman, and Commissioner Govostes

Feb. 25 - Strategies, Planning Action Meeting for Legislative Breakfast, Letter Writing

Mar. 18 (tentative) - Breakfast Planning / or Review + Action Meeting

years and older to become more involved with our parent group so you will better understand the state budget process and can advocate with us for services for your child as he or she approaches that age of 22.

As a group we have been trying to become more proactive and not wait until there is a budget crisis to contact our legislators. On October 3rd, we sponsored a "Legislative Breakfast" at the State House inviting Legislators to meet us, the Commissioner of MCB, and staff from the Regional Center. The purpose of this breakfast was to inform the legislators of the unique needs our children have as adults and why they require special services. We plan to have another breakfast in the spring to coincide with the budget process for the coming year.

Parents of teenagers please come to our January meeting with Rep. Jay Kaufman and David Govostes, Commissioner of the MA Commission for the Blind. At this meeting we will address issues impacting our childrens' transition to adult services. If you are unable to attend this meeting please send us a written endorsement supporting our efforts. A simple expression of your concerns and needs regarding your child and future program planning is needed. **WE NEED EVERY VOICE!**

Give us your support, input, ideas, and questions!

Dr. Heidi Miller 617-962-8373

Elissa Hoover Gould 617-776-2944

NEC: 617-972-7515 Fax: 617-972-7354

Email: nec@perkins.org

Brothers and Sisters: Strategies for Supporting Siblings of Children who are Deaf-Blind

This article is a reprint of a Fact Sheet by California Deaf-Blind Services.

Brothers and sisters who have siblings with combined hearing and vision problems are first of all people and important members of the family. Siblings will probably want to know why this happened to their brother or sister and how it will affect them personally. This is especially important at the time the family is dealing with a new diagnosis; siblings need to be remembered at these times and have their questions answered and their concerns addressed. It will be helpful for siblings to understand exactly what and how much their sibling may see and hear, and about additional disabilities the sibling may have. Being open and actively listening to siblings may be tough for parents as they deal with a child who is deaf-blind, but these conversations are likely to be as healing for the parents as they are for the siblings.

Things to consider:

Emotional Stages. Learning to live with a child who is deaf-blind requires going through all kinds of emotional stages—anger, grief, sadness, hope and acceptance. To help deal with these emotions, it's a good idea to meet other parents of children with disabilities, share stories with them, and attend family support groups. Many times these various emotions come up at different times for individual family members. Birthdays and holidays are often tough on families, and this should be remembered and worked through as a family. For birthdays, sometimes it is very nice to celebrate each member of the family separately, if financially possible; if not, do not feel guilty about celebrating the siblings in a special way, or siblings might think there is a preference for the child who is deaf-blind.

Take a break! Giving the family a break from the responsibilities of caring for a child who is deaf-blind may be helpful, and provides family members the time to concentrate on other relationships in the family. Respite care or camps are a good idea for parents and siblings. Each child in the family has a need for individual care and attention, and giving this attention may require special effort and energy from parents. It is important for professionals working with the child who is deaf-blind to let the family know that it is okay for them to say we are tired, or we need help, and also emphasize that they are there to serve the entire family, not only the child who is deaf-blind.

There are positives as well as negatives. Having a sibling who is deaf-blind can have both positive and negative effects on the family. Different "behaviors," surgeries, and illnesses are tough on all family members. For these moments of struggle, the family and friends as well as other people involved need to be united and provide all the support possible. Even time spent just holding hands or giving/receiving hugs can help soothe these moments. On the positive side, the ability to enjoy the accomplishments of a person who is deaf-blind, no matter how big or small, can bring joy to all members of the family. The best way is to "celebrate," meaning make a big deal out of these accomplishments.

Have a back-up plan. It is important for therapists and teachers to be open to the siblings' presence and their questions. The most important thing for therapists and teachers to do is be honest with families, and express if they are okay with the presence of siblings during therapy sessions, knowing that this might be a little disruptive. For parents, it is better if there is another older person in the house who can take the siblings someplace else while the therapy is given, because parents do not want the siblings to have hurt feelings if the professionals are not open to their presence.

Families need all the help they can get. It is necessary for medical professionals and counselors as well as regional center workers and related project personnel to offer each family all the help they can use, and provide all the resources in the community for the entire family and not just for the child who is deaf-blind.

Siblings may feel responsible for their brother or sister who is deaf-blind. These feelings of responsibility may be emotional, and later in life related to financial matters. Families often may not realize the specific concerns that siblings have. To avoid or prevent these future feelings, it is necessary to have conversations with the siblings that address all the important issues and concerns related to the child who is deaf-blind. It is important to give each individual sibling their own space and not overload them with extra responsibilities on top of the ones they already have. It is important to include siblings in planning for the future of the child who is deaf-blind. Using a person-centered planning approach is a good way to focus attention on the individual who is deaf-blind while at the same time including everyone who cares about the individuals' future in the process.

Younger siblings need special consideration. It is important for parents as well as professionals working with children who are deaf-blind to remember that young siblings might have sensitive feelings that can be easily hurt. To avoid making the siblings feel left out or not wanted, we can make them feel they are important and include them in various activities throughout the day, e.g., bath, play.

We are all unique. Cultural and religious differences may strongly affect the way a family deals with a child with disabilities. Family and individual counseling may be helpful, but each family will likely have their own unique way of dealing with issues related to the child who is deaf-blind, and this needs to be understood and respected by the professionals involved with the family.

Babies Count: Registry Project

by Marianne Riggio

The recent emphasis on developing early intervention services necessitates that accurate, dependable, and consistent data be collected. Despite the need to develop services which are responsive to the needs of children who are visually impaired, no national data system currently exists that identifies those characteristics specific and/or unique to blind and visually impaired children—such as incidence of specific eye conditions, presence of hearing impairment, ethnicity, geographical distribution, socioeconomic status, and presence of other additional disabilities.

The availability of this information would allow decision-makers to identify trends that have important implications for the future in preventative medicine, education, teacher training, funding, and service delivery. Such information would provide early intervention and special education services by providing the demographic and statistical information that can guide policy development, document the needs of young children with visual impairment and their families, and project the future needs of school-age children with visual impairment.

The American Printing House for the Blind has now assumed the leadership role in establishing **Babies Count: National Registry for Children with Visual Impairments, Birth to Three**. Participant agencies will work with epidemiological and demographic information on young children with visual impairment. This information will be sent to APH and entered into the national database then analyzed and interpreted by UNC Chapel Hill.

Currently there are seventeen states actively collecting data. The American Printing House for the Blind (APH) is interested in adding to this number. For further information about this project contact Mr. Burt Boyer at bboyer@aph.org.

What's Working Well With Transition?

Models of Success

**Do you have.....a favorite transition story?
A strategy that has worked?
A successful program or project?**

**Please NOMINATE THEM - They may be
Models of Success!**

These models will be used in online trainings focusing on secondary special education and transition.

Monetary awards will be provided to selected nominations.

Any individual with a disability, family member, teacher or school or community program can be nominated.

**Nominate online at
www.transitioncoalition.org**

Nominations reviewed on a quarterly basis starting December 30, 2002.

Questions?

Contact:

E-mail modelsofsuccess@ku.edu or call 785/864-0686 and ask about **Models of Success**.

The Transition Coalition is part of the Department of Special Education at the University of Kansas. The activities of the Transition Coalition are supported by the Office of Special Education Programs, U.S. DOE award numbers H325D010050, H325H000022, H325N010018 and H324R010011.

Matchmaker Project: A Communication Competency Model for Educational Teams Working with Children and Youth who are Deafblind

The New England Center is in the final year-the dissemination phase-of the Matchmaker grant. The grant focuses on seven Massachusetts deafblind students and their teams. Mary Hill Peters worked tirelessly with each team to collect photographs and video footage to create individual communication portfolios. The primary goals of this project are...

- To illustrate the communication abilities of learners who are deafblind with their families, friends, and Teams (teachers, and other service providers) through communication books and videos.
- To increase the competence of the learner's communication partners.
- To improve the learner's communication abilities.

Purpose of the Communication Book and Video

The communication book and video provide effective and efficient information regarding the child's communication abilities and needs. The book and video are for use by educators, related service personnel, family members, friends and peers.

The information provided in the communication book and video illustrates the present level of student performance and services necessary for the child to access the general curriculum. Therefore, team members should review information in the communication book and video prior to conducting alternate assessments and developing IEP's.

Thinking beyond the Grant

NEC will be offering training in the development of these communication materials for families and educational teams. We hope to work collaboratively with the Comprehensive System of

Personnel Development (CSPD) to provide this Training Module. In collaboration with the Massachusetts Department of Education, NEC will use the Matchmaker process and materials to develop a larger-scale training module for children with similar communication issues and other low-incidence disabilities.

Communication Books

The communication books can easily and inexpensively be added to on an on-going basis to illustrate the learner's progress and improve the competency of communication partners. The books decrease the amount of time communication partners need to understand the learner's history and communication abilities. The materials also are a reference point for highlighting the child's skills, abilities, and needs.

Videos

Videos provide a visual baseline of the learner's skills, abilities, and needs. Teams may incorporate

videos in their on-going assessment process and as part of the alternate assessment process.

Technical Assistance

Technical assistance practices pioneered in the project will be incorporated into future collaborative efforts between the New England Center Deafblind Project and the Massachusetts Department of Education. NEC will document technical assistance practices that develop and use communication books effectively in a procedure manual, which will be available at the end of this project. Individual student communication books will be easy and inexpensive to replicate. The New England Center will encourage the development and use of communication books for all students on the registry beginning with those who need the most intensive technical assistance.

If you would like more information about the Matchmaker Project, please contact Susan M. DeCaluwe, at 617-972-7516.



Mary Hill Peters (left) and Susan DeCaluwe (right) organized the Matchmaker Program. Mary worked with the students and Teams to collect information and photographs. Susan is heavily involved in the information dissemination phase of the program. She has presented the program in Washington, DC and is developing a manual for expanding the Matchmaker model throughout Massachusetts and the New England Center region.

Summer Institute 2002

Perkins School for the Blind Outreach, in collaboration with the New England Center Deafblind Project, UMASS/Boston, Boston College, Institute for Community Inclusion, and the Connecticut Board of Educational Services for the Blind presented Summer Institute 2002 during the week of June 22-26. The Institute focused on the topic of critical issues in the assessment of children with multiple disabilities or who are deafblind. Participants from Canada, Massachusetts, Rhode Island, and New Hampshire were “teamed together” based on the age of their students. Basic information and assessment instruments were presented regarding vision, hearing, communication, development, team collaboration and writing appropriate goals and recommendations. The week was tightly packed and participants attended class all day and had evening assignments to complete. All participants had the opportunity to make the Summer Institute professionally relevant to their students and to refresh and share their own abilities and backgrounds. Time was devoted to identifying “hot topics” in education and program development, and collaboration and support for sharing potential solutions. In addition, a panel of parents spent an evening in an informal discussion about their experiences with early assessments by medical services and later by educational teams.



Some of the Participants in Summer Institute 2002...

**Top (from left): Evelyn Kelso, Tom Banning, David Conaway, Bonnie Albert
Bottom (from left): Merrilyn Holcomb, Laine Tulipano, Timothy Traut-Savino,
Andrew McCara, Helena Armstrong**

“Save the Dates”

Upcoming Trainings, Workshops, and Events

Date	Event	Location
January 1, 2003	Happy New Year!	
January 9, 2003	Open House – Adaptive Design Center	Bangor, ME
January 21, 2003	Massachusetts Deafblind Family Alliance Meeting with MCB Comissioner David Govostes and Rep. Jay Kaufman – 6:30PM	Perkins School, Watertown, MA
January 24-25, 2003	Part I Project INSITE – Training for North River Collaborative 8:00AM-5:00PM	Rockland Public Library Rockland, MA
January 24-25, 2003	Part I Project INSITE – Maine Center for Community Inclusion 9:00AM-5:00PM	Arboretum Augusta, ME
January 27, 2003	MA Instate Planning Meeting	Watertown, MA
January 27-28, 2003	Creative Constructions with Molly Campbell	Perkins School, Watertown, MA
February 25, 2003	Massachusetts Deafblind Family Alliance Meeting – 6:30PM	Perkins School, Watertown, MA
March 6-7, 2003	Working with Challenging Behaviors in Teaching Students who are Visually Impaired with Multiple Disabilities, including Deafblindness	Hartford, CT (3/6) Hampden, CT (3/7)
March 18, 2003	Massachusetts Deafblind Family Alliance Meeting – 6:30 PM (tentative)	Perkins School, Watertown, MA
April 1, 2003	April Fools Day!	
April 4-5, 2003	Part II INSITE	Perkins School, Watertown, MA
May 2-3, 2003	Part II INSITE – Training for North River Collaborative	Rockland Public Library Rockland, MA
May 3, 2003	20 th New England Regional Seminar for Children with Visual Impairments and Their Families (Birth-7)	Perkins School, Watertown MA
May 9-10, 2003	Part II Insite – Maine Center for Community Inclusion 9:00AM-5:00PM	
May/June 2003	Intro training for Teachers & Service Providers Working with Children with Deafblindness/Multiple Disabilities	Portland, ME Orono, ME
June 21-25, 2003	NEC Summer Institute (Tentative)	Perkins School, Watertown, MA
August 5-10, 2003	13 th DbI World Conference on Deafblindness www.dbiconferencecanada.com	Mississauga, Ontario, Canada

New England Center Deafblind Project Contact Information

NEC

New England Center
Deafblind Project
175 North Beacon Street
Watertown, MA 02472
TTY: (617) 924-5525
Fax: (617) 972-7354
www.necdbp.org

Barbara Mason
Project Director
(617) 972-7502
Barbara.Mason@perkins.org

Tracy Evans Luiselli
Project Coordinator
(617) 972-7517
Tracy.Luiselli@perkins.org

Kevin Still
Project Assistant
(617) 972-7515
NEC@perkins.org

Shaun Skeya
Project Assistant
(617) 972-7515

Massachusetts

Susan DeCaluwe
Education Consultant (MA)
(617) 972-7516
Susan.DeCaluwe@perkins.org

Mary Hill Peters
Education Consultant (MA)
(617) 972-7514
mmhpeters@rcn.com

Connecticut

Board of Educational Services for the
Blind
184 Windsor Avenue
Windsor, CT 06095
(860) 602-4191

Karen Olson
Education Consultant (CT)
karen.olson@po.state.ct.us

Kathy Morgan
Education Consultant (CT)
katherine.morgan@po.state.ct.us

Janette Peracchio
Family Specialist (CT)
janette.peracchio@po.state.ct.us

Andrea Garewski
Family Specialist (CT)
andrea.garewski@po.state.ct.us

Maine

Charlotte Cushman
Education Consultant (ME)
PO Box 84
Thomaston, ME 04861
(207) 596-6209
ccushman@midcoast.com

Catholic Charities Maine
1066 Kenduskeag Avenue
Bangor, ME 04401
(617) 972-7514
www.ccmaine.org

New Hampshire

Cate Weir, ASSETT
Project Co-Director
117 Pleasant St., Dolloff Bldg.
Concord, NH 03301
(603) 226-2900

Janet Halley, M.I.C.E. Program
Program Director
PO Box 2274
Concord, NH 03302
(603) 228-1028
miceprogram@juno.com

New England Center
Deafblind Project
175 North Beacon Street
Watertown, MA 02472

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