

# in touch



Summer 2002

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*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](http://www.necdbp.org)

## **Its That Time Again!**

Time to break out the beach towels, locate the umbrella and beach chairs, buy new bottles of sunscreen and mosquito repellent, watch the grass grow, and hopefully take a break from the busy world we live in. However - before you do that - the staff at the New England Center Deafblind Project (NEC) would like to ask that you think of adding "one more thing to your list." Here it is: please send updated vision and hearing records for your child to the NEC office. (Refer to the address above.) The Federal government requires that NEC update records each year and it is often difficult for us to locate correct information. NEC needs assistance from both families and professionals to help keep this information current in order that our records truly reflect the children we work with in Connecticut, Massachusetts, Maine, and New Hampshire. These documents also are used to determine our training needs and plan topical workshops that address child-related issues. So, if your child or a student you work with has had an updated vision and/or hearing assessment or evaluation in the past year, please send us a copy. We will gladly reimburse you for your mailing costs. And special thanks to those families and professionals who have already provided us with the updated information.



*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.*

As an update on our past spring activities, the New England Center was fortunate in March 2002 to have Dr. Christine Roman from Marshall University conduct trainings on cortical vision impairment. There were 145 attendees in the Massachusetts training and 50 in the Connecticut training, demonstrating a high interest in this topic. Dr. Roman presented an assessment protocol for use with individuals who have cortical vision impairment along with examples of intervention strategies. A follow-up presentation at Perkins School for the Blind is scheduled for fall of 2002. Dr. Roman also will present in Maine on October 29th and 30th, and in New Hampshire on November 4th and 5th, 2002 (see enclosed "Save the Dates" section). Other NEC activities include our upcoming Summer Institute 2002 (in collaboration with Perkins Outreach Services and UMASS/Boston) in late June, and INSITE "Train the Trainer" workshop in July of 2002.

Lastly, the staff at NEC want to wish everyone a safe and relaxing summer. We would like to thank everyone who has assisted with and/or attended NEC workshops and trainings, taken time to convey ideas and suggestions, and offered support via our instate and multistate planning teams and Advisory Committee. Please let us know if you have special training interests or questions (families and professionals). We will make every effort to respond to your requests.

**Enjoy some summer fun!**

# Key Elements for Effective Assessment of Children who are Deafblind

Prepared by Evelyn P. Kelso, M.A.

Children with deafblindness or multiple disabilities tend to experience the world as it exists within their immediate reach (Miles, 2000). Many of these children may have some residual vision and/or hearing. However, the combination of this dual sensory impairment limits the extent of interaction they have with people, access to information about events and objects at a distance, incidental learning acquired just by seeing and hearing, and development of meaningful concepts about home, school, and community. School teams must assess these children differently from other students to effectively address their unique learning needs.

## SUCCESSFUL ASSESSMENTS SHOULD INCLUDE

### #1: FAMILY PARTICIPATION

- Incorporate active family involvement throughout the assessment process.
- Interview the family regarding their priorities, immediate goals, and long term dreams.
- Include family input in planning assessment activities.
- Use family members to facilitate some assessment activities, as they are familiar and trusted by the child.
- Give attention to any family concerns that remain following assessment.

### #2: TRANSDISCIPLINARY ASSESSMENT GUIDELINES

- Assessment of the child across natural settings (i.e. home, classroom).
- Selection of a variety of familiar, everyday activities where different skills can be assessed.

- Use of a transdisciplinary team approach in which educational team members share knowledge from their areas of expertise for other team members to incorporate in their practice.
- Follow-up team assessment by using information to plan the educational program.
- Focus IEP goals and short-term objectives on behavioral skills to be developed or expanded.
- Conduct ongoing assessment throughout the school year, with changes to the IEP made as the child masters critical skills (short-term objectives).

### #3: ASSESSMENT STRATEGIES

- Base interactions on data in most recent vision and hearing reports. Select toys or other objects that use the child's preferred colors, textures, and sounds. Present the objects in the positions where the child has the best vision and hearing. After the child is engaged, move the toys to varying positions to assess any response.
- Use the child's current communication program if one exists. Interpret the child's changes in behavior as communication, and prolong the exchange to learn more about how the child communicates.
- Select a single team member to act as activity facilitator to decrease the number of people with whom the child will interact.
- Choose activities based on family routines.
- Include components that apply to classroom instruction and appropriate age level activities.
- Ask the child to make choices, follow steps in a routine, or indicate what comes next in an activity,
- Embed critical skills within activities to assess the child's level of understanding and

response. Does the child initiate activity?  
What level of support or prompts are needed?  
What is the child's response if the routine is changed or sabotaged? What kind of choice-making is shown?

- Σ Create a report in which team members contribute to one comprehensive final document based on areas assessed. The report should include ideas for planning and educational programming.

#### #4: ESSENTIAL ASSESSMENT DOMAINS

- *Social/Communication:* (Vocalizations, gestures, eye gaze, changes in movement, alertness, verbalizations, signing.) What methods does the child use for receptive and/or expressive communication? How does the child use these? How does the child respond to the assessment facilitator, parent, peer? i.e. cues, verbal requests, pauses for turn-taking.
- *Sensory/Motor:* What are the child's likes/dislikes? tolerance for different types of sensory input? willingness to explore new, unfamiliar sensory input? How does muscle tone affect the child's ability to participate in activities? (Motor planning? Stamina? Reach and grasp?) What supports and physical modifications are used and what are the results of each? What positioning works best for stabilization, comfort and greatest range of motion?
- *Functional Vision:* Does the child appear to have useful remaining vision? What focusing and tracking patterns are present? How does the child use near vision? distance vision? What is observed about the visual field—use of central or peripheral viewing? Do visual fields appear to be intact? Does the child look at an object while interacting with it or look away, and then act? Does the child show color preferences? preference for movement rather than still objects? Are eyeglasses or low vision

aids recommended? tolerated? in use? What is the child's preferred learning mode: visual, auditory, or tactual?

- *Functional Hearing:* Is the child aware of sound? Does s/he alert to sound, orient to sound, localize sound, isolate a specific sound in the presence of other sounds? Does the child respond to a selected sound among other sounds? Does the child appear to use hearing to respond during the assessment—to voice? music? speech? Are hearing aids recommended? tolerated? in use?

All of these areas need to be assessed because they are interrelated in their influence on the child's ability to make sense of the world. Accurate functional data on vision and hearing is particularly critical since it is the combined effect of the dual sensory impairment that requires instructional approaches differing from either vision or hearing strategies. Only when the child is assessed in settings where s/he is familiar with the facilitators, routines, and materials will s/he have the opportunity to respond in a way that gives a true indication of developmental/cognitive level. The child will demonstrate competencies and areas where skills are emerging or as yet undeveloped. The more accurate the assessment of the child, the more effective will be the next steps toward greater meaning and participation at home, school and in the community.

Miles, B. (2000) Overview of Deaf-Blindness, DBLink, Revised July 2000.

This article was prepared as a partial requirement of the New England Center Deafblind Project/Summer Institute 2001. The information compiled here represents an outline of the information presented by Dr. Jennifer Grisham-Brown (University of Kentucky), Patty Mason (South Shore Educational Collaborative), Debbie Gleason (Perkins School for the Blind), Vicki Wilson (Perkins), and Darick Wright (Perkins).

*Evelyn Kelso is an educational consultant with ATECH/ASSETT in New Hampshire.*

## Connecticut Update

The New England Center Deafblind Project and Board of Educational Services for the Blind in Connecticut are pleased to announce that Connecticut has two new family specialists! Welcome to Andrea Garewski and Janette Peracchio. They will be working with Kathy Morgan and Karen Olson to administer NEC grant activities in the state of Connecticut. Their primary responsibilities will be to update and maintain the NEC census, assist with state-wide and NEC trainings, work with the Connecticut parent group, disseminate NEC information to families and state agencies, and be a resource to families relative to deafblind issues. We are thrilled to have Andrea and Janette aboard!



*from left to right: Karen Olson, Andrea Garewski, Janette Peracchio, Kathy Morgan*

### Distance Learning Pilot Presentation

On May 29, 2002 Board of Education & Services for the Blind (BESB) and the Lighthouse Voc-Ed Center in Groton, CT, with the assistance of the American School for the Deaf (ASD) and UCONN at Avery Point, piloted a distance learning module on tri-wall applications. Kathy Morgan, Deafblind Consultant at BESB, was at the Avery Point location along with Kathy Green, executive director of the Lighthouse, and Tonya Reed, tri-wall designer/builder to present a variety of tri-wall constructions made for children who have visual impairment and multiple disabilities. Meanwhile, ASD participants, Karen Olson (Deafblind Consultant at BESB), and a small audience consisting of vision consultants, OTs, PTs, and parents watched the live, interactive presentation which included photographs and videotapes via big screen TV. We were all able to interact with each other, asking questions throughout the presentation. We felt the pilot presentation was a huge success and hope to do more of these in the future.



# **Matchmaker Show and Share**

by Mary Hill Peters

## **Communication Take Outs**

Steve Peck, of the Revere Public Schools, has invented and built this portable communication schedule box system for one of the students in his class. Steve wanted to teach a solid foundational use of the same objects in multiple environments, before moving on toward more representational pictures. Steve considers this system very successful for his student, and he has been in contact with the American Printing House for the Blind for production possibilities!



Jeanne Duffy, of the GLEC Collaborative, is a teaching assistant who dreamed about her student's need for a "communication carryover" into the home and community. With portability, durability, and stability needs in mind, as well as the students' learning style, Jeanne created and crafted this user friendly "communication box to go."



## **Parents' Perspectives on... Important Practices In Communication**

- 1) Families and professionals need to gain an understanding of various communication techniques, strategies, and modes in order to give the child an individualized and appropriate communication system that reflects the child's assessed needs and respects the family's choice. Children should be provided with multiple communication approaches including total communication, sign language, pictures and augmentative communication methods in both home and school environments.
- 2) Teachers and services providers must understand that all behavior has a communicative function and should not be a "problem." Individuals who are deafblind should have the opportunity to express their needs and frustrations without being judged.
- 3) Each individual who is deafblind should be provided a communication facilitator (certified interpreter, trained intervenor, teacher assistant, etc).
- 4) Training should be provided to ensure that a variety of people are able to communicate with the child.
- 5) Children and adults who are deafblind should be given the right to communicate and be "listened to" with adequate time to respond.
- 6) Children and adults who are deafblind should be provided with the necessary tools to encourage acceptance into his or her preferred community (i.e. deaf community or other appropriate communities).
- 7) Individuals who are deafblind should be provided the opportunities to succeed, take risks and even fail.
- 8) American Sign Language should be offered as a foreign/second language in school and community settings.
- 9) Community and businesses should provide access to communication (in a variety of modalities).
- 10) Professionals and paraprofessionals should be appropriately trained and required to maintain high standards of practice.

*NTAC/NFADB National Parent Workshop, 1998*

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**WE NEED YOUR HELP!**  
**Please return NEC Library  
materials by July 15th, 2002**

## **Helpful Resources** *for Parents and Providers*

**The Perkins Vision Rehabilitation Clinic** combines the educational expertise from Perkins School for the Blind and the clinical expertise from New England Eye Institute to provide clinical and functional vision examinations to individuals throughout New England. Educators, parents, and optometrists work side by side during the clinical examination to determine the current level of visual functioning so as to prescribe devices (as needed), develop appropriate therapies, and offer education/rehabilitation recommendations. In addition, we serve as a resource for education and clinical professionals in the areas of pediatric low vision and educational services for children with visual and multiple disabilities.

For more information about the clinic, call Darick Wright the Clinic Coordinator at 617-972-6355. The clinic is open every Tuesday and Wednesday and accepts reimbursement from most insurance companies. If you would like to schedule an appointment call our office assistant at **617-972-7296**.

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**The Maine Adaptive Design Collaborative** is up and running! This new project combines the efforts of parents, United Cerebral Palsy of Maine, Husson College Department of Occupational Therapy, Education Services for Blind and Visually Impaired Children (through Catholic Charities Maine) Division for the Blind and Visually Impaired, and New England Center Deafblind Project to increase the independence of people with disabilities through the creation of special equipment. Using techniques such as building with tri-wall (cardboard), simple electronics (switches), fabric, and other materials, the collaborative seeks to train parents and service providers to make the special equipment that they need for their child. Sample projects made at recent workshops include communication devices, positioning equipment, play and activity centers, and sensory integration materials.

We offer a series of trainings on specific topics, as well as open workshop times when people can work on their own projects. At the moment, we are using Camp Capella in Dedham (between Bangor and Ellesworth), courtesy of UCP, but we hope to have a more permanent space in the future. We are always looking for volunteers, as well as donations of tools, materials, toys, etc. If you would like more information, please contact the UCP Tech Center at **207-941-2952 x227** or email **teccentr@midmaine.com**

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Your state's **Vision Resources Library** is an excellent resource for locating Large Print and Braille Textbooks, as well as other educational and classroom materials for students with vision impairments. In Massachusetts, contact Carrie Brasier at **1-800-827-7772**. In northern and eastern Maine, contact Jeff Jones at **207-561-4021**. In central and southern Maine, contact Alice Gay at **207-624-5145**.

Students who are deafblind are eligible for registration through their Teacher of the Visually Impaired (TVI). Registration makes them eligible for a range of free materials and devices.

## *Planning Your Child's Individualized Education Program (IEP): Some Suggestions to Consider*

Before the IEP team meeting:

- Consider the vision you have for your child for the future as well as for the next school year.
- List your child's strengths, needs, and interests and your major concerns about his or her education.
- Consider how your child's disability affects his or her education.
- Think about your child's educational progress. What has been working and what has not?
- Request a written copy of your child's evaluation results or a meeting with school staff to discuss the evaluation before the IEP meeting. This gives you an opportunity to understand the evaluation before the IEP team meeting for your child.
- Consider the evaluation results. Do these results fit with what you know about your child? Is the evaluation complete and accurate? If you disagree with the school's evaluation, you may request, in writing, an independent educational evaluation (IEE) at no cost to you. The school must pay for the evaluation or show the due process hearing officer that its evaluation is appropriate. The results of an IEE must be considered by the IEP team in planning your child's IEP.
- Consider a variety of ways to involve your child in developing his or her IEP, starting at a young age if appropriate. Self-advocacy skills are important to develop.
- If needed, plan to bring someone with you to the meeting with knowledge or special expertise regarding the child, such as a spouse, relative, friend, related service personnel, or representative from a local disability organization.

At the IEP team meeting:

- The IEP meeting is very important. You, the school personnel, and other IEP team members attending the meeting will review and discuss information about your child to develop the IEP. It provides an excellent opportunity to ask questions and share important insights about your child, whom you know better than anyone else does. The school needs to know what your child is like at home and in the community, as well as what your child's interests and activities are.
- Make sure others at the IEP meeting never forget that the meeting is about a real child - your child.
- Share your visions for your child, both short-term and long term.
- Discuss your child's strengths and needs and any concerns about your child's education.
- Remember that diagnostic tests and assessments do not present the total picture.
- When you believe that the teacher and school personnel are doing a good job, tell them so. Praise, when deserved, is a great thing.
- Be a good listener. Ask questions.
- Make sure you understand. If you don't understand something, ask to have it explained in a way that you can understand.

- **Expect that what you know about your child will be used in making decisions.**
- **Use school data, your child's progress reports, and other information you know about your child to make decisions.**
- **You may not want to agree to a proposed IEP at the end of the meeting. Review the proposed IEP document at home. If you disagree with what is being proposed in the IEP document, you must notify the school as soon as possible to resolve the disagreement.**

After the IEP team meeting:

- **Your child's IEP must be reviewed at least once a year to determine whether the annual goals have been achieved and to revise the IEP if necessary.**
- **Your child's school must inform you regularly about your child's progress, at least as often as parents who have children without disabilities are informed about the progress their children are making. Schools can do this by providing periodic report cards. You will be informed about whether your child is making progress toward meeting the annual IEP goals, and whether the progress is enough to reach the goals. For your child is not making adequate progress, an IEP meeting should be held to review the IEP and make needed changes.**
- **You may request an IEP meeting at any time during the year if you believe it is important to consider changes in your child's IEP.**

*The information above is a product of the PACER Center, Inc.,  
the coordinating office for Families and Advocates Partnership for Education (FAPE)  
8161 Normandale Blvd., Minneapolis, MN 55437  
1-800-248-0822      www.fape.org*

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## **Massachusetts Deafblind Family Alliance Update**

On May 7th, the Massachusetts Deafblind Family Alliance met with Commissioner David Gavostes, Bob Dowling, Deputy Commissioner for MCB Services, and Mitchell Sanborn, Director of the MCB's Deafblind Unit. The meeting was chaired by Dr. Heidi Miller and Elissa Hoover Gould. We discussed status of the budget for MCB's Deafblind Unit. The Family Alliance also met on June 3rd to develop strategic plans for advocacy efforts over the upcoming year.

In order to receive information regarding the state budget and funding alerts, please contact NEC to ensure that you are on our phone tree and mailing or email lists.

The next meeting of the MDBFA will be September 24 at 6:30 pm at Perkins School for the Blind in the Hilton Building Lounge. All are welcome to attend. Light refreshments will be served.

# **“Save the Dates”**

## *Upcoming Trainings, Workshops, and Events*

<b>Date</b>	<b>Event</b>	<b>Location</b>
June 22-26, 2002	New England Center Deafblind Project and Perkins Outreach Summer Institute	Northeast Tower, Perkins School, Watertown, MA
July 8-11, 2002	Summer Institute with Dr. Susan Edelman and Dr. Jennifer Grisham-Brown	American School for the Deaf, West Hartford, CT
July 13-17, 2002	INSITE Train the Trainers (Howe Building)	Perkins School, Watertown, MA
July 22-23, 2002	Creative Constructions with Molly Campbell	Perkins School, Watertown, MA
August 26-28, 2002	NTAC Topical Workshop	Atlanta, GA
September, dates TBA	Region 1 Trainings	Western Massachusetts
September, dates TBA	Deafblind Networking Team	Board of Educational Services for the Blind, Windsor, CT
September 23, 2002	NEC MA Instate Planning Team Meeting	Perkins School, Watertown, MA
September 24, 2002	MA Deafblind Family Alliance Meeting 6:30-8:30 PM	Perkins School, Watertown, MA
September 30, 2002	Cardboard Carpentry with Molly Campbell	Perkins School, Watertown, MA
October 2, 2002	NEC Deafblind Professional Alliance Meeting	Perkins School, Watertown, MA
October 8, 2002	Strategies and Techniques for Paraprofessionals Working with Students with Multiple Disabilities, including Deafblindness	Hartford, CT
October 9, 2002	Strategies and Techniques for Teaching Children who are Visually Impaired with Multiple Disabilities, including Deafblindness	Hartford, CT
October 29-30, 2002	Cortical Vision Impairment workshop with Dr. Christine Roman	Samoset Resort, Rockport, ME
November 1-2, 2002	Literacy Issues and Case Studies in Cortical Vision Impairment with Dr. Christine Roman	Perkins School, Watertown, MA
November 19, 2002	MA Deafblind Family Alliance Meeting	Perkins School, Watertown, MA
November 20-22, 2002	NE/AER Northeast Conference: “Take a Chance...Make it Happen”	Farmington, CT
December 2, 2002	NEC Multi-state Planning Meeting	Perkins School, Watertown, MA
December 3, 2002	Advanced Cardboard Carpentry workshop for adaptive seating especially for OT's, PTs, and EI's, with Molly Campbell	Perkins School, Watertown, MA
December 4, 2002	NEC Deafblind Professional Alliance Meeting	Perkins School, Watertown, MA
December 5-6, 2002	Creating Personal Portfolios with Martha Majors	Hartford, CT
March 6-7, 2003	Working with Challenging Behaviors in Teaching Students who are Visually Impaired with Multiple Disabilities, including Deafblindness	Hartford, CT (5/6) Hampden, CT (5/7)

# Web Watch

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*a list of useful web sites with information and resources*

## **[www.wemedia.com/ebay](http://www.wemedia.com/ebay)**

eBay has created a place to buy and sell disability products online. Visit eBay's "Disability Resources" page (via the wemedia web site) to take advantage of new, pre-owned, and one-of-a-kind merchandise. While you're there, check out the rest of [www.wemedia.com](http://www.wemedia.com) for coverage of issues important to millions of people with disabilities interested in living a quality life without compromise.

## **[www.specialchild.com](http://www.specialchild.com)**

This online publication provides educational resources and emotional support to parents and care-givers of children, adolescents, and young adults with disabilities. You can read and share stories with other parents and providers, as well as locate useful resources and products. Special Child is provided by The Resource Foundation for Children with Challenges (RFCC), a nonprofit charity organization.

## **[www.freetranslation.com](http://www.freetranslation.com)**

This site offers instant, free, and easy-to-use web-based translation services that work very well for quick notes from school, progress reports, service requests, or just to keep in touch with people who speak a language different from your own. Languages include English, Spanish, French, German, Portuguese, Italian and Norwegian. The site is a service of SDL International, which also offers more advanced translation services for more complex needs.

## **[www.healthylegs.com](http://www.healthylegs.com)**

This site provides socks, foot care items, and support products for sensitive feet. Look at their socks that fit over AFOs!

## **[www.fape.org](http://www.fape.org)**

This is the site for the Family & Advocates Partnership for Education. The Partnership is a new project which aims to inform and educate families and advocates about the Individuals with Disabilities Education Act of 1997 and promising practices.

## **Maine Links**

### **[www.abilitymaine.org/deafblind.html](http://www.abilitymaine.org/deafblind.html)**

Deafblind Resource Guide for Maine

### **[www.linkmaine.org](http://www.linkmaine.org)**

Maine Disability Resource Guide

## New England Center Deafblind Project Contact Information

### **NEC Contact Information**

#### New England Center

#### Deafblind Project

175 North Beacon Street

Watertown, MA 02472

TTY: (617) 924-5525

Fax: (617) 972-7354

#### Barbara Mason

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### **Massachusetts Contact Information**

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#### Mary Hill Peters

*Education Consultant (MA)*

(617) 972-7514

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### **Maine Contact Information**

#### Charlotte Cushman

*Education Consultant (ME)*

(207) 596-6209

ccushman@midcoast.com

PO Box 84

Thomaston, ME 04861

#### Catholic Charities Maine

1066 Kenduskeag Avenue

Bangor, ME 0440

www.ccmaine.org

### **Connecticut Contact Information**

#### BESB

184 Windsor Avenue

Windsor, CT 06095

(860) 602-4191

#### Karen Olson, Education Consultant

nosloke@aol.com

#### Kathy Morgan, Education Consultant

kathybmorgan@hotmail.com

### **New Hampshire Contact Information**

#### Therese Willkomm, ASSETT

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Concord, NH 03301

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#### Janet Halley, M.I.C.E. Program

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## New England Center Deafblind Project

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