



IN TOUCH

New England Consortium of Deafblind Projects

Happy Winter Greetings To All

By Tracy Evans Luiselli, Project Director

Best Wishes for a Healthy and Happy New Year in 2010!

Here are a few suggestions for New Year's Resolutions even if you have already started a new diet or new exercise program:

Parents and Families

- ◆ Remind yourself regularly that you are not alone. You might find it helpful to connect monthly to the NEC Family Phone Network - a monthly phone conference where families connect and share ideas. Also, let us know if you have suggestions for specific topics.
- ◆ Have your son or daughter's vision and hearing checked annually - make sure your child's team is aware of the results. Specific accommodations might help your child in a variety of ways.
- ◆ Since you are your child's best advocate, make a list of the

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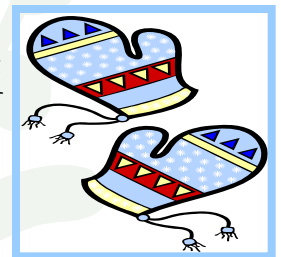
top three things your family really wants your child to learn this year. Make sure your goals are included in your child's IFSP, IEP or ITP and that the team is aware of your list and working toward your goals. It may be necessary to speak directly to your team liaison or reconvene your child's team to review your list and make sure everyone is on the same page. We all get busy and need reminders to stay on course....

- ◆ Contact your state's deafblind project if you want information/training for your child's team. Contact information is listed at the end of this newsletter.
- ◆ For specific information regarding deafblindness, effective

learning strategies, parent supports and resources, check out the New England Consortium of Deafblind Project's (NEC) website at www.necdbp.org or the National Consortium of Deafblind Technical Assistance website (NCDB) at www.ncdb.org

Teachers and Service Providers

- ◆ Too often teachers and service providers feel overwhelmed and do not receive adequate support and supervision, especially those working with children who have low incidence disabilities and complex needs. You might find it helpful to attend one of our in-state or regional trainings and connect to other service providers working with children who have similar issues. The learning needs of children who are deafblind are often diverse and require training for classroom personnel along with additional planning and communication time for the team.
- ◆ Reach out to the family of your student who is deafblind. Outside of the IEP meeting, take the time to ask - "what do you think are the most important skills for your child to learn this year?" Given the low incidence nature of the disability, combined vision and hearing loss (deafblindness) can isolate the family as well as the child. Pass along information you have learned from one of our trainings or gathered from our website or NCDB.
- ◆ Increase your commitment to teach others so that instruction is consistent for the child - across people, settings, and learning activities.
- ◆ Increase your commitment to gather data on a regular basis to monitor student learning and program effectiveness. Remember to consider the impact of vision and hearing loss throughout the child's day, across environments, and provide accommodations accordingly. If you need help - contact your state deafblind program for consultation and team training. Contact information is listed at the end of this newsletter.



Happy Winter Greetings To All - *continued from page 1*

Administrators

- ◆ Administrators who are responsible for programs that serve children with deafblindness or multiple disabilities are often working in challenging situations with limited budgets. Yes - remind yourself that you are not alone! Contact your state deafblind project to make a referral, request training for your staff/program, or to connect with other agencies/programs serving infants, children and youth with similar issues.
- ◆ Consider ways to increase your support to staff that are working with a child who has combined vision and hearing loss. Often, classroom personnel are required to spend additional hours adapting materials and learning new instructional strategies. Encourage your staff to attend one of our trainings to learn information that will support the entire team.

For All of Us

- ◆ Your voices and stories really do make a difference! As services are reduced or in some cases eliminated, it's critical that we increase awareness about deafblindness and the impact of combined vision and hearing loss on learning - the need for specialized supports in early intervention, school programs, work opportunities and independent living. Please take a moment to contact your legislators and let them know the importance of services and supports to infants, children and youth who are deafblind and their families. For contact information to your legislators, log on to <http://www.wheredoivotema.com/bal/myelectioninfo.php> in MA
- ◆ While we work together to improve outcomes for learners who are deafblind and their families - let's make a resolution this year to re-energize our program, classroom, and home goals and celebrate our successes!

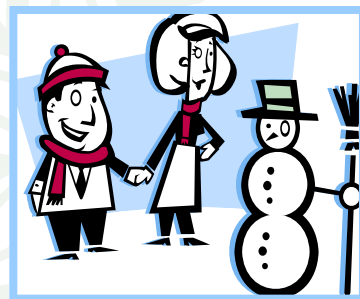
Beyond Helen Keller:

MEETING THE DIVERSE NEEDS OF CHILDREN WITH COMBINED VISION AND HEARING LOSS.

The following thoughts were presented by Debbie Chase (Parent and NEC Family Phone Network Specialist) as part of a panel discussion at the Next Steps Conference, Boxboro, Massachusetts, November 2009. Thanks Debbie for your openness and sharing your wisdom!

Panel Question #1: " What has been your biggest challenge as a parent of a child with combined vision and hearing loss....."

Before I begin to answer the questions before me I want to say a little about who I am as context is important. Twenty years ago I was a psychologist working with children and their families in a variety of clinical settings; hospitals, schools and private practice. I also wanted to begin my family, and that is where the rudiments of the answers for today's posed questions began.



After what was a closely watched pregnancy, our world was ready to welcome our first child. This child would be the first grandchild for my husband's family, and a long awaited grandchild for my family. As family, friends, and colleagues waited for news of the birth and whether it would be a boy or a girl, we labored and were greeted with the most beautiful baby, a girl with black hair who was vibrant with ten toes and ten fingers but who could not take her first breath. It was at that moment of the culmination of the excitement of having wanted a child since I was a child, it was at that moment of the culmination of that excitement of the natural order of things that I, with a sense of immediacy, learned that we were diverging from the path of what is "typical" and that something very different was to occur. That for her very survival I had to hand her to a professional, whom I did not know, and trust that they would do their very best so that she could simply survive.

Continued to page 3

Beyond Helen Keller - *continued from page 2*

I have been asked to speak of the challenges of embracing a child with combined vision and hearing loss and there are many. But first I cannot emphasize enough the fundamental shift that occurs when one discovers and learns and begins as a parent to understand that the hopes and dreams that are carried for so long for his/her child are changing. In our situation that shift happened quickly, at her birth, but as we have learned more about her these nineteen years it has shifted and changed and continues to evolve in ways I could have never predicted. And it will continue to change and shift as she grows further into adulthood for I have learned that while our path is not typical it is not static. As a parent I have learned that my journey is very much inextricably intertwined with how my child fares. As her mother when she is doing well, I am doing well and when she is struggling while maybe not visible to others who are not so close to me, I am struggling.

As a psychologist I knew these things about the depth of the attachment, that bond between mother and child. But when I became a mother I knew it in a different way. I learned that my world would need to include people with expertise in areas, some of which I had never even known existed. But I learned also that I was the expert in reading my child, and her father and I would be the ones who would need to be there to carry her through; we were her "constant". When she was born and early on I had not labeled it, but what I was doing and developing and needed to do was to use my radar for who it made sense to include on our team and who got a "pass". I had to develop another domain of my advocacy skills and listen to that feeling of when something feels right and when it does not, and then figure out how to act on it.

In raising a child with combined vision and hearing loss it is necessary to bring the world to that baby, to that child, and in my parental gut I knew it. Also, I knew it would be different and I knew I needed help. We were fortunate that excellent medical and educational help was there. Sometimes people will wonder "...if I had to lose my vision or my hearing - which would be worse?" I've never heard one intellectually pose the question "...what would happen if I lost both?" *To not be able to rely on vision to ameliorate a hearing loss or on hearing to ameliorate a vision loss.* I learned how important the sense of touch and the sense of smell and the sense of taste would be in our lives. I learned how small our world could become without striving to make it bigger. I learned how isolated one could be for having a child who did not process in the same way as most everyone else. I learned how there are those who try as they may, have difficulty understanding, and there are those too pre-occupied with their own matters to understand. Yet, there are those who do and I cannot emphasize enough the importance of surrounding oneself with a network of people who "get it."

As to my biggest challenge, actually there are three. The first lies with myself - not being hard on myself as I travel this road. It is not out of a sense of self blame that I can be hard on myself but what I want for my daughter is for her to be the very best that she can be. I question if I am doing all that I can to support her in that quest. The second is allowing her to be who she is and embracing her dreams and hopes and considering what she needs to make them come alive. It involves a balance that has always been there from the moment she was born - embracing her and letting her go in ways that make sense for her. The third is being mindful and forgiving of those who I have perceived as not helpful and not getting stuck in the negative emotions that can sometimes swirl, especially those concerning the bureaucracy that can occur when a child needs special education or medical attention, the IEP process, the layers of insurance.....the budget crisis.

Panel Question #2: "What has been most helpful to you in addressing the needs of your child?"

In looking back as to what has been most helpful to me it is to look at my child. She is my guide and I follow her. Years ago I envisioned myself following her running on the beach as I carried the sand pails as she took off in another direction on her adventure with me, picking up after her, hoping that I had all the things she needed, the pail, the shovel, the sand and a bit of ocean mixed in to make the sand soft and malleable so she could create the sculpture of her life. I realize now, and thankfully, that we are not alone on that beach. While not crowded, it has been filled with people, some I knew just for a short moment and others for a very long time but that her journey and mine are intertwined. It is a journey rich in hope and laughter but like so much in life we have had to take the responsibility to create it.

Interagency Collaboration And Transition

-Mattessich,
P. and

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"Collaboration is a way of thinking and relating, a philosophy, a paradigm shift, an attitude change. It requires a set of behaviors, beliefs, attitudes, and values. The result is a sense of shared ownership, shared responsibility, shared success."

-Bishop, K.K. (1993) *Family/Professional Collaboration for Children with Special Health Needs and Their Families (Monograph)*, Burlington, Vermont: Department of Social Work, University of Vermont, pg. 11-12.

As parents anticipate the transition of their student with disabilities from school programs to adult services they are faced with significant challenges. In order to accomplish the complex planning and successful outcomes desired, effective collaboration between parents and professionals is essential.

"No one can do it alone. Improving the quality of life and the education of children with disabilities and their families requires the collective knowledge, skills, experience and expertise of all family members and professionals. It requires that the community and all service systems work together to achieve the goals of the child and family."

-IBid.

What is Collaboration?

An adaptation of a working definition of collaboration is "a mutually beneficial and well-defined relationship entered into by two or more [individuals or] organizations to achieve common goals. The relationship includes a commitment to: a definition of mutual relationships and goals; a jointly developed structure and shared responsibility; mutual authority and accountability for success; and sharing of resources and rewards." This definition establishes the premise from which successful collaborative relationships in transition planning can begin.

"Collaboration involves parent and professional, professional and child, parent and parent, professional and professional, agency and parent, federal and state administrators, and others. Collaboration will not look the same for all families and professionals. Some collaborative relationships will be simple to develop, others will be much more complex and demanding. Collaboration must be developed between and among all of us."

Money, B. (1992). *Collaboration: What Makes It Work*, p.7.

What is Transition?

Transition simply defined, is "passage from one state to another." It is change. It is movement. Throughout life there are many transitions - the movement of young people with disabilities from school to the adult community is one of the most important transitions in their lives.

Transition as defined by the Individuals with Disabilities Education Act (IDEA Amended 1990, P.L. 101-476) and the Rehabilitation Act Amendments (Rehabilitation Act of 1973, as amended by the Rehabilitation Act Amendments of 1992, P.L. 102-569) is:

"A coordinated set of activities for a student, designed within an outcome-oriented process, which promotes movement from school to post-school activities..."

The coordinated set of services included in the Individualized Education Program (IEP) should be based on the student's needs, interests and preferences and might include, but not be limited to the following services:

- post-secondary education
- vocational training
- integrated employment
- adult services
- independent living
- community participation

Why is Collaboration Important in Transition?

"The reason I want to collaborate is because I want something for my daughter that otherwise would simply not happen. There's no way I'm going to be able to accomplish for her the kind of future she wants for herself and that I want for her without some really powerful partners."

-Janet Vohs, Parent

Transition services and transition planning began as one of the many ideas for increasing the quality of life for young adults with disabilities. Today, transition from school to adult services is more than a nice idea, it is a

requirement of the law! The Individuals with Disabilities Education Act (IDEA) requires that transition services be included in every student's IEP. This requirement includes, when appropriate, a statement about how agencies will work together to provide needed services after the student leaves the school setting. The foundation of the plan needs to be a coordinated effort **among the student, parents, schools, adult service providers** to achieve a desirable future for the individual.

"The best way to predict the future is to invent it."
-John Scully, *Odyssey*, 1987

Parents of students with disabilities have had to call upon creative resources throughout the life of their child. "Inventing the future" usually requires that parents, their student and planning team members look beyond "the systems," beyond conventional answers and requires them to consider anything that works.

For many students, the school has been the primary provider of services. When a student leaves school, needs and issues often change. Assistance and support from multiple agencies, organizations and providers may now be required. Eligibility may need to be determined for services that were mandated before.

When Do We Collaborate for Transition Planning?

The transition plan is the part of the IEP that outlines what training and supports a student will need to live, work and participate in the community as an adult. The transition plan should be part of the IEP as soon as appropriate based on individual needs, but **must be included** when the student is 16 years old. The transition plan becomes part of the IEP. The purpose of the meeting between collaborating members of the IEP team should be to:

- determine the needs of the student
- target the services available
- develop a formal transition plan
- monitor the performance of the student
- provide education and training for parents

Who Should Collaborate During Transition Planning?

Transition plans are most effective when they are developed by many people working together. Members of the planning team could be:

- the student
- parents
- family members
- special educators
- vocational rehabilitation counselors
- independent living counselors
- other adult service providers
- anyone else who can provide information or support

How Do Team Members Collaborate in Transition Planning?

Team members might collaborate as previously defined by coming together to:

- communicate and decide how to work together (relationship and structure);
- consider needs, interests and preferences of the student as well as input from the parents in determining and agreeing to goals that will be worked on (mutual goals);
- include the student, parents and those who can represent the various agencies, organizations, providers or others who can assist in providing support and/or services that are needed to accomplish the goals and objectives of the plan (responsibilities and accountability for success);
- share resources, knowledge, unique experience and expertise;
- benefit from successful outcomes (shared rewards).

As partners in an vital planning process, parents need effective interagency collaboration between the many agencies and providers of adult services to ensure a "seamless transition." As transition planning team members share dreams and a vision for the future, generate ideas, explore options, develop and implement a plan, and effectively follow-through, successful outcomes will be achieved for students with disabilities as they transition into the adult community.

Person Centered Planning

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A person centered plan can help those involved with the focus person see the total person, recognize his or her desires and interests, and discover completely new ways of thinking about the future of the person."

Beth Mount & Kay Zwernik, 1988

Person Centered Planning is an ongoing problem-solving process used to help people with disabilities plan for their future. In person centered planning, groups of people focus on an individual and that person's vision of what they would like to do in the future. This "person-centered" team meets to identify opportunities for the focus person to develop personal relationships, participate in their community, increase control over their own lives, and develop the skills and abilities needed to achieve these goals. Person Centered Planning depends on the commitment of a team of individuals who care about the focus person. These individuals take action to make sure that the strategies discussed in planning meetings are implemented.

Purpose

To look at an individual in a different way.

To assist the focus person in gaining control over their own life.

To increase opportunities for participation in the community.

To recognize individual desires, interests, and dreams.

Through team effort, develop a plan to turn dreams into reality.

Who is involved in person centered planning?

The focus person and who ever they would like can be involved. It is best when there is a facilitator and a person to record what is being shared. The facilitator should be a person that is neutral and unbiased, leads the group through the process, handles conflict and assures equal opportunity for all to participate. Others that may be included are parents/guardians, other family members, friends, professionals, and anyone else who has a personal interest in the person.

Where is person centered planning done?

At focus person's home or somewhere comfortable, informal and hospitable.

When should person centered planning take place?

At anytime in a person's life. It is best done before transition services are determined. person centered planning can be a very useful tool to develop the transition plan.

Tools needed for person centered planning

A flip chart or large pieces of paper to record the information shared. Several different colored markers.

The Steps of Person Centered Planning

1. Develop a history or personal life story of the focus person. This is accomplished by everyone sharing past events in the person's life. The focus person's parents and family may share the largest amount of this information. Things such as background, critical events, medical issues, major developments, important relationships, etc., may be shared.
2. Description of the quality of the focus person's life is shared next. This may be accomplished by exploring the following: Community participation, community presence, choices/rights, respect and competence.
3. Personal preferences of the focus person. Things the focus person enjoys doing. Also including the things that are undesirable to the person.

The meeting to develop the personal profile usually occurs several days before the planning meeting so the participants have time to reflect on what is shared. The meeting, which takes about two hours, may use graphic symbols in place of words to help stimulate creativity and encourage participation.

The Next Step...the planning meeting

1. Reviewing the personal profile. The group at this point has the opportunity to make additional comments and observations.
2. Review trends in the environment. Identify ongoing events that are likely to affect the focus person's life.
3. Share visions for the future. Through brainstorming participants are challenged to imagine ways to increase opportunities.
4. Identify obstacles and opportunities. Things that make the vision a reality.

5. Identify strategies. Action steps for implementing the visions.
6. Getting started. Identifying action steps that can be completed within a short time.
7. Identify the need for service delivery to be more responsive to individual needs.

For a plan to be successful it is best if:

The people have a clear and shared appreciation of the talents and capacities of the focus person.

People have a common understanding of what the focus person wants.

The group involved agree to meet regularly to review activities.

The group include a strong advocate or family member assuring that the interest of the focus person is being met. That the group include a person committed to making connection to the local community.

This is the beginning of a process that continues throughout a lifetime. Not a product.

Online Resources

- Cornell University's Person Centered Planning Education Site
- Person-Centered Planning: A Tool for Transition, a February 2004 Parent Brief from PACER and the National Center on Secondary Education and Transition (NCSET)
- Beach Center on Families and Disability articles about Person-Centered Planning
- Cornell University - The Person-Centered Planning Education Site
- Increasing the Chances for Deeper Change through Person-centered Planning , an inventory developed by the Center on Human Policy, Syracuse University
- Indiana's Person Centered Planning Guidelines
- Institute for Community Inclusion Research to Practice Brief "Building Authentic Visions: How to Support the Focus Person in Person Centered Planning"

- Institute on Community Inclusion Brief, Starting with Me: A Guide to Person-Centered Planning for Job Seekers
- Institute on Community Inclusion Brief, More Than Just a Job: Person-Centered Career Planning
- Missouri MPACT: Transition to Empowered Lifestyles Project Person Centered Planning (on-line PowerPoint presentation)
- National Center on Workforce & Disability/Adult: Starting with Me: A Guide to Person-Centered Planning for Job Seekers
- National Guardianship Association
- "The Guide to Future Planning" by PEATC, Inc. (a Virginia parent information and training center) from the Next Steps series
- The Origins of Person-Centered Planning: A Community of Practice Perspective (2000) by Connie Lyle O'Brien and John O'Brien, a 24 page article from the Syracuse University, Center on Human Policy
- The Politics of Person-Centered Planning (1999) a five-page article by John O'Brien and Connie Lyle O'Brien
- VCU Person Centered Planning Self Study Course

WIN-MILL Michigan's Center of Expertise received support from the Technical Assistance on Transition and the Rehabilitation Act (TATRA) Project to strengthen its expertise and build a resource library on this topic in order to serve as an information and referral resource to parent training projects funded by the Rehabilitation Services Administration.

The above information was prepared for the Technical Assistance on Transition and the Rehabilitation Act (TATRA) Project in 1997 by the Education Transition Choices (ETC) Project of the Utah Parent Center. The ETC Project was funded by the Rehabilitation Services Administration (RSA) and received support from the TATRA Project to share its expertise on interagency collaboration with other RSA funded parent training projects.

Personal Futures Planning

By Susan DeCaluwe, reprinted with permission from Dr. Beth Mount, website: <http://www.ilr.cornell.edu/edi/pcp/course01.html>

Personal Futures Planning is an on-going process that encourages an awakening of the potential that exists in every human being to be a contributing and integral member within their community. Personal Futures Planning suggests a series of tasks that are useful in discovering capacities, and in identifying opportunities in the local community that are responsive to the unique interests and needs of each individual. The process requires the individual student to engage in conscious awareness and self-reflection about the relationship between how one feels, thinks, and acts. It is their beliefs that form thoughts that give rise to words that lead to action and that, in turn, creates experiences.

“Deafblindness is one of the most complex disabilities faced by our system of special education.”



Representation of Personal Futures Planning Graph

Dr. Beth Mount has developed a graphic representation of Personal Futures Planning (2000). Dr. Mount places O'Brien's five valued outcomes in the center of the circle. These values are identified as relationships, places, valued roles, choices and contribution.

The Personal Futures Planning process is flexible, creative, and open to trying what might be possible. It is a process that enhances the humanity and dignity of each person. It

is a process that looks for the good in people and helps to bring it out.

If you would like more information please go to her website at <http://www.ilr.cornell.edu/edi/pcp/course01.html> The book, Person-Centered Planning: Finding directions for change, is available from the web site: www.capacityworks.com

31st Annual Massachusetts Early Intervention Consortium Conference



Tuesday, April 13th and Wednesday, April 14th, 2010
Best Western Royal Plaza Hotel, Marlborough, MA 01752

The MEIC Conference is an annual educational event for service providers and families of children birth to three years who have or are at risk for developmental delays. This two-day conference provides an opportunity for practitioners, researchers, physicians, higher education faculty, families and policy makers to join together in learning and networking together. Contact Tara Cornell at 508-478-2631 x208 or email: tcornell@critterionchild.com

CT Student Wins National Art Award

By Karen Olson, Educational Consultant, CT Deafblind Project

Toni Pruitt is a 13-year old student who attends the American School for the Deaf. Last year, she was declared the 1st place winner of the Marie Jean Philips Art Competition in her category, 9-12 year-old deaf students who also have additional special needs.

The inspiration for her art work came from Julia Brace, the first deafblind

person to attend ASD. Working with her art teacher and para, Toni created an art project with photographs that illustrated tactile signing, Julia's mode of communication. She also wrote a short explanation of her work.

Toni was so proud of herself, as were her family, friends and teachers!

Congratulations Toni!



Toni Pruitt, holding her 1st Place Exhibit.



Will from Massachusetts

Visitors Are Always Welcome!

A Halloween visit from one of our little ones after a meeting at the Infant/Toddler Program. If you are in the area we would love to see you too! Stop in anytime and say Hi.

Getting Help With Our Mailing

By Cheryl Harvey, NEC Project Assistant

When you read your newsletter you may not be aware of what went into the mailing process. But for four very dedicated workers of the Perkins Deafblind Program workroom it is hard work. These wonderful young men and women have worked diligently to help label and fold our newsletters to prepare them for mailing to you. Meet them to the right.

A great big thank you for all your hard work! It is greatly appreciated!



Above: Katherine Garewski and Wendy Bridgeo



Above: Nick Julian and Christopher McLaughlin



Right: John Mack with Myra O'Neill

Perkins Outreach Short Courses

By Beth Caruso, Director of Outreach Services, Perkins School for the Blind, 175 North Beacon Street, Watertown, MA 02472, Phone: 617-972-7434, Beth.Caruso@Perkins.org

Perkins Outreach Short Courses offer a variety of activities, paired with support and training from staff, in age groups that range from elementary through high school for students who are blind or visually impaired. We provide overnight opportunities for school-aged students to focus on areas of the Expanded Core Curriculum (ECC), which are skills that are crucial for this population due to their unique needs in order to achieve the highest level of independence. The 9 components of the ECC are important aspects of a student's Individualized Education Program (IEP): compensatory or

functional academic skills(including communication modes); orientation & mobility; social interaction skills; independent living skills; recreation & leisure skills; career education; use of assistive technology; sensory efficiency skills and self-determination.

The ECC can be difficult to address within a structured school day. Outreach Short Courses provide training and reinforcement of these vital skills during weekends, school vacations, and summer breaks. Staff work with family members and teachers to identify the best program fit for each student. Each program concludes with an informational meeting for families in which the program's activities are outlined and specific skills are discussed. The goal is to

encourage and support families in carrying over the skills into the home and school environment. During these meetings, families are also able to share experiences and ideas with each other.

The flyer for the winter, spring & summer courses will be available in January on the Perkins website in both English and Spanish. Activities planned include winter sports, theater, vocational exploration, space exploration, basic daily living skills, sibling's weekend, a program in New York and more! Limited scholarships may be available. To be added to our mailing list and for any questions contact: Kelly Cote, Supervisor of Outreach Short Courses at 617-972-7867 or Kelly.Cote@Perkins.org.



Family Day At Berlin Orchards

Annually we have a Family Day Event, all the families that are registered with the center are invited to attend with their family for free. This event is partnered with MAPVI and NEC.

Apple cider, cider donuts, cookies, guided pumpkin carving, face painting, petting zoo, hay rides, oh and apple picking! Don't miss out on the fun next year!

If you are a family registered with the center, this is one of the activities we plan annually for all families, it is free of charge.

Families from Connecticut, New Hampshire, Maine, and Massachusetts came and met. It was a great way to make a connection to other families in your area.

We look forward to seeing you at next years event!

Top: Boy Scout Troop 77 Hudson, Scoutmaster Dennis Rawley, Matthew Sullivan and dad Mike, family and friends.

Above: Sai Pitman, Matteo Faso,

Right: Win Edwards.

USHER Syndrome Family Conference

*By Karmen Trzupsek, Genetic Counselor, HearSeeHope Board Member
email: karmen@hearseehope.com*

The next annual Usher syndrome family conference will be held on July 9-10 in Seattle, Washington. This will be a wonderful opportunity for families to get together to meet other families, learn about current and upcoming research, and meet some of the physicians and researchers working on the west coast. The location will obviously bring in families from the western part of the US; in addition, we are hoping to attract families from all over the country who might want to turn the conference into a short family getaway vacation. Seattle is a wonderful place to visit! We are planning a casual family BBQ on Friday

night, followed by a full-day conference schedule on Saturday at Children's Memorial Hospital in Seattle. Activities for children will be planned throughout the day so that parents can attend the meetings. On Saturday night, the HearSeeHope Foundation will host a fun dinner event for the entire family.

For all of you who see patients, we would greatly appreciate your help in getting the word out about the conference. If you or someone on your staff could forward this information to your patients and families in the next few weeks, we should be able to get the conference on everyone's calendars early.

At this point, the agenda and speaker schedule is undetermined, but we definitely plan to devote part of the day on Saturday to current and upcoming research and therapy for retinitis pigmentosa (RP). Due to the location of last year's conference, and the fact that it piggy-backed onto the Molecular Biology of Hearing Loss and Deafness conference, last year's conference focused largely on the hearing issues with Usher syndrome, so this will be a good opportunity to discuss vision loss in US in detail.

The Pacific Northwest is glorious in July... We hope to see you there!

Three Types Of USHER Syndrome

*Taken from the USHER Website
<http://www.nidcd.nih.gov/health/hearing/usher.asp>*

Usher syndrome is the most common condition that affects both hearing and vision. A *syndrome* is a disease or disorder that has more than one feature or symptom. The major symptoms of Usher syndrome are hearing loss and an eye disorder called retinitis pigmentosa, or RP. Retinitis pigmentosa causes night-blindness and a loss of peripheral vision (side vision) through the progressive degeneration of the

retina. The retina is a light-sensitive tissue at the back of the eye and is crucial for vision. As retinitis pigmentosa progresses, the field of vision narrows, a condition known as "tunnel vision," until only central vision (the ability to see straight ahead) remains. Many people with Usher syndrome also have severe balance problems.

There are three clinical types of Usher syndrome: type 1, type 2, and type 3. In the United States, types 1 and 2 are the most common types. Together, they ac-

count for approximately 90-95 percent of all cases of children who have Usher syndrome. For more information, additional addresses and phone numbers, or a printed list of organizations, contact:

NIDCD Information Clearinghouse, 1 Communication Avenue, Bethesda, MD 20892-3456, Toll-free Voice: (800) 241-1044, Toll-free TTY: (800) 241-1055, Fax: (301) 770-8977
E-mail: nidcdinfo@nidcd.nih.gov

Deafblindness: Educational Service Guidelines

By Marianne Riggio, National Education Consultant, Training and Educational Resources Program, Perkins School for the Blind, Marianne.Riggio@perkins.org

Deafblindness is one of the most complex disabilities faced by our system of special education. The challenges of providing a free and appropriate public education to students with deafblindness requires that state and local education agencies recognize their educational needs and put into place systems that will assure equal access to a quality education as their sighted-hearing peers.

The publication *Deafblindness: Educational Service Guidelines* was developed as a collaborative effort among leaders in the field of Deafblindness that included State deafblind projects, university training programs in Deafblindness, NFADB, NCDB and NASDSE. The purpose of this document is to provide a best practice guide that educational administrators at the state, local and program levels can use to understand the implications of combined vision and hearing losses on learning; to recognize the need for specialized assessment, program planning and service delivery.

The document is designed very similarly to the publications *Meeting the Needs of Students Who are Deaf or Hard of Hearing: Educational Service Guidelines* and *Blind and Visually Impaired Students: Educational Service Guidelines* in that it addresses the same five chapter titles: Foundations, Personnel, Assessment, Program, Services and Placement Options and Supportive Structure and Administration.

At the heart of each of the chapters are some key themes:

- Deafblindness is a very unique and complex disability. Educators who serve students who are deafblind must have the necessary knowledge and skills to provide adequate services.
- Students and educational teams require the guidance of a deafblind specialist who is someone with the knowledge and skills necessary to guide planning and to provide technical assistance and direct services.
- Communication, which is the foundation for all learning and the building of social relationships, is a primary need that must be addressed in a thoughtful and comprehensive way when developing and implementing the Individualized educational program for students who are deafblind. Most students require one-on-one communication support in order to access the learning and social environments. This may be in the person of an intervener, who is a paraprofessional with specific training to meet the needs of students who are deafblind.
- Students who are deafblind require unique and creative skills on the part of assessment team members. They must understand the impact that deafblindness has on students' development; they must understand and be able to use the communication forms that are appropriate for students who are deafblind; and they must be willing to work as cohesive teams on which members share information that will result in a fair appraisal of students' abilities, challenges, and priorities for instruction.
- While every special education team must by law embrace parents and other family members as central team members, this is especially critical for students who are deafblind. Family members possess a unique understanding of their child's communication and learning abilities that educational teams

Continued to page 13

Deafblindness - *continued from page 12*

need in order to complete appropriate assessments and to deliver appropriate educational services.

- The determination of services and placement for students with deafblindness require very thoughtful and personalized decision making. The goal of placement in the least restrictive environment (LRE) will only be realized when the student has full access to the curriculum and educational environment in his/her own communication forms, has authentic interactions with both peers and professional personnel, and can achieve to the highest performance standards as possible. Services must be well coordinated and implemented in a collaborative manner to meet the identified needs of the student.
- It is important that state and local administrators work collaboratively and creatively with existing resources, and develop new resources when necessary to expand state capacity and to assure that students who are deafblind receive the specialized services necessary to have equal access to education as their peers.

Critical to the successful use of this publication in guiding state and local service development and implementation will be the training that will accompany the guidelines. Currently, the Hilton/Perkins Program, National Consortium on Deaf-Blindness (NCDB) are working with leaders in the field to provide training in individual states for both providers of special education and for parent organizations.

The New England Consortium of Deafblind Projects is pleased to announce...



The NEC Family Phone Network

Please join us for a conversation around the topic of:

TOPIC: SUMMER PLANS

WHEN: Monday, FEBRUARY 1st at 8:00 PM - 9:00 PM

This FREE teleconference CALL is part of a monthly series of topics offered to families in Connecticut, Maine, Massachusetts and New Hampshire who are registered with NEC. The conference call is facilitated by Deborah Chase, Ph.D. NEC Family Network Specialist. Calls are free from land lines.

**SAVE
THE DATE**



FREE

Call: 1-888-387-8686
Enter Conference Room
Number: 2502812

If you have a topic you would like to discuss in this free open forum, please email NEC@perkins.org with your idea.

Future Topics:
March 1
Transition

The Importance Of A Deafblind Classification On An IEP Form

By Janette Peracchio, CT Family Specialist

If you have a copy of your child's IEP Cover Page on hand, take a look to see what is checked for their "primary disability". If your son or daughter is registered with The New England Center (NEC), their main disability should be Deaf Blindness.

When your child is classified as deaf blind, they will receive extra services that your school system does not offer. The New England Consortium of Deaf Blind Projects will provide Technical Assistance (TA) to parents and school teams so children and youth can fully participate in their homes, schools and communities. Parents are invited to

participate in teleconferencing, workshops and conferences to help them become strong advocates for their child and foster self-determination in their young adult. Some of the themes of these workshops include: How to Have Non-Verbal Conversations with a

"When your child is classified as deafblind, they will receive extra services that your school system does not offer."

Child Who is Deaf Blind; Developing an Object Communication System at Home and School; What you Need to Know about Transition from High School; Cortical Vision Impairment; Futures Planning and *Reaching for the Stars*. School teams and families can attend and are taught by the experts in the field of deafblindness.

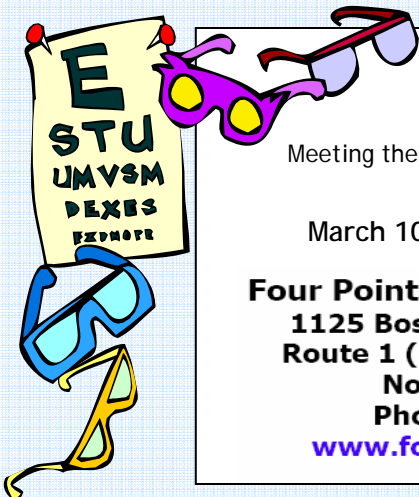
As a family, you are able to attend New England Center (NEC) sponsored family activities, picnics, and meet other families who are dealing with issues common to your family. The world of deaf blindness is scary and mysterious to families in the beginning, but

having the New England Consortium on your side is so valuable, it is worth having the label of deaf blindness on the IEP

form. We recommend that all NEC students should have the classification of deaf blindness to insure that your child's needs met, which is the true point of it all.



"Focus" On Vision Impairment & Blindness Conference



"Focus" on Vision Impairment & Blindness Conference

Meeting the Needs of Individuals with Intellectual Disability & Vision Loss

March 10, 2010 at 8:00 am - 3:30 pm

Four Points by Sheraton Norwood
1125 Boston-Providence Turnpike
Route 1 (18 miles south of Boston)
Norwood, MA 02062
Phone: 781-769-7900

www.fourpointsnorwood.com

Registration Information

1. Please fill out the registration form and return BY FEBRUARY 22, 2010 to:

Ann Flynn / Shriver Clinical Services Corporation, 607 North Ave. Door 14, Wakefield, MA 01880

2. For questions regarding Registration, please contact Ann Flynn:

AEFLYNN@aol.com or phone 781-279-3141.

3. Please make check payable to: Shriver Clinical Services Corporation

Go to the website for the registration form and agenda at:

http://www.mass.gov/Eeohhs2/docs/dmr/events_focus_brochure.pdf

CHARGE Syndrome

Reprinted with permission from the CHARGE Syndrome foundation website:

www.chargesyndrome.org

New Parent Information:

Find out how to receive a packet of information designed to help parents of a new baby (or newly diagnosed child understand what CHARGE syndrome is, frequently asked questions, what to do now, information about the CHARGE Syndrome Foundation, and a listing of some helpful resources.

[View more resources.](#)

CHARGE Syndrome: FAQ

Who, what, when, where, why...some of the most commonly asked questions about CHARGE syndrome are answered in this [FAQ document](#).

CHARGE Syndrome Fact Sheet

Facts about CHARGE syndrome are provided in this [one-page document](#).

CHARGE Syndrome Conference - 2011



Photo Credit: Rosen Shingle Creek

The Foundation's 10th International CHARGE Syndrome Conference will be held in 2011 in Orlando, Florida at the [Rosen Shingle Creek Hotel](#)

Start planning now, as you do not want to miss it!

The conference chair for 2011 is [Janet Murray](#). Please contact either Janet or the [office](#) with any questions or ideas for 2011.

Scholarship information will be posted closer to the conference date, both on the website and in our newsletter, *CHARGE Accounts*. "The info isn't up all the time on our website because some of the scholarship monies are dependent on how much fundraising we've been able to accomplish, thus it may change from conference to conference."

For more information contact:

141 Middle Neck Rd · Sands Point, NY 11050 · 800-442-7604 · info@chargesyndrome.org

Grants Available For Families Struggling With Health-Related Expenses

Taken from the United Health Care Children's Foundation website: uhccf.org

The United Healthcare Children's Foundation (<http://uhccf.org/>) has announced that new grants are available to help children who need critical health care treatment, services, or equipment not covered or not fully covered by their parents' health benefit plans.

UHCCF provides grants to families to help pay for child health care services such as speech therapy, physical ther-

apy, occupational therapy sessions, prescriptions, and medical equipment such as wheelchairs, orthotics, and eyeglasses.

Parents and legal guardians may apply for grants of up to \$5,000 each for child medical services and equipment by completing an online application at the web-site.

To be eligible for a grant:

1. The child or children must be 16 years of age or younger.

2. Families must meet economic guidelines, reside in the United States.
3. Families must be covered by a commercial health benefit plan.

Review the [application criteria](#) and [application checklist](#) at: http://uhccf.org/apply_applicant.html

Deadline: OPEN

New Staff In New Hampshire

By Brooke Buchanan, NH Educational Consultant

New Hampshire has a new Deafblind Consultant and Family Specialist:

It is a year of changes for the New Hampshire Deafblind community. Early in 2009, Kim Conlon, the NH Deafblind Education Consultant, announced



Left to right: Brooke Buchanan, Deafblind Educational Consultant, and Susan Hollis, Family Specialist

that she would be moving to Alaska with her family. Everyone was sad to see Kim go. She provided exceptional services to students, parents and educators all over the state. Not only was she a great consultant, but she

was a teacher, advocate and friend.

The good news is that New Hampshire not only has a new Deafblind Education Consultant but now has a Family Specialist. Brooke Buchanan has been hired as the new Deafblind Education Consultant and Susan Hollis has been hired as the Family Specialist for New Hampshire.

Brooke graduated from Boston College in 2006 with her Masters in Education focusing on students with multiple disabilities, including deafblindness. She had the opportunity to do her student teaching at Perkins School for the Blind in the Deafblind Program. "I loved my time at Perkins", Brooke said "Not only did it fully prepare me to be a teacher of students who are deafblind, but it also installed in me a love for the work." After graduating, Brooke returned home to Hawaii to teach. After a year as a Teacher for the Visually Impaired she returned to New England to live. When asked how she could leave Hawaii for

New Hampshire she replied, "I have always loved New England, especially New Hampshire. And really Paradise can get boring after awhile (plus my Dad still lives there so I can visit whenever I get the chance.)" Brooke started work in September at Atech Services and will be working with education teams of students who are deafblind.

Sue Hollis is a parent of 2 children who are deaf/blind; ages 14 and 10. In addition to being very busy with her kids, she is also a psycho-therapist and works out of Massachusetts. She graduated from Boston University School of Social Work with an MSW. Sue also graduated from Wheelock College with a BS in Education. She worked as a special education teacher, specializing in deaf/blind and developmental delay for 10 years. "All my education and experience has prepared me for the most important job; being the parent of these wonderful kids." She now works part time, volunteers, and is a strong advocate for her children and

other families across the state. Sue will be working with families as a support to the program Sparkle. It is a resource tool for parents to help educate themselves on all the different aspects of having a child who is deaf blind. In addition it will help organize all the records and information that parents have to keep and pass on to professionals and providers. If interested in this program, contact Sue, she will be happy to be of any assistance. She is very excited about this new position as the Family Specialist and believes that she can make a difference for families that have children who are deaf/blind.

We are constantly amazed by the abilities of individuals who are deaf blind. We look forward to being a resource and of service for families. Do not hesitate to reach either of us for questions, concerns or support.

Meet The NEC Staff

By Cheryl Harvey, NEC Project Assistant

NEC or "The New England Consortium of Deafblind Projects" is a federal grant made up of four states of deafblind projects including: The Connecticut Deafblind Project, the Maine Deafblind Project, the Massachusetts Deafblind Project and the New Hampshire Deafblind Project. The four deafblind projects get together for our annual consortium meeting a few times a year to review census data, mandated grant procedures, create a calendar of events, and implement strategies to help us attain our grant goals.



Left to right (Top): Paula LaBella, Jean Small, Susan DeCaluwe, Janette Peracchio, Kathy Morgan, Cheryl Harvey, Susan Hollis, Brooke Buchanan

(Bottom): Karen Olson, Tracy Evans Luiselli, Debbie Chase

Educational Interveners For Children Who Are Deafblind

Deafblindness:

Deafblindness is a unique disability. It involves a combined vision and hearing loss, to the extent that neither of these primary information gathering senses (vision or hearing) can adequately compensate for the lack of the other sense. For children with combined vision and hearing loss, the natural flow of auditory and visual information does not occur automatically. Bits and pieces of information may be available, but these will be incomplete, distorted, and/or unreliable. The incidental information that sighted and hearing children receive without effort is not readily accessible to those with combined losses. Deafblindness creates a disability of access to visual and auditory information about people, things, and events necessary for learning, communication, and overall development. This results in isolation and disconnection from the world, and can prevent equitable access to learning and participation in educational environments.



The Educational Impact of Deafblindness:

Children with deafblindness pose unique challenges to the educational system because they have a wide range of diverse needs that require highly individualized programming. The educational and functional impact of combined losses on each child will vary depending upon the degree and type of vision and hearing losses, the stability of the losses, the age of onset of each loss, and the presence or absence of additional disabilities. The effects of both vision and hearing loss together are not additive in nature but rather multiplicative. Sometimes even children with seemingly mild simultaneous vision and hearing losses can be greatly impacted by them. Deafblindness can result in significant difficulties in developing educational, vocational, avocational, and social skills.

Effective Intervention for Children Who Are Deafblind:

Effective intervention for children who are deafblind must connect them to the world and provide clear and consistent information needed for learning and development. This connection to the world can be made through an intervener. By definition, an intervener is a person who works one-to-one with children who are deafblind and who has specialized training and skills in deafblindness. The intervener helps the child gather information, learn concepts and skills, develop communication and language, and establish positive relationships. The intervener provides a bridge to the world for the child who is deafblind and encourages independence rather than dependence.



The Role of the Intervener in Providing Effective Intervention:

The role of the intervener is three-fold. The intervener: 1) facilitates access to environmental information that is usually gained through vision and hearing but which is unavailable or incomplete to the child who is deafblind; 2) facilitates the development and/or use of the child's receptive and expressive communication skills; and 3) maintains a trusting, interactive relationship with the child that promotes social and emotional development and well-being. This three-fold role of the intervener is the key to effective intervention for children with deafblindness.

The Intervener and IDEA:

"Access" is a key term in the requirements of IDEA, and under IDEA, a Free and Appropriate Public Education (FAPE) is mandated for all children with Disabilities. FAPE provides for access to general education, the general curriculum and activities, and specialized educational services in the Least Restrictive Environment (LRE). Access is a critical issue for children who are deafblind. Many educational environments are restrictive to these children because of their inability to benefit from the flow of visual and auditory information that other children receive automatically and that is necessary for learning and interaction. The intervener is an individualized support that provides this needed access and facilitates participation and progress in general and special education environments.



The National Deafblind Intervener Initiative

Purpose:

The purpose of the National Deafblind Intervener Initiative is to establish the use of qualified Interveners as an accepted practice for individuals who are deafblind, to emphasize the need for competency-based training for Interveners, and to support the recognition of Interveners as related service providers under IDEA laws.

Goal:

To have Interveners listed as a related service under IDEA.

What is Deafblindness?:

Deafblindness involves a combined vision and hearing loss to the extent that neither of these senses can compensate for the lack of the other one. Deafblindness creates a disability of access to the visual and auditory information about people and things in the environment that is necessary for learning, communication, and overall development. This results in isolation and disconnection from the world, and adversely impacts equitable access to learning and participation in educational environments.

What is the Educational Impact?:

“Access” is a key term in the requirements of IDEA, and under IDEA, a Free and Appropriate Public Education (FAPE) is mandated for children with disabilities. FAPE involves access to general education, the general curriculum and activities, and access to specialized educational services in the Least Restrictive Environment.

“Access” is a critical issue for children who are deafblind, because educational environments are restrictive without “access” to the information needed for learning and interactions. The Intervener is an individualized support that facilitates “access,” participation, and progress in the general education curriculum.

What is an Intervener?:

Perhaps the most well-known example of an Intervener is Annie Sullivan who acted as Helen Keller’s Intervener and connected her to the world. An Intervener is an individual who works consistently one-to-one with a child who is deafblind and who has training and specialized skills in deafblindness. The Intervener provides: (1) Access to clear and consistent visual and auditory information, (2) Support for the development and use of receptive and expressive communication, and (3) Support for social and emotional well-being.

What is the Need?:

Currently under IDEA, an “Interpreter” is listed as a related service for children with hearing loss in order to provide them with access to language and communication. The law also mentions “special interpreting services” for children who are deafblind, but this is broad in scope and refers to varied methods of interpreting. The term “Intervener” should be specifically listed as a related service under IDEA for children with both hearing and vision loss, in order to provide them with access to language, communication, and environmental information.

For more information contact:

For More Information contact:

Linda Alsop - UT

linda.alsop@usu.edu
(435) 797-5598

Clara Berg - NY

Clara.berg@qc.cuny.edu (718)
997-4855

Vivecca Hartman - TX

Hartmanfam28@sbcglobal.net
(713) 231-7508

Melanie Knapp - TX

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(281) 302-5454

Kim Lauger - AZ

klauger@comcast.net
(520) 907-2842

Cheryl Levasseur - MA

Cherlv5@comcast.net
(978) 632-9580

Sally Prouty - MN

Sa.prouty@comcast.net
(651) 484-5929



Christian Knapp with his Intervener,
Ann Bielert



“Ever since she took my hand on the
doorstep of my home, she has been
not only my eyes and ears, but also a
light in all dark places, a bond
between me and the life of the
world.” Helen Keller
Christian Knapp with his Intervener,
Ann Bielert

Universal Access

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Indoor Opportunities on Ice

Ice Skating at the Asiaf Rink in Brockton:

Assisted skating during public skating time on a separate section of the rink using ice sleds and skate walkers. Sundays 2:40 -4:40pm. Call All Out Adventures at 413-527-8980 to sign up.

Jan 24 Feb 28



Power Chairs on Ice: Help us develop a new recreation activity and try out spinning, sliding and obstacle course challenges at the Cronin Rink in Revere.

Call Universal Access at 413-545-5353 to get involved.

Sled Skate on Your Own: Use ice sleds on your own during public skating hours at state rinks in the following cities and towns: *Auburn, Boston, Brighton, Brockton, Cambridge, Franklin, Greenfield, Holyoke, Hyde Park, Medford, Milton, Newburyport, North Adams, Plymouth, Quincy, Revere, Springfield, Taunton and Worcester.*

Outdoor Programs

Explore winter outdoors with instruction, adaptive equipment and assistance provided free of charge. Programs take place from 11am - 3pm.

Weston Ski Track: Come to the Leo J. Martin Golf Course in Weston to enjoy cross-country skiing, kicksledding and snowshoeing on a groomed course. Call Stavros Outdoor Access at 413-259-0009 to sign up. (Conventional ski and snowshoe rentals and sitski available on site for independent use 7 days a week.) Sundays: Jan 31, Feb 7, Feb 14

Mt. Tom State Reservation:

Snowshoeing, kicksledding, cross-

country skiing and ice skating and winter explorations as conditions permit in Holyoke. Call All Out Adventures at 413-527-8980 to sign up. Two Saturdays and a Wednesday: Jan 16, Feb



17, Feb 27

Wendell State Forest: Explore the wilder side of winter in western Massachusetts. All activities including snowmobile rides as conditions permit. Call All Out Adventures at 413-527-8980 to sign up. Saturdays: Jan 30, Feb 13, Mar 13

Call Universal Access at 413-545-5758 for information about rink locations or visit www.mass.gov/dcr/skating.

“Snowshoe and sitski rentals available on site for independent use 7 days a week.”

ASL UNIVERSITY—Free Sign Language

By Cheryl Harvey, Project Assistant

While researching ASL I stumbled on this FREE site. It has the first 100 signs with photos as well as several lessons that both parents and educators are free to use. There is dictionary that has several signs that may be of use. The website is at: <http://www.lifeprint.com/asl101/pages-layout/concepts.htm>. It is a little confusing to manipulate, but it's FREE. Feel free to use the various lessons and resources for self-study at no cost. There is no need to register or pay. These resources are free for personal study. If you are a teacher, you have permission to use the lessons to teach your in person classes.

Described And Captioned Media Program

By Thomas F. Lohman, Communications Services Specialist, National Association of the Deaf, Described and Captioned Media Program

I am the communications services specialist for the Described and Captioned Media Program (DCMP), a non-profit organization funded by the U.S. Department of Education and administered by the National Association of the Deaf. Our primary function is to serve as a free-loan lending service for accessible (captioned and described) educational media to benefit K-12 students who are deaf, hard of hearing, blind, visually impaired, or deaf-blind. We also advocate for increased accessibility in educational media, maintain a clearinghouse of information about captioning and description, and evaluate captioning and description vendors who wish to appear on the U.S. Department of Education's approved vendors list.

I've noted that the State DB Listserv is primarily intended for directors of state deaf-blind programs. Since our service is educational in nature, and completely free of charge for parents, teachers, and others involved with educating qualifying students (our information services are available to everyone, regardless of relationship to qualifying students), we were hopeful that you might post a message to parents, letting them know about our service, which has been quite useful for our thousands of members, many of

whom are faced with a severe shortage (or complete absence) of accessible educational media in their children's schools.

Our Web site (www.dcmp.org) provides a wealth of information about our services, and those interested in applying for our free-loan service should consult our site to sign up.

The second purpose of my message today is concerning Read Captions Across America (RCAA - www.dcmp.org/about/prelations/events.aspx), an annual campaign (now in its third year) affiliated with the National Education Association's (NEA) Read Across America campaign (www.nea.org/readacross). For anyone not familiar with Read Across America, it is celebrated every year on the birthday of Dr. Seuss (this year, March 3rd), and its purpose is to increase awareness of childhood literacy. Our RCAA campaign stresses the utility of reading captions to the goal of improving literacy. On our RCAA Web page (again, www.dcmp.org/about/prelations/events.aspx), we have linked a multitude of informative information about the literacy benefits of captioning, as well as a host of useful materials for parents and teachers (and others) to utilize in planning RCAA-related events.

Also, this year, we were pleased to learn that 20th Century Fox plans to release the CGI animated film "Horton

Hears a Who" on March 14th, which is right on the heels of RCAA. Even more exciting is that "Horton" will be released with captions and description to participating theaters (those which have the MoPix Rear Window Captioning or DTS-CSS Subtitling system installed). We are hopeful that a groundswell of support for accessible films will encourage the major studios and distributors to include accessibility in more films.

DCMP's January 2008 newsletter, just completed, provides a quick look at RCAA, including information about "Horton." You can access the newsletter at www.dcmp.org/outreach/newsletter/january2008.html.

As stated above, we hope that you will consider posting some (or all) of this information for State-DB's members. Please feel free to draw from the Public Relations page on dcmp.org (www.dcmp.org/about/prelations/default.aspx), where logos, quick "blurbs" and other materials are available.

Thank you for considering DCMP, and for the service you provide to your members! If you have any questions, please feel free to e-mail me directly.

1447 East Main St, Spartanburg, SC 29307 www.dcmp.org

Hearing Aides For Children Coalition

By Lisa Adams, Parent

Hi everyone- I am very excited to report that we, as parents of children who are deaf or hard of hearing, have formed a group called the Massachusetts Hearing Aides for Children Coalition. The purpose of the group is to organize and to foster communication regarding current legislation (House Bill 910) that would compel insurance

agencies in Massachusetts to cover the cost of hearing aids for children. We have a Yahoo group site that is up and running and we welcome both families of children who are deaf or hard of hearing and professionals who work with our children to join our group.

Please check out the yahoo group page and consider joining! Also,

please feel free to forward this message and/or the yahoo group link to other families or professionals who might be interested.

Thanks and I look forward to seeing you on-line.

<http://health.groups.yahoo.com/group/MassHAFCC/>

SPARKLE Carepages

By Shannon Butalla, Parent, Lincoln, Nebraska

We have a Carepage for my son, Sam, who just turned 7. He has a Peroxisomal Biogenesis Disorder, causing his deafblindness and many other issues. His latest hurdle is that he was diagnosed with Acute Lymphoblastic Leukemia November 13, 2008.

If anyone wants to follow his story, the link is

www.carepages.com/carepages/sambutalla. You'll have to create an account...but once you've checked it, you'll get notification whenever I write a new update.

Child Profile and additional information at the SPARKLE website: <http://www.sparkle.usu.edu/>

Technical support: sparkle-owner@lists.usu.edu

Toll free SPARKLE phone number: 1-888-800-1487

The NEC participates in the SPARKLE program in all four of our states. For more information contact your state facilitator.

State Facilitators are listed at: http://www.sparkle.usu.edu/about_us/facilitators.asp

BARD: Braille And Audio Reading Download

Reprinted with permission from the November PerKIDS Newsletter

The Library of Congress' downloadable audiobook and magazine service has a permanent home at nlsbard.loc.gov.

Sign up for BARD to download books to the Library's new digital talking book player and to Victor Reader Stream players.

You can download an unlimited number of books, visit the "most popular" and "recently added" book lists, and enjoy the redesigned magazine section.

Access the BARD online application at nlsbard.loc.gov.

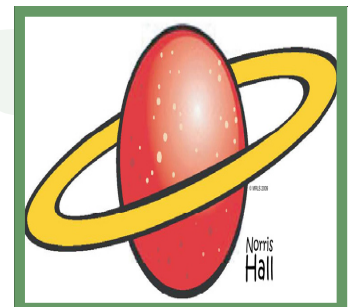


Adaptive Tech Offer

Reprinted with permission from the November PerKIDS Newsletter



Perkins Products is able to give a limited number of high tech devices, including Victor Streams, GPS devices, and magnifiers, to blind or visually impaired students in New England.



Contact the Perkins Braille & Talking Book Library for an application and for more information 617-972-7240 or 800-852-3133, or email library@perkins.org.

New England Consortium of Deafblind Projects

Providing Technical Assistance to Children, Youth and Families in CT, ME, MA & NH

175 North Beacon Street, Watertown, MA 02472
Principal Investigator—Barbara Mason
Project Director—Tracy Evans Luiselli
Project Assistant—Cheryl Harvey

MA Deafblind Project

Perkins School f/t Blind
175 North Beacon Street
Watertown, MA 02472
617-972-7516
Susan DeCaluwe
Susan.Decaluwe@perkins.org

NH Deafblind Project

NHVHN- NH Vision Hearing Network
117 Pleasant Street, Dolloff Bldg
Concord, NH 03301
603-226-2900
Kathy Thonis
kathy.thonis@crotchedmountain.org

CT Deafblind Project

BESB-Board of Ed Services f/t Blind
184 Windsor Ave
Windsor, CT 06095
800-842-4510
Karen Olson
karen.olson@ct.gov

M.I.C.E. (Birth-2)

PO Box 2274
Concord, NH 03302
603-228-1028
Jan Halley
miceprogram@juno.com

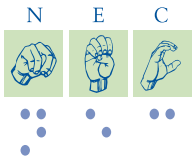
ME Deafblind Project

Catholic Charities, 1066 Kenduskeag Ave., Bangor, ME 04401
207-941-2855 Jean Small, jsmall@ccmaine.org

Save The Dates

- Jan 20th 4-PT Training, Reading, MA (Part 1) Deafblind Training Series (Feb 24, Mar 24, April 28 & May 19) Contact: susan.decaluwe@perkins.org
- Jan 29th 4-PT Training, Milford, MA (Part 5) Topic: Curriculum Contact: susan.decaluwe@perkins.org
- Feb 1 Family Phone Network Conference Call 8-9 PM
Topic: Summer Plans Just call in: 1-888-387-8686 Room 2502812
- Feb 16 Life After High School: A Workshop for Parents Time: 7-9 PM,
Merrimack High School, NH contact@merrimackpact.com
- Mar 1 Family Phone Network Conference Call 8-9 PM
Topic: Transition, Four Steps Just call in: 1-888-387-8686 Room 2502812
- Mar 9 Building the Skills that Building Social Capital: Time: 7-9 PM,
Merrimack High School, NH contact@merrimackpact.com
- Mar 10 Focus Conference, Norwood, MA contact: Lisa DiBonaventura @state.ma.us or
508-384-5539 www.mass.gov/dds/visionloss
- Mar 16 Extended School Year(ESY): Who, What, Why & What Else: Time: 7-9 PM,
Merrimack High School, NH contact@merrimackpact.com
- Apr 13-14 MEIC, Marlborough, MA contact tcornell@percs.info or 508-478-2631 x208
- Apr 20 Alternate Dispute Resolutions: Understanding the Options, Time: 1-4 PM
contact@merrimackpact.com
- TBD Portfolios Workshop, Part II, CT contact karen.olson@ct.gov

For more detailed information regarding any event check out our web-site at www.necdbp.org and go to the calendar section.



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