



In Touch

Spring/Summer Greetings!

By Tracy Evans-Luiselli, Ed.D.
Project Director

As we roll into the months of fun in the sun - we want to let you know about NEC's Parent Leadership Training which occurred this past April and is still on-going. The purpose of the training is to develop leadership and advocacy skills of parents who have children with vision and hearing loss. We are fortunate to have Katharine Shepherd (University of Vermont), Djenne Morris (North Carolina Deafblind Project, and Susan LaVenture (National Association for Parents of Children with Vision Impairment) as our guest speakers. Parents and Family Specialists from our four states (CT, ME, MA and NH) came to our first session to learn about parent leadership, gather ideas of how to advocate for their child, and to learn how to address issues related to their child's education and development. The training began with a key activity in which parents were asked to identify three issues that are of concern to them and their family, and to present these issues to the group. The purpose of this

step was to start turning issues into goals that parents can address in their leadership internship. The group focused on the following questions:

- What's going on?
- What worries me?
- What's the "good news" in this situation?
- What are some potential goals to work on?
- Ideally, I would like to see...

Next - the group re-read all the ideas that had been generated and parents chose one or more ideas to become the focus of their leadership internship with the idea in mind that for parents of children with vision and hearing loss *"...our obstacles often make us better advocates for our children"*. Parents were coached to choose a leadership activity that they will conduct in their state based on these elements:

- High interest
- Seems "do-able"
- Will challenge but not seem overwhelming
- Will stretch their skills and experiences as a leader

Some of the key leadership skills presented involved strategies to facilitate collaboration with your team, listening skills, asking clarifying questions,

compromising, and setting goals. Some of the individual Parent Leadership Activities chosen included: organizing a state group of parents to attend the CHARGE conference; developing communication materials to improve my daughter's access to our community playground; organizing a Project SPARKLE Boot Camp to encourage other parents to use the materials; increasing awareness of others regarding my child's diagnosis - Cornelia deLange Syndrome; participating on our state low incidence task force; and organizing a community outing for families of children with vision and hearing loss. Parents who attended our April training will return in October to check in and review their leadership activity, identify successes and obstacles and offer support to each other.

Please note that NEC's Parent Leadership Training - Tier 2 will begin in October 2011. If you are interested in further information regarding our next session, please contact Tracy Evans Luiselli at: tracy.luiselli@perkins.org or call 617-972-7517.

Reference:
Creative problem solving: Resources for CPS practitioners. Omniskills LLC.

New England Consortium of Deafblind Projects

Spring/Summer 2011

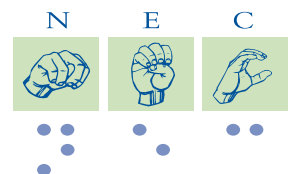
Volume 7, Issue 2

Helpful Conferences

- Usher Syndrome Family Conference
- CHARGE Conference
- Cochlear Implant Convention
- AER Regional Conference

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Developing Daily Routines for the Summer

By Christine Martin, Educational Consultant, NH Deaf-blind Project

After such a long winter, it's hard to believe that summer is just around the corner. Along with the change of season come changes in our daily routines. Routines provide all of us with an organized framework that help us

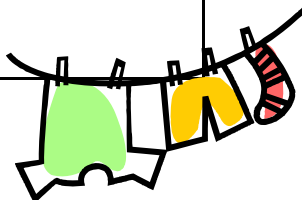


predict what will happen next and by definition it is a sequence of actions regularly followed. For all children, but particularly for children with combined vision and hearing loss, daily routines are critical to providing them with a sense of security by helping them anticipate what

will happen next. Routines also help children increase participation within the activity, develop communication skills and learn about the world around them.

Examples of Routines at home

- Toileting
- Brushing teeth
- Eating
- Bathing
- Story time
- Going to the store
- Going to visit a relative
- Dressing



To help with the transition from school to being home, consider developing routines for your child throughout the day. The following are strategies that you may find useful in developing daily routines for the summer:

If you have any questions or need support, please contact me at: Christinem@atechservices.org

Resources: Washington Sensory Disabilities Service. Routine-Based Learning. <http://www.wsdsonline.org/deafblind/routines/overview.html>

- Determine your child's daily routine. Will the day begin with a bath or breakfast? Will the day end with a bath or quiet music? Be consistent with the routine and write it down to ensure that others follow the same daily routine.

- Determine the order of steps within a routine that occurs often. For example, when brushing teeth the routine may involve gathering items needed, filling cup with water, applying toothpaste to the brush, brushing the top teeth, brushing the bottom and then rinsing with water. For another child all of the items may be organized in a basket and the act of brushing is the focus and needs to be sequenced.



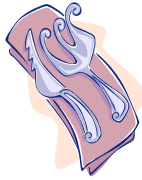
- Provide a clear and consistent beginning to each activity. Signaling that an activity is about to begin can be done with pictures, objects, signs, or spoken language prior to the start of the activity. For some children it's appropriate to present an object that is used within the activity. For example, prior to a bath a bar of soap could be shown to the child to represent the activity.
- Identify how your child will participate. For example, during tooth brushing the child's participation may be to reach for the tooth brush. For another child, participation might include gathering the items needed.
- Provide a clear ending to the activity. Signaling that the activity is ending can be done again at the child's level of communication. For some children this may include using an "all done" basket. Items used within the activity are placed in the "all done" basket and signal that the activity is over.

Changes in our daily routine can be frustrating for child and adult but there are ways to minimize the frustration! Through thoughtful planning of everyday routines frustrations can be minimized and new routines can bring new opportunities.

The Frustrations of Mindful Feeding

By Susan Hollis, Parent and NH Family Specialist

When my children were very young, I had the fantasy of the four of us sitting at the family table every evening for dinner. We would review our day, tell jokes and make future plans together. Then reality set in. Both my children, in addition to being deaf-blind, are also medically fragile. As so many of you know, that brings on a host of challenges and difficulties; especially around eating. Both my kids have reflux problems, swallow disorders and have been "failure-to-thrive". Eating, which used to be such a simple thing, had become the most complicated issue of the day.



My daughter used to eat. The doctors would tell us she was "borderline" in weight where she may need to get a feeding tube. I was horrified. We, my husband and I, worked very hard on getting her to eat orally. We did well until she was 4 years old. She stopped eating entirely. She lost

weight, was pallid and lost the protein in her hair. We knew we needed to act. We were told that she was shutting down as a way to protect herself. She had the g-tube put in, what a relief. No more fights and frustrations when she wouldn't eat.

My son was born that same year. It became evident to us pretty quickly that his eating problems were going to be worse. He couldn't coordinate his breathing, suck, and swallow response. He had a sub mucous cleft palate that affected his ability to eat. During his first year of life, he had a g-tube placed as well.

Now more challenges. We were learning that both children had severe food allergies. Everything we were feeding them was making them sick. We made huge changes in their diets, no dairy or gluten, no berries or additives and in addition, my son can't have eggs, soy, or corn. Do you know



that all formulas on the market for our kids are corn based? So we need to home make all their formulas and foods that they ingest by g-tube.

Today, now 10 years later, we are still dealing with challenges. My daughter eats a lot by mouth. We have to limit what she eats due to allergies, meaning no eating out, and no traveling. My son eats hardly anything by mouth. Just a few teaspoons of pureed fruits and veggies, his favorite being pumpkin pie filling, yum. We can't go to restaurants, too over stimulating and have a hard time eating anywhere out of the home. There are times where we are all together during meal times, but it's not the idyllic memories associated with my fantasies from years past. Now we focus on the gains both in calories and weight. We find other things to do together as a family that is idyllic to us.

Free EyeNote Software Application

For IMMEDIATE RELEASE Contact: Dawn R. Haley (202) 874-3545 Darlene Anderson (202) 874-2229 Bureau of Engraving and Printing Launches EyeNote(tm)App to Help the Blind and Visually Impaired Denominate US Currency (Washington, DC -April 20, 2011)

The Bureau of Engraving and Printing (BEP) has developed a free downloadable application (app) to assist the blind and visually impaired denominate US currency. The app is called EyeNote(tm). EyeNote(tm) is a mobile device app designed for Apple iPhone (3G, 3Gs, 4), and the 4th Generation iPod Touch and iPad2 platforms, and is available starting today through the Apple iTunes App Store.

EyeNote(tm) uses image recognition technology to determine a note's denomination. The mobile device's camera requires 51 percent of a note's scanned image, front or back, to process. In a matter of seconds, EyeNote(tm) can provide an audible or vibrating response, and can denominate all Federal Reserve notes issued since 1996. Free downloads will be available whenever new US currency designs are introduced.

Research indicates that more than 100,000 blind and visually impaired individuals currently own an Apple iPhone. The EyeNote(tm) app is one of a variety of measures the government is working to deploy to assist the visually impaired

community to denominate currency, as proposed in a recent Federal Register notice.

These measures include implementing a Currency Reader Program whereby a United States resident, who is blind or visually impaired, may obtain a coupon that can be applied toward the purchase of a device to denominate United States currency; continuing to add large high contrast numerals and different background colors to redesigned currency; and, raised tactile features may be added to redesigned currency, which would provide users with a means of identifying each denomination via touch. More information is available at

www.eyenote.gov

A Family's Journey

By Rachel McCullough, Parent

When I am asked to write about my family, I am always trying to figure out what is most beneficial to write about. I would like to be able to write something helpful or insightful to others who are just finding themselves in a similar situation. Or for those of us who have several years under our belts, it can be a great comfort to experience some similarities, which can be so rare.

My husband Kevin and I are parents to two daughters, Katie and Lauren. Katie is 21 and a senior in college and Lauren is 19. Lauren was born with Smith-Lemli-Opitz Syndrome (SLO). She is the most severe child alive with SLO and the only child alive with the two gene mutations that she has inherited. The impact of SLO in Lauren includes but is not limited to being blind, CVI, deaf, non-ambulatory, g-tube fed, sleep disorder, sensory integration disorder, processing disorder, seizure disorder, non-verbal, limited use of hands and limited range of motion. Lauren's physical disabilities, her motor limitations along with her medical fragility represent quite a complex and challenging scenario for Lauren.

One of the first things we noticed the day Lauren was born was that she had extra fingers and an extra toe. The obstetrician was quick to point out that this was a very common birth defect. The fact that she had a birth defect at all was shocking to us. Over the next hours and days, the challenge of just trying to get Lauren to nurse became impossible. It was very apparent she was not capable of managing such a task. It felt defeating in many ways, because what I should be able to do for Lauren, I could not. We went home the next day, feeding her with a dropper every two hours. Lauren really didn't care very much, she just slept. We were getting so little nourishment into her, yet she did not demand a thing. When you woke her, she would stir very quietly and gaze at you, but would rarely cry.

When I called my pediatrician, he was very concerned about Lauren's poor eating and wanted to see her right away. At the appointment, he started talking to us about the abnormalities that Lauren was born with and the need to see a geneticist. He explained that they would try to group her abnormalities together to get a diagnosis and therefore, hopefully, appropriate medical treatment. We were overwhelmed, but also a little angry. We didn't want anyone labeling our baby by what might not be normal.

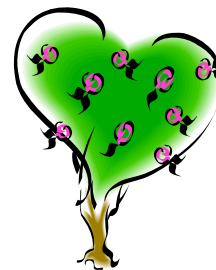
The next morning found us enroute to New England Medical Center. We had never been exposed to needing to find medical treatment outside of our small town. It was overwhelming. Once we managed to get there, we met with a geneticist who is Lauren's doctor to this day. She was admitted to the NICU unit within hours. This was just the beginning.

It became apparent in a short period of time that Lauren was very different. During this time in the hospital, she was evaluated by at least a dozen different specialty doctors. Every one of them found something "wrong" with her. During one evaluation by a young pediatrician in the NICU unit, I was having a very difficult time and was crying during our discussion. She very gently said to me to be very careful with my sadness around Lauren, that she strongly felt it.

That made me realize that if she felt my grief, then she would also feel all the love, comfort, encouragement and strength that we could give her. It also granted me time to establish a very valuable connection with Lauren. I stopped being so afraid of my surroundings, the doctors, the questions, and of Lauren. We started the most important journey of all, to "listen" to Lauren as she taught us not to minimize the inherent bonds that we give to our children.

When we realized that they were not sure exactly what Lauren had, she was diagnosed as "failure to thrive". Our mission was to get nutrition into Lauren, because even though she has a long list of abnormalities, nothing mattered unless she starting eating and gaining some weight. We were trained on how to put an NG tube in so that we could give her nasogastric feedings to supplement what she was not able to take by mouth. We took her home hoping to get her to gain some weight. Little did we know that the mission would take years.

By the time she was two months old, her pediatrician discovered that her liver was enlarged. We were sent to a specialist and many tests were done. None showed the reason for the enlargement. It was decided that she should have a liver biopsy, and also a g-tube placement because she still was not eating by mouth at this time.



The liver biopsy also did not show a reason for the liver disease. After reviewing her blood tests, there was one common issue since her birth, and that was very low cholesterol levels.

Her doctor decided to send some blood and her liver biopsy to a specialist. A month later, he called me at home, with the news that Lauren did have Smith-Lemli-Opitz Syndrome (SLO). But that wasn't all. Although SLO has always been known as a genetic disorder, the cause was not known for the first 30 years after its description. They had discovered, in Lauren's liver biopsy sample that children with SLO are unable to make cholesterol. The discovery of abnormal cholesterol metabolism in SLO has made possible not only a laboratory test for more precise diagnosis, but also provided a rationale for treatment of affected children. The defect is caused by a deficiency of the 7-DHC reductase enzyme needed to convert 7-dehydrocholesterol to cholesterol, the final stage in chole-

A Family's Journey (continued)

terol synthesis. The result is a large concentration of the 7DHC precursor and a cholesterol deficiency significantly affecting individuals with this diagnosis. He was elated. It was such a huge discovery. This news was overwhelming to say the least.

At her next geneticist appointment, it was found that she no longer had an enlarged liver. She was checked several times, by many different specialists to confirm this had actually happened. Her geneticist, to this day, says that every time she thinks of that day, a shiver goes through her. It was as if Lauren had the enlarged liver to let them know where to look. And they did.

Lauren was making very slow gains both physically and mentally. She had services through Easter Seals, and the MICE program. When she was about a year old or so, we had hoped that Lauren would be able to communicate through signing, so my family started to learn sign language. She was very engaging and happy with her many therapists and professionals. At this time, she was even able to say the word "mama" at times.

When Lauren was three, she was integrated into the preschool program, but her health began to deteriorate and she got very ill. It was decided that a home program would be medically necessary for her. Her illness also necessitated the need for nursing care three days a week. Lauren did not have the ability to communicate in any structured fashion, it was really our link to each other that enabled me to be able to read her so well and be able to address all her needs. It was a huge adjustment to have someone else caring for Lauren. It was apparent that sign language was not going to be appropriate for someone like Lau-

ren and she was no longer saying her one and only word, mama, so things were changing.

Lauren's teacher, that she still has to this day, had to initiate introducing her and all of us to an object communication system. A communication system that consists of real objects that are attached to laminated 4x6 cards to be used for communication, transitions or choice making. If you close your eyes and rely on your sense of touch, it is easier to understand how some of these objects have a clear meaning to Lauren. When Lauren needs to transition from one activity to the next, by giving her the object she can anticipate the activity. We call Lauren's objects her "words". Having her words takes the stress and chaos out of her life and empowers her in her day to day decision making.

Lauren is engaging, perseverant, funny, creative, intelligent and has a strength and determination that we continually admire. Her ability to communicate with those around her and her ability to control her environment has been such a rewarding experience, for her and for her family.

I think it would literally take me at least a hundred pages to continue describing everything that has happened to Lauren, our family and our lives. During the doctor appointments, the hospitalizations, the daily care and the dependency it continues to this day. But we have learned the invaluable. For everything that seemed insurmountable, there was ease. For everything that was devastating, there was great comfort. For everything that was heartbreaking, we were uplifted. For everything that was complex, you could find the simple. And we cherish Lauren's milestones, great and small.



Families Connecting in Connecticut

By Andrew Jeruss.

Andrew was quoted for the newsletter:

"Andrew Jeruss is a young man with Charge Syndrome. He had visited Aidan and his family one afternoon in May. Aidan also has Charge Syndrome."

These two families are connecting with each other in Connecticut with the help of Kathy Morgan, CT Educational Consultant (seen here to the right) and their parents.



Aidan Gaucher Left, Andrew Jeruss right.



CHARGE Syndrome Conference

By Cheryl Harvey, Project Assistant and the CHARGE website: <http://www.chargesyndrome.org>

The New England Consortium will be sponsoring 6 NEC families to attend the CHARGE Conference in Orlando, Florida this year. If your family has a child with CHARGE Syndrome and you would like to attend this conference please contact Tracy Evans Luiselli at 617-972-7517 or email Tracy.Luiselli@perkins.org to have your families name added to the list of potential candidates. 10th International CHARGE Syndrome Conference, hosted by the CHARGE Syndrome Foundation on **July 28-31, 2011 in Orlando, Florida**. For more information on this event, please visit: <http://chargesyndrome.org/conference-2011.asp> 141 Middle Neck Rd, Sands Point, NY 11050, Telephone 800-442-7604 info@chargesyndrome.org

Summer Reading

Below is a list of available summer reading materials from the Braille and Talking Book Library. To contact the Library, call 617-972-7240, 1-800-852-3133, or email Library@Perkins.org. The fax number is 617-972-7363 and the TTY number is 617-972-7690. A staff member will be available to assist you during regular library hours (8:30 am - 5:00 pm Monday - Friday except holidays).

Non-Fiction Books

All Souls: Family Story From Southie by Michael Patrick MacDonald DBM 666
The author grew up in "the best place in the world" - the projects of South Boston. Tragic and comic events fill this story of a proud, poor family surviving in a world of gangs, crime, and prejudice. Some strong language and some violence. Narrated by Ana Maria Quintana.

Born to Play: My Life in the Game by Dustin Pedroia DBM 1123

The inspirational story of the Red Sox second baseman --a small man (5 foot 7 inches tall) who defied the naysayer's to become the American League's Rookie of the Year in 2007 and its Most Valuable Player in 2008. Narrated by Bette Lavery.

Boston's North End: Images and Recollections of an Italian-American Neighborhood by Anthony V. Riccio DBM 1044
Elders who have lived in Boston's Italian-American neighborhood for many years reminisce about everything from family life, the Great Molasses Flood, and the Sacco and Vanzetti trial, to work, holidays, and the "New Boston." A collection of personal, easy-to-read stories of long ago and now, lovingly taken down word-for-word by the author during many interviews. Narrated by Bette Lavery.

Callgirl: Confessions of an Ivy League Lady of Pleasure by Jeanette Angell DBM 951

The author had just earned a doctorate in social anthropology and was lecturing part-time when her boyfriend took all of her

money and left her. She had to find more work. She passed up low-paying jobs for a more lucrative one as an escort. Here, she explains how she made that decision, and describes what happens to escorts behind closed doors. Contains explicit descriptions of sex. Narrated by Ana Maria Quintana.

Douglass and Lincoln: How a Revolutionary Black Leader and a Reluctant Liberator Struggled to End Slavery and Save the Union by Paul Kendrick and Stephen Kendrick. DBM 1096

Frederick Douglass and Abraham Lincoln had only three meetings but their influence on each other and on the nation altered the course of slavery and the outcome of the civil war. Drawing on unpublished letters and other neglected sources, the authors recount an epic contest of wills that brought out the greatness in both men. Narrated by Ann Eldridge.

Fat to Skinny Fast and Easy: Eat Great, Lose Weight, and Lower Blood Sugar without Exercise by Doug Varrieur DBM 1182
The key to weight loss is understanding the ingredients that create fat and pack on pounds. The author, who dropped 100 pounds at middle-age and has kept them off ever since, exposes the hidden sugar in so much of our diet and provides delicious recipes and meal plans that can help anyone maintain a healthy weight without feeling deprived. Narrated by Doug Varrieur.

Generous Faith: Stories to Inspire Abundant Living by Sister Bridget Haase DBM 1194

A Collection of stories that give shape and face of three practices: Living in the moment, Trusting in In process. Divine care, and Experiencing God's presence. The people in these stories ask us to re-examine our own journey and change our perspective. In so doing, we take a second look at our life, and realize that what we have is more than enough for it is, quite simply, most abundant. Narrated by Sam Silverman.

The Gardner Heist: the True Story of the World's Largest Unsolved Art Theft by Ulrich Boser DBM 1086

In March of 1990 the greatest art theft in history occurred at the Isabella Stewart Gardner Museum in Boston. Ulrich Boser delves deep into the art underworld to help reveal the trail of the still unsolved crime of how over a dozen masterpieces were stolen and the leads on how they can hopefully be recovered. Contains some strong language. Narrated by Bart Morse.

The Greatest Presidential Stories Never Told: 100 Tales from History to Astonish, Bewilder, and Stupefy by Rick Beyer DBM 1031
Lincoln's duel, Jimmy Carter's UFO sighting, and the president who went skinny-dipping in the Potomac every day are just a few entries in this fascinating compendium of little-known, true stories about United States presidents. Narrated by Jeff Ferrannini.

If Only They Could Speak: Stories about Pets and their People by Nicholas H. Dodman DBM 1118

The joys and rewards as well as the frustrations and failures of pet ownership are explored by the author who examines the complexities of the human-animal dynamic from both the pet and owners point of view. Narrated by Debby Perugini.

Moving the Chains: Tom Brady and the Pursuit of Everything Else by Charles P. Pierce DBM 975

Skilled, disciplined, and fortunate, Tom Brady was a sixth-round draft choice who became the youngest quarterback to win a Super Bowl, and the only one to win three while still in his twenties. Here is the story of his climb to the top, and his fight to stay there. Narrated by John Deming.

Red Sox Rule: Terry Francona and Boston's Rise to Dominance by Michael Holley DBM 1098

With the exclusive cooperation of Red Sox manager Terry Francona, this fasci-



Summer Reading (continued)

nating volume goes into the clubhouse and deep inside the conference room to reveal the strategies that have made the team a budding dynasty. Some strong language. Narrated by Bruce Lundeen.

Watching Baseball: Discovering the Game Within the Game by Jerry Remy with Corey Sandler. DBM 973
Red Sox broadcaster and former major league player Jerry Remy's guide to baseball has been a standard source for years. Here is the 2006 revised and updated edition which includes the story of the Boston Red Sox's historic World Series victory. Approximate reading time: 15 hrs. Narrated by Mark Agney.

Fiction Books

Animal Crackers: Stories by Hannah Tinti DBM 941

Eleven stories of people and animals. An artist is bothered by a stuffed bear; a young woman is lured by the freedom of monkeys in the trees of Africa; a husband projects his anger onto his wife's pet rooster. Some violence, some descriptions of sex. Narrated by Mark Angney.

Boys by Richard Marinick DBM 903
The author grew up running with Boston's gangs during the era of Whitey Bulger. Using authentic, gritty detail, he tells the story of "Wacko" Curran and his brother Kevin, shrewd and brutal soldiers in the Irish mob. When these boy's rebel against paying tribute to mob boss Marty Fallon, they discover that Marty has plans of his own for the upstart Currans. Extreme violence and strong language. Narrated by Greg Massing.

Dedication by Emma McLaughlin DBM 1023

The authors of *The Nanny Diaries* (RC 54032) introduce readers to Kate Hollis, who manages to survive the modern world. Kate's ex-boyfriend disappeared on prom night eleven years ago, and has now become a mega star, recording songs about her. Kate decides to confront him when he visits their Vermont hometown. Some sexual content and some strong language. Narrated by Jean Kriedberg.

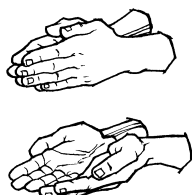
Flashback by Michael Palmer DBM 944
An eight-year-old boy remembers every moment of what should have been a simple operation with adequate anesthesia. Now, he lives in terror. The hospital has been making horrible mistakes. Can it be stopped before there is another victim? Time is running out. Contains strong language, and some descriptions of sex. Narrated by David Curtis.

The Ladies' Man by Elinor Lipman DBM 725

After jilting Adele Dobbin at the altar, Harvey Nash has the audacity to show up and apologize thirty years later. He is just in from the coast where he has reinvented himself as Nash Harvey, composer of jingles. He brings disruption, comedy, and change to the well-ordered lives of Adele and her two sisters. Approximate reading time: 7 hrs, 20 min. Narrated by Ana Maria Quintana.

My Only Story by Monica Wood DBM 1004

Rita Rosario, a thirty something divorcee, and John Reed, a lonely stranger who needs her help, begin to fall in love. When he reveals his story to her, Rita is determined to reconnect him with his young, orphaned niece. But family members intervene, and John begins to grow away from Rita. Meanwhile, Rita's sister comes to stay with her. A compelling family story. Narrated by Yvonne Fuller.



New World Greetings: Inspirational Poetry and Musings for a New World by Mary McManus

DBM 1030
Mary McManus overcame paralytic polio as a young girl, and dealt successfully with post polio syndrome years later. In this collection of inspiring poems, she shares the profound faith and love that has increasingly filled her life. Narrated by Mary McManus.

Children's Books

Escapade Johnson and the Witches of Belnap County by Michael Sullivan DBM 1104

When a weird trio of elderly women appear one snowy afternoon in Sanbornton's library, the overactive imaginations of Escapade and his buddies shift into overdrive. Has a coven come to town? Grades 2 to 5. Narrated by Ken Durand.



Flamingos on the Roof by Calef Brown DBM 1005

29 nonsense poems full of words that are fun to say. Come to the Soggy Circus, meet Tiny Baby Sphinx, and visit Weatherbee's Diner. For grades 2-4. Narrated by Yvonne Fuller.

Honk!: The Story of a Prima Swanerina by Pamela Duncan Edwards DBM 818

Honk is a swan who loves ballet. When she manages to join the other dancers in a performance of *Swan Lake*, Honk wins acclaim. For preschool-grade 2. Narrated by Ana Maria Quintana.

Lemon the Duck by Laura Backman DBM 1192

This book is based on the inspirational true story of Lemon the Pekin Duck, who was born in an elementary school classroom. Neurological issues make Lemon unable to walk, but with the support of a compassionate teacher and her students, Lemon is still able to become one happy duck. For Kindergarten - Grade 2. Narrated by MaryBeth Wise.

Timberrr... by Mary Morton Cowan DBM 1151

From the seemingly endless woodlands encountered by early European settlers to today's scientifically managed forests, New England has a long and intriguing history with its mighty trees. This lively volume tells the colorful story of logging and illuminates the industry's cultural, economic, and technological contributions to the region. For junior/senior high and older readers. Narrated by Sharon Brecher.

Top 25 Websites for Gamers who are Blind/Visually Impaired

By Cheryl Harvey, NEC Project Assistant.

Below are the top 25 accessible gaming sites. About half are blind-accessible some are deaf-accessible, Most sites offer FREE games (ages 2-adult). Word, puzzle, card and video games are offered.

1. PCSGames www.pcsgames.net

It offers an ever growing volume of descriptions of, and highly annotated links to over 300 FREE and Commercial blind-accessible games and game sites.

2. Audyssey www.audyssey.org

An excellent resource for quick technical help and game hints. A good place to tell independent developers just what you want to find in a game. Also, entertaining animated discussions among developers and gamers.

3. AudioGames www.audiogames.net

It offers a database of 380 FREE and Commercial blind-accessible games with descriptions of each game. These games can be downloaded from this Web site or from their Commercial sites. It also offers 45 Indie audio games - all available through their Experimental Audio Games section, as well as MOD downloads that make a number of games blind-accessible.

4. Kitchens Inc. www.kitchensinc.net

This independent developer offers 30 FREE audio-only self-voicing games, including the popular Homer on a Harley game, as well as trivia, racing, arcade, sports, word, and puzzle games.

5. The Zone BBS www.zonebbs.com

Has nearly 6,000 registered participants, with well over a hundred people logged in at any given time. The greatest user login record set 24 January, 2010 at 199. Offers blogs, Zone BBS by Phone, Voice Chat, Private email, Graffiti chat, Person Watch, Quicknotes, and Boards (forums.)

6. Azabat Games www.azabat.co.uk

Offers 34 Commercial audio and audio-video blind and visually-impaired accessible card, puzzle, and crossword games. Includes 4 Commercial word games for children ages 5 - 11. Also offers blind-accessible word processing, email, and typing tutor programs.

7. AbleGamers www.ablegamers.com AbleGamers Foundation

www.ablegamers.org The first place to go for industry news on accessible gaming, especially about the largest developers. It's influence, especially in the US, is growing. In 2010 AbleGamers added self-voicing to its articles and reviews.

8. 7-128 Software, www.7128.com Cynthia a Geller, VP Sales and Marketing

(978) 745-4573 Offers 31 blind-accessible games, including 26 Commercial games and 5 FREE games. Games include: word games, puzzle games, the Inspector Cyndi in Newport mysteries, and educational games for young children. Home of the ALERT (Accessible Learning through Entertainment and Recreation Tools) project, FREE information on applying accessible computer games in a learning environment.

9. Spoonbill Software www.spoonbillsoftware.com.au/blindgamers.htm

Offers 17 FREE blind-accessible puzzle and card games.

10. Gaming Galaxy! www.galaxy.tmantv.net

The site is a work in progress and offers over 70 FREE and Commercial games directly downloadable from 12 different developer Web sites.

11. VIP Gameszone www.vipgameszone.com

Offers 15 blind-accessible games: 7 Commercial games: arcade adventure, sport multiplayer games, strategy multiplayer games. 5 FREE games: Puzzle, maze, strategy, shooter. 3 FREE special educational applications for kids who are blind or visually impaired.

12. USA Games www.usagamesinteractive.com

Offers 12 FREE games, including their own Star Trek, plus games from Draconis, and games formerly offered by DanZ games and PB-Games.

13. Draconis Entertainment www.draconisentertainment.com

Offers 12 blind-accessible games: 10 Commercial games including Pinball, Alien Outback, and the popular Sarah and the Castle of Witchcraft and Wizardry. Also offers 2 FREE games.

14. L-Works www.l-works.net

Offers 11 audio games: 7 Commercial games include the well-known Super Liam, Judgment Day, L-Works Arcade Vol. 1: a pack of 5 arcade games, and 4 FREE games.

15. Braillesoft www.braillesoft.net

Offers 9 of their own FREE blind-accessible games, including Crocodile Dentist, plus links to the 6 X-sight Interactive games mentioned below.

16. BPCPrograms bpcprograms.com

Offers 9 games that are blind-accessible: 7 FREE and 2 Commercial games, Treasure Hunt, and 3-D Velocity, the first-ever fully blind-accessible fighter jet simulator that was released in 2010.

17. BlindSoftware www.blindsoftware.com

Offers a total of 9 Commercial blind-accessible games, including the popular Troopanum and Deekout.

18. GMA Games www.gmagames.com

Offers 8 accessible games, including 5 Commercial games such as the popular Tank Commander, Lone Wolf, Star Trek, and Shades of Doom games, as well as 3 FREE games.

19. X-Sight Interactive x-sight-interactive.net

Offers 6 FREE blind-accessible games including: AceFire, Danger City, Giftatum, River Raiders, as well as Self Destruct and Savage Gamut, which are abandonware they took over.

20. Blast Bay Studios www.blastbay.com

Offers 1 Commercial blind-accessible game: Q9 Action Game, and 2 free games, Kringle Crash and Palace Punch-Up.

21. IGDA - Game Accessibility SIG gameaccessibility.blogspot.com gameaccesssig.forumotion.com

Forum with separate areas for games addressing Visual, Auditory, Motion, and Learning disabilities. Has separate pages discussing games for the Visually Impaired, Audio Impaired, Motion Impaired, and Cognitively Impaired. These pages include discussion of relevant games and annotated links to sites where you can get those games.

22. The Game Accessibility Project www.game-accessibility.com

Much that one would want to know about the design and development of accessible games in general.

23. PIN Interactive www.pininteractive.com

Offers 1 Commercial game, the award-winning blind-accessible Terraformers. Developed by Thomas Weston, co-founder of the IGDA Game Accessibility SIG.

24. SoundRTS <http://jlp.free.fr/soundrts>

Offers 1 FREE audio realtime strategy game, the popular SoundRTS. Includes Brazilian Portuguese, English, French, Chinese, Dutch, German, Italian, Polish, Russian, and Spanish translations.

25. Niels Bauer Games www.nielsbauergames.com

Offers 1 Commercial game that is blind-accessible: Smugglers 4.

Family Phone Network

Networking families of children with combined vision and hearing loss. The purpose of the NEC Family Phone Network is to provide a support network for families of children and youth who have combined vision and hearing loss (deaf-blindness).

Through discussion of key issues, families from Connecticut, Maine, Massachusetts and New Hampshire will share ideas and strategies in parenting a child with sensory loss.

Facilitated by: Dr. Deborah Chase, NEC Family Network Specialist. Deborah is a Licensed Psychologist in Massachusetts and a Nationally Certified School Psychologist. For over twenty-five years she has worked with children, adolescents and their families in a variety of settings including hospitals, mental health agencies, schools and private practice. Deborah has a special interest in working with families who have a child or children with special needs. She is a mother of a teenager who has combined vision and hearing loss.

Phone Number: 1-888-387-8686 (Free Call)
Enter Conference Room Number: 2502812
Time: 8:00 pm - 9:00 pm - ALL CALLS

Facilitated Call Schedule:

- **September 12th** - Developing Feeding Skills
- **October 3rd** - Strategies to Improve Better Sleep
- **November 7th** - Holiday Tips for Busy Families

Let us know what topics interest you. E-mail us at:
NEC@Perkins.org

Upcoming Training in Your Area... Save the Date!!!

Connecticut Contact Janette.Peracchio@Perkins.org

Sept 27 DB Multi-Handicapped Training Series (Paras)
Sept 28 DB Multi-Handicapped Training Series (Teachers)
Oct 14 CT DB Networking Team
FALL TBD - INSITE

Massachusetts Contact NEC@Perkins.org

Oct 28 Parent Leadership (Location TBD), Continued
Nov 3, 4 Deafblind Advisor Training (Tier II)

New Hampshire Contact NEC@Perkins.org

June 24 Charmingfare Farm, Candia, NH 10-2, Family Day Join Us!
July 8 SPARKLE Boot Camp, ATECH, Concord. Contact Sue at Snbhollis@yahoo.com (Date is changing)
Sept 21 NH Deafblind Project Overview Webinar
Oct 18 NH Deafblind Project Overview Part I
Nov 16 NH Deafblind Project Overview Part II
Nov 17 Transition Symposium, 9-11:30 am

Maine Contact NEC@Perkins.org

TBD INSITE Training (see our website www.necdbp.org for details)

On-Line Courses Contact NEC@Perkins.org

FALL UTAH On-Line Intervener Training Courses (see page 12)
TBD Deafblind Webinar Series—**topics and dates TBD**;

Creating a Fotobabble for the Holidays; ScreenR - Child Profile; Hearing Aides; Types, Audiogram, Impact on Hearing Loss and Learning; Cochlear Implants; Families (Resources and Advocacy); CDLS (Cornelia de Lange Syndrome) Learners; Calendar Systems; CVI

Overview; Low Vision Aides; Helen Keller National Center; Personal Futures Planning; Deafblind Organizations, and Interveners are a few of the topics planned.

Easter Seals MA Upcoming Events/Workshops (Fees)

June 30 iDevices in Schools 9:30-12:30pm - Worcester
June 23 Kurzweil 3000 Version 12, 9-12pm - Worcester
July 28 Kurzweil 3000 Version 12, 9-12pm - New Bedford
July 15 Get the most from your iPad/iPod, 9:30-12:30pm - Boston
Aug 31 Get the most from your iPad/iPod, 9:30-12:30pm - Worcester
July 20 eBooks, Audio books and Mobile Devices 10-12pm - Boston

For registration contact Jeff McAuslin 800-244-2756 ext 448 or email: jmcauslin@eastersealsma.org Most of these are \$75.

Regional Trainings/Conferences

July 8 Usher Conference, Sturbridge, MA (page 6)
k.scheall@decibelsfoundation.org
July 8-10 2011 NE Cochlear Implant Convention, Sturbridge, MA
<http://www.neci2011.neci-convention.org>
Convention_Information.html
July 28-31 CHARGE Conference, Orlando, FL contact:
info@chargesyndrome.org
Aug 12-14 AER Regional Conference, Park Plaza Hotel, Boston, MA
Email: aer@aerbvi.org
Oct 22 Discover Conference, Perkins School for the Blind—Grousbeck Center—Topic Technology details to follow

Usher Syndrome Family Conference—Friday July 8th

In conjunction with the [Northeast Cochlear Implant Convention](#), Sturbridge, Massachusetts

The [Coalition for Usher Syndrome Research](#), the [Decibels Foundation](#) and the [Usher Syndrome Foundation](#) are proud to sponsor the third family focused Usher syndrome conference in conjunction with the Northeast Cochlear Implant Convention. Come join us to learn the latest on the causes, management, and treatments of Usher syndrome.

About Usher Syndrome

Usher syndrome is a genetic disorder causing various degrees of congenital hearing loss and deafness, a progressive debilitating vision disorder known as retinitis pigmentosa (RP), and in many cases, vestibular dysfunction. Usher syndrome is the leading cause of deaf-blindness in the western world. Hearing aids and cochlear implants are often successful in hearing loss. To date, no proven therapies exist for RP. This presentation offers talks that emphasize both research and living with Usher syndrome

Intended Audience

Families of children and adults with Usher syndrome, ophthalmologists, otolaryngologists, geneticists, genetic counselors, teachers of deaf-blind, and service providers.

Program Objectives

Participants will:

1. Learn about current research and therapies for Usher syndrome.
2. Understand and navigate current and upcoming clinical treatment trials.
3. Network with other families and professional regarding Usher syndrome.
4. Learn about research and treatments for Usher syndrome.
5. Identify strategies for living with Usher syndrome.



Information

Childcare and special requests must be received no later than Friday, July 1st. Travel and accommodation details can be accessed at:

<http://www.neci2011.neciconvention.org/Hotel.php>

For additional questions, contact Krista Scheall at k.scheall@decibelsfoundation

Learn more about the presenters

William J. Kimberling, Ph.D., is a senior scientist at the Boys Town National Research Hospital in Omaha, Nebraska and a professor of Ophthalmology at the University of Iowa, Carver School of Medicine. Dr. Kimberling has published more than 250 scholarly papers on a variety of topics from population cytogenetics to kidney disease. He has recently focused his studies on the genetics of sensory loss, specifically on combined vision and hearing loss, including Usher syndrome. His laboratory has been responsible for the identification and characterization of several genes that cause Usher syndrome.

Heidi Rehm, Ph.D., is a board-certified clinical molecular geneticist, Director of the Laboratory for Molecular Medicine at the Partners Center for Personalized Genetic Medicine and Assistant Professor of Pathology at Harvard Medical School. She studies genetic hearing loss and Usher syndrome and has developed novel approaches to molecular diagnostic testing including a recent test called the OtoChip for identifying a genetic cause of hearing loss or Usher syndrome

(<http://pcpgm.partners.org/lmm/tests/hearing-loss/OtoChip>). Dr. Rehm has also created many resources to help educate physicians and families about the genetic causes of hearing loss.

Mark Dunning is the father of a daughter with a profound hearing loss, a by-product of Usher syndrome. He is also a founding member of the Coalition for Usher Syndrome Research, the President and co-founder of the Decibels Foundation, a member of the Board of Directors for the Hear See Hope Foundation, and the IT Director for L.E.K. Consulting, a global strategic consulting firm.





The Deafblind Advisor Training Project

ADDRESSING THE NEEDS OF INDIVIDUALS WITH DEAFBLINDNESS (B-21 YRS)

Deafblindness is a unique disability requiring that team members have knowledge and skills about the impact of dual sensory losses on learning. The Deafblind Advisor Training Project will provide participants with in-depth knowledge and skills in the fields of deafblindness and multiple disabilities, addressing topics related to: Language/communication, motor development, orientation and mobility, and access to the general education curriculum.



**This Project Runs from
Spring 2012—Spring 2013**


Project Requirements:

DB Advisors must commit to the two year training project by attending 3, 2-day training modules at Perkins School for the Blind, interim phone/video conferences, and a final portfolio. Also, DB Advisors will submit data regarding:

- (1) pre and post self-rating report
- (2) vision, hearing, communication, and classroom environmental assessments
- (3) family interview and needs assessment

All DB Advisors will be required to have direct access to a child who has combined vision and hearing losses for direct observation, assessment, and program development.

NEC is in the process of pursuing graduate credit opportunities. At least forty-eight Professional Development Points will be offered.

 * CEU's will be offered in CT only.



The key goals of this project are to:

- (1) facilitate a "community of practice" in the field of deafblindness in the states of CT, ME, MA, NH that encourages the sharing of information about effective practices in deafblind education
- (2) provide collegial support to staff working with children and youth who are deafblind
- (3) increase the number of personnel trained in the field of deafblindness within the New England region
- (4) support team consultation and instate training to team members and state agencies, and
- (5) develop state action plans and conduct state activities to address the technical assistance needs of children who are deafblind, their families and service providers



For further information:

Contact Tracy Evans Luiselli at nec@perkins.org, or download the application at www.necdbp.org and fax it to 617-972-7354

Fall On-Line Deafblind Intervener Training Courses

A preservice online training program in deafblindness is now available through Utah State University. Based on the National Intervener Competencies, the courses are designed to prepare paraprofessionals to work as interveners with children and youth who are deafblind. It can also be useful to teachers, parents, administrators, and adult service providers. This coursework won the 2007 Blackboard Greenhouse Exemplary Course Award, which recognizes it as one of the top ten online courses in the country. Classes have been offered since Fall 2009. The deafblind coursework is designed to be taken consecutively beginning with Introduction to Deafblindness.



Undergraduate Credit:

- COMD 4660 Introduction to Deafblindness (4 credits)
- COMD 4840 Vision and Hearing Loss (4 credits)
- COMD 4250 Practicum Work Study (2 credits)

Graduate Credit

- COMD 6660 Introduction to Deafblindness (4 credits)

COMD 6840 Children with Vision and Hearing Loss (4 credits)

The following options are available to interested students:

Option 1: Students can take the training program in deafblindness that consists of two 4-semester credit hour classes to be offered in the Fall and the Spring.

Undergraduate tuition is \$227/credit hour with no out-of-state fees. Upon successful completion of the coursework students will be awarded a certificate of completion from USU. These courses can also be taken for Graduate credit at \$288/credit hour.

Option 2: Students can take the coursework as part of an Associate's Degree program in General Studies with a Focus in Deafblindness. This online program includes 30 semester hours of general education classes and 30 hours of coursework that includes the deafblind classes and other related topics.

Undergraduate tuition is \$227/credit hour with no out-of-state fees.

Option 3: Students can take the two-course training program on a non-credit basis for \$110/credit hour with no Out-of-state fees. Upon successful completion of the coursework, students will receive a certificate of completion from USU. *If you choose to take the course for non-credit, contact Fran Payne (435) 797-5591 or fran.payne@usu.edu, for a non-credit registration form.

HOW TO REGISTER:

NEC will be pre-selecting candidates from CT, MA, ME & NH and will cover tuition costs. Please send your applications to NEC requesting a selection. For an application visit our website at www.necdbp.org and Fax 617-972-7354 or email NEC@Perkins.org with your completed request for acceptance to NEC/Attn: Tracy.

I	ndependence	The Intervener fosters independence, encourages and teaches direct interactions.
N	ot For	The Intervener does activities " <u>with</u> " the student. Involves the student in everything to the fullest extent possible.
T	rust	The Intervener establishes and maintains a trusting, interactive relationship with the individual.
E	yes & ears	The Intervener provides consistent access to visual and auditory information.
R	esponsive	The Intervener structures her reactions appropriately, encourages and acknowledges all communication attempts, and fosters an environment that is reactive, <u>NOT</u> directive.
V	igilant	The Intervener is watchful, alert and observant of the individual, their actions and nonverbal communication.
E	stablishes a bond	The Intervener takes time to establish a bond with the individual. A Trusting and safe relationship is the foundation from which learning and growth can occur.
N	ever	The Intervener never says "never." She believes in her student's ability to learn and communicate. The Intervener explores and tries all options of Intervention, techniques and strategies. The Intervener networks with other professionals, is open to new ideas and continues learning from and sharing with others.
E	mpowers	The Intervener always encourages the individual to be active participants in the world, have opportunities to problem solve and gives them control over their lives.
R	espect	The Intervener gives respect and teaches respect. The Intervener shows respect by remembering each individual is unique; takes time to know the individuals method of communication (including their likes and dislikes); Takes time to plan activities to do "with" the individual; is flexible enough to follow the individual's lead; is patient; listens with their ears, eyes and heart; is creative; and knows how to have fun!

By Cheryl Levasseur, Gardner MA Cherlv9@aol.com

Supporting
Parent
Access to
Resources,
Knowledge,
Linkages, and
Education

Project SPARKLE Boot Camp

Join us for SPARKLE Boot Camp! Friday, July 8th from 10 am—3 pm.

This will be a fun filled afternoon exploring the Project SPARKLE website and reviewing the Project SPARKLE Guide Book materials.

Let us help you get started! This day will be hosted by Susan Hollis, Parent of 2 children and NH Family Specialist for the New Hampshire Deafblind Project and Christine Martin the Educational Consultant for the NH Deafblind Project.

We will complete the SPARKLE pre-test, review the modules, and start your child's profile section

This SPARKLE website includes topics on Deafblindness, Vision, Hearing, Touch, and Concept Development.

SPARKLE is a unique training program that is designed specifically for families of children and youth who are deafblind to use in their homes. You will be able to use this information at your convenience at home whenever its convenient for you. This program is designed to help you apply what you've learned to better address your child's developmental and educational needs.



This is a FREE Event for registered NEC families!

Please bring your SPARKLE Guidebook with you, (Please notify us if you need a binder)

A light lunch will served.

Location:
ATECH Services
Training Room
57 Regional Dr.
Concord, NH
Contact: Susan Hollis
Email:
snbhollis@yahoo.com

Not currently participating in Project SPARKLE? If you would like to become part of this great project contact Tracy Evans Luiselli at 617-972-7517 or Tracy.Luiselli@Perkins.org

INSITE Training Coming Soon

The **INSITE** Curriculum consists of a two-volume manual containing home-based programming for families of deaf-blind and other children who are multi-sensory impaired, and a copy of the **INSITE** Developmental Checklist.

Volume I contains information for the role of the parent advisors, and the INSITE communication and hearing programs. The sections outline information on psycho-emotional support; supportive services; home visit planning; delivery/reporting and getting started.

Volume II contains the INSITE curriculum vision, cognition, and motor impairments programs. It also contains a Developmental Resource Section providing information to parents in the areas of gross motor, fine motor, self-help, and social-emotional development.

4-Day Training Agenda Includes:

- INSITE Overview & Family-Centered
- Principles & INSITE checklist
- Simulation Experiences
- Characteristics/Needs of MDSI Children
- Early Communication, Informal and Formal
- Creating a Communicative Environment
- Part I (Bonding)/Part II (Cognition/Play)
- Augmentative Communication Options
- Anatomy/function of hearing mechanism
- Audiological testing/managing hearing aids
- Assessing/teaching auditory skills
- Anatomy/function of vision mechanism
- Medical aspects/implication of eye conditions
- Assessing/teaching visual skills
- Normal/abnormal motor development
- Posture and Movement disorders
- Learning through touch

Participants must commit to:

- Attend all sessions of training
- Purchase two training manuals, (*EI Staff will receive discounted materials*)
 - HOPE, Inc materials cost \$141.63 – Payable to Hope, <http://www.hopepubl.com/> (*Price is not final*)
 - Home study manual cost \$50.00. (**Payable to Perkins.**)
- Complete home study assignments.

NEC will assume your registration is a firm commitment to attend the training.

Registration is limited to 36 individuals; we must have 26 participants to offer the workshop. NEC reserves the right to limit the number of staff attending from one program.

Priority will be given to persons working in programs with young children who have a combined vision and hearing impairment, and who are registered with NEC.

Participants can register to receive:

- Credit from UMass Boston
- 40 Professional Development Point's
- EI Specialists can use INSITE curriculum and assignments to meet some DPH CEIS Portfolio requirements in Entries 1, 2, 3 & 4. Upon completion of this training, the following Entry 1 competency indicators will be awarded: 1.2, 1.3, 1.4, 1.6, 1.7, 2.2, 2.3, 2.4, 2.6, 2.8, 2.9, 3.1, 3.2, 3.3, 3.4, 5.2, 5.3, 5.5, 6.1, 6.2, 6.3, 6.4, 6.5, 6.6, 6.7, 6.8, 6.9, 6.10, 6.11, 7.3, 7.6.

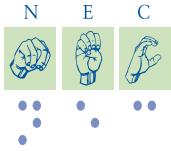
A Home Intervention Model for Families of Infants, Toddlers, and Pre-school Aged Children with Sensory Impairments and Additional Disabilities.

PURPOSE:

To provide effective delivery of the INSITE Home Program model to children who have a sensory impairment with at least one additional disability:

- Early Intervention (EI) Specialists at all levels of experience.
- Early Intervention (EI) Clinicians working toward certification
- Parents

For further information:
Contact Tracy Evans Luiselli at nec@perkins.org



New England Consortium of Deafblind Projects

Regional Office: 175 North Beacon Street, Watertown, MA 02472

Phone: 617-972-7515 ■ Fax: 617-972-7354
■ E-mail: NEC@Perkins.org ■ www.necdbp.org

MA Deafblind Project

Affiliated Agency:
Perkins School f/t Blind
175 North Beacon Street
Watertown, MA 02472
617-972-7516
Tracy Luiselli
Tracy.luiselli@perkins.org

NH Deafblind Project

Affiliated Agency:
ATECH Services
7 Regional Dr., Suite 7
Concord, NH 03301
603-226-2900
Christine Martin
christinem@atechservices.org

CT Deafblind Project

Affiliated Agency :
BESB-Board of Educational
Services for the Blind
184 Windsor Ave
Windsor, CT 06095
800-842-4510
Karen Olson
karen.olson@ct.gov

ME Deafblind Project

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

New England Consortium of Deafblind Projects

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(IDEA)"
