

# IN TOUCH



## NEW ENGLAND CONSORTIUM OF DEAFBLIND PROJECTS

### Summer Fun Has Just Begun!

By Tracy Evans Luiselli, Project Director, New England Consortium

Here's wishing our families and colleagues a fun, relaxing and healthy summer! It's wonderful to have a reprieve from ice storms and snow shoveling. As the weather heats up we finally have more opportunities to get outside and play. Take a look inside our newsletter to gather ideas on how to have fun outdoors within your community and strategies to support literacy and communication when you're "on the go". Most importantly, we hope you have an opportunity this summer to step back, have fun, and enjoy your child/student's growth and successes.

As for our grant activities, we are carrying on with the following:

**DB Advisor Training Project:** Together with the states of Connecticut, Maine, Massachusetts, New Hampshire and Vermont, we recently completed a second face-to-face training (see picture simulation above) involving 44 DB Advisors focusing on the important aspects of communication within natural conversations and connections. We were fortunate to have Barbara Miles (Vermont), Chris Jett (Massachusetts), Sharon Stelzer and Bethany Provost (Perkins/Deafblind Program) present on strategies to develop and support conversations, and presymbolic/symbolic communication.

Chris Jett spoke about his own life experiences and challenges learning Tadoma, sign language and Braille. Chris encouraged us

to keep trying and emphasized patience and perseverance in our work with children who have combined vision and hearing losses. The next fall session in October 09 will continue to address the topic of communication.

**Envision Conference:** During March 09, NEC collaborated with Perkins School for the Blind, the National Consortium on Deafblindness (NCDB), and the National Association of Parents of Children with Visual Impairments (NAPVI) regarding the conference - *ENVISION the Future... Transition from School to Adult Life.*

Dr. Jerry Petroff offered a wealth of information regarding strategies for successful transition from school to adult life for youth with deafblindness. Also, Dave Power, a parent of a young man who is deafblind, presented his suggestions for parents (page 7) regarding the transition process and key steps to success. Recently, Dave Power has been instrumental in organizing parents of children and adults in Massachusetts to ensure that necessary supports and services are secured in the Massachusetts state budget. Dave's efforts and effectiveness remind us of the importance of parent voices and connecting with legislators to advocate for critical services for individuals who are deafblind, one of our most vulnerable populations. Thanks Dave - you've been an inspiration to us all!

**NEC Family Phone Network:** We have conducted four monthly phone conferences this year as part of our series - NEC Family Phone Network. Dr. Debbie

Chase, a licensed psychologist and mother of a young woman with vision and hearing loss, has lead the calls and facilitated discussion around the following topics:

1. Getting out of the House, Going to the Grocery Store and Connecting with My Community
2. How to Support Inclusion at School, in My Community and Within My Family
3. Being on the Outside and Looking In: Combating Isolation
4. Summer Time: Can I Make the Living Easier

As the NEC Family Phone Network evolves - we welcome your suggestions for topics that might be of help. Please contact Debbie Chase at [lifespah@verizon.net](mailto:lifespah@verizon.net) and send her your suggestions.

Along with the enclosed "Save the Dates", (page 18) please stay tuned for some important training opportunities coming your way:

- ◆ Parent Leadership Training Series
- ◆ State Family Activities (apple picking)
- ◆ NEC Family Phone Network
- ◆ Training on the new Deafblind Guidelines in each state
- ◆ Intervener Training: The Role of the Intervener and Possible Training Models for Your State

**Best Wishes for a Terrific Summer with Family and Friends!**

### Volume 6, Issue 6

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**Deafblind Advisor Training Simulation Activity**



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## Deanna's Journey

*By Jessica Conte-Falcone M.Ed, Deafblind Itinerant Teacher, Worcester Public Schools 6/9/09*

Deanna Turner is a six year old inclusion student in the first grade attending Quinsigamond Elementary School in Worcester, Massachusetts. Deanna was born with a visual impairment, known as Leber's Amaurosis and recently started losing her hearing rapidly just last year. When I began with Deanna in September of 2008, she had no exposure to sign language. I began teaching her the fundamentals which included conversational signs, basic communication, signs pertaining to her daily schedule, letters of the alphabet and numbers up to 10. In addition to this, she needed to learn how to become aware of her surroundings as a deafblind individual by using tactual awareness. Deanna already had a language base since she had just recently lost her hearing. At that time, she was unable to learn new words due to her profound hearing loss. Therefore, sign language and total communication would be the best option for her. Once exposed to these signs, Deanna would repeat them and use them on her own and without prompting.

Her team included a Deafblind Itinerant

Teacher, a classroom teacher, a one-on-one assistant, Physical Therapist, Occupational Therapist, Speech Pathologist, Principal, SPED Chair Person, APE Teacher, Audiologist and Mobility Instructor. Most of the team had no knowledge of sign language nor had ever worked with a deafblind child like Deanna. In order to help the team work with her, Deanna and I developed a CD that depicted her using signs she knew and her individual communication style. Deanna was a star of her own sign show and enjoyed watching herself on the screen! She began to understand her need to communicate with others who do not sign. Once her skills grew and her sign language comprehension increased, I introduced her to more signs and also put them together to form phrases. An intern from Holy Cross College, Lauren Donovan, was able to put together the second CD for the team as part of her project. She signed phrases and put signs together to help the team as well as additional academic signs, such as numbers up to 31, animals, temperature/weather, days of the week etc....

At this time, Deanna's use of sign language has increased significantly. She is able to communicate her wants and needs appropriately and without frustration. She is more

receptive to tactual sign language and is eager to learn more. Deanna is able to sign the letters of the alphabet and numbers up to 31. She has a countless understanding of signs.



**Deanna at the computer**

When taught a sign, she is able to mimic it, use it accordingly and without prompting. On June 12th, Deanna received a cochlear implant. We are hoping that this change will benefit her and eventually she will be able to use her speech and her hearing as she has in the past. Deanna has come so far in such a short time and we are so proud of her!

To view Deanna's CD go to the NEC website and [www.necdbp.org](http://www.necdbp.org) and click on the resources page. ■

## Chris Jett Speaks at the State House

*By Christopher Jett, Consumer*

*Below is his speech to help restore deafblind funds for the state of Massachusetts.*

I feel honored to stand before you today to give Massachusetts Commission for the Blind my support. For those who do not know me, my name is Christopher Jett and I am here today on the behalf of individuals who are deafblind to give you an example of why we are here today.

To the Senators and State Representatives, I am an educated young man who is deafblind and I have the intelligence and capabilities to be a contributing citizen of Massachusetts. I am an active member of the Massachusetts community. I have an apartment in Newton, I work part time and I am a registered voter.

Without the support of the Deafblind Unit at Massachusetts Commission for the Blind and their skilled staff that understand the needs of adults who are deafblind, the Senators and State Representatives are convicting many

deafblind adults to a life of isolation, possibly darkness and silence. The staff in the Deafblind unit have the unique experience and knowledge necessary to know how best to support people who are deafblind.

They know what kind of equipment that is available to us and how to use it. They understand how to make a home or work space more accessible. They know sign language and the importance of communication for individuals who are deafblind. They know the importance of having the opportunity to work and how to adapt jobs so that deafblind people can contribute to their community. The staff who work in the deafblind unit at MCB possess the specialized skills to train others regarding the needs of deafblind individuals and their support has helped many deafblind individuals to be successful.

If it weren't for Massachusetts Commission for the Blind, then it would have not been possible for me to have the capacity and the desire to succeed and to be an active member of the Massachusetts community. Without



**Chris Jett at the Podium with translator**

their continued support I fear that I and others who are deafblind may no longer be able to be successful.

I strongly urge for Massachusetts Commission for the Blind, to remain an independent agency. To the Senators and State Representatives, please restore the funds for the line items 4110-2000. I invite you to come forward to introduce yourselves so we can talk personally.

Thank you all for coming and it was my pleasure to be here today. ■

## Staying Strong in Silence

### Budget cuts remove support for deaf-blind individuals

By Daniel Castro, *THE GARDNER NEWS*

GARDNER - Struggling for sight, this reporter could barely make out the hazy outline of the figures in front of him, and with their voices barely audible, all sense of where he was and how to communicate his discomfort quickly diminished.

It was the most vulnerable this reporter has ever felt, and this is what deaf-blind individuals face every day of their lives.

Yet deaf-blind citizens in Massachusetts may be put in an even greater position of vulnerability with Gov. Deval Patrick's proposed 7 percent cut to the Massachusetts Commission for the Blind for fiscal 2010, and the elimination of Account 4110-2000, a budget line item that provides dedicated funding to support deaf-blind adults and the care providers through the families and guardians that support them — like the Levasseurs.

Glenn Lavallee with his parents, Roger and Cheryl Levasseur.



Less than a minute earlier, this reporter had been greeted with a smile by Roger Levasseur at the door of his family's home, where this reporter would be interviewing his wife, Cheryl, and their deaf-blind foster son, Glenn Lavallee.

"Cheryl has one request before you meet Glenn," he said, showing this reporter earplugs, industrial sound dampeners, and a makeshift bubble wrap blindfold that was intended to significantly blur vision.

Although part of this reporter was reluctant, he had corresponded with Ms. Levasseur enough before that he had trusted them — and since learning about her son this reporter had become curious about his own ability to endure through the difficulties of being both deaf and blind.

Mr. Lavallee is 37 years old, and was born with CHARGE syndrome — a recognizable genetic pattern of birth defects that occurs in one in every 9,000-10,000 births worldwide, according to the CHARGE Syndrome Foundation. As a result, he has multiple sensory disabilities that include deafblindness and issues with the senses of balance, touch, temperature, pain and smell — along with other complex chronic medical issues.

Under deaf-blind simulation, this reporter was lead around a tour of the Levasseurs home, directed over steps and through hallways — all the while relying on the faint voices that assured he would be safe.

Ms. Levasseur explained how she had created a home for Mr. Lavallee as his home care provider and intervener for the past 12 years, where he has shared his life with her, her husband, and her stepson. "I consider Glenn my son," she said, calling him "a loving and amazing family member."

Throughout the tour, this reporter was explained the various devices Mr. Lavallee depends on — an adapted alarm system that vibrates the bed to alert him if there is smoke or carbon monoxide, flashing lights that correspond to the phone ringing or a knock at the door, along with specialized computer software — all items provided by

the Commission for the Blind "and necessary for Glenn's safety and to be able to access his world," according to Ms. Levasseur.

"Deaf-blindness is a disability of access; access to auditory and visual information that most of us receive effortlessly," Mrs. Levasseur explained, "Individuals with deaf-blindness often use nonverbal means of communication including, but not limited to sign language, tactile sign, gestures, touch cues and augmented communication systems."

When this reporter met Mr. Lavallee for the first time, all he saw was his silhouette in the light, and though this reporter could hear the sound of Mr. Lavallee's voice, he could not make out his words.

"It's nice to meet you, Glenn!" this reporter said, or most likely yelled. Though everything was blurred, this reporter saw Mr. Lavallee's hands reaching out, and instinctively this reporter extended his. They met somewhere in the middle.

Mr. Lavallee receives residential and day program funding from the commission, which through their deaf-blind unit also provides specialized services, including advocacy, support, resources and counseling.

With this support, Mr. Lavallee has been able to surmount the obstacles presented by his disabilities and give back to the community; working as janitor for the past 12 years, actively volunteering for the Ahimsa Haven animal rescue, providing animal foster care in the Levasseur's home, serving as an adult mentor for school-age children, and every spring raising money and walking in the Relay for Life to fight cancer.

-Continued to Page 4

## Staying Strong in Silence-Continued from page 3

### Budget cuts remove support for deaf-blind individuals

Yet the proposed budget cuts threaten to consolidate specialized services for the deaf-blind. "I fear that if the state service providers are consolidated, it will dilute the quality services provided for deaf-blind individuals which could have devastating effects," said Mrs. Levasseur. "I believe that by doing so, the specialized and unique services, adaptive equipment and competent staff needed for the minority of deaf-blind individuals will succumb to the needs of the majority."

Mrs. Levasseur compared this consolidation to going to have eye surgery or cancer treatment through a primary care physician instead of through the eye surgeon or cancer treatment center. "Would you do that to your family member? Services will become so generic," she emphasized.

In addition to the Commission for the Blind, which has been in operation through both world wars, the commonwealth has a legacy of educating and supporting deaf-blind individuals, said Steven Rothstein, president of the Perkins School For the Blind, where Helen Keller was formally educated in the 1880s.

"It's important to have a separate line item for individuals who are deaf and blind, because with the proper support and education they have so much potential," said Mr. Rothstein, who said that although Ms. Keller's own father had called her

"uneducable," with dedicated support she was able to go on to do great things.

"By helping individuals to be independent, to be self-supporting, many have been able to continue being an active member in society," Mr. Rothstein said.

In line with this, Mrs. Levasseur added that she felt the state would be "moving in the wrong direction by cutting, eliminating, or trying to consolidate" these support services.

"The Legislature should look at the process of providing services," she said, noting there "are plenty of ways to lower and cut costs while simultaneously providing the appropriate level of support."

One of these methods could potentially include looking at the way day programs are still set up based on the "large group institutional model," according to Mrs. Levasseur.

"This 'one size fits all' warehouse model is not appropriate for many individuals, especially deaf-blind individuals," she added, explaining that if day services were provided at home, individuals could be more comfortable, services normalized, and "day program's rent, utilities, maintenance, company paid cars and vans, and other associated costs would not be an issue because the services would be provided in the individuals home (and) community."

State Rep. Jennifer Flanagan, who has also visited the Levasseurs' home, saw for herself that "Glenn's foster parents do a great job," but explained that providing level funding for the commission and restoring the line item for the deaf-blind "is all a question of revenue, and where the state is going to get the money," as the cuts are going to affect "almost every realm of services."

Rep. Flanagan did say the Senate was putting together their own budget and their own proposal, that could differ greatly from Gov. Patrick's.

While this reporter's own experience with deaf-blindness could be removed quickly, Mr. Lavalley depends on the continued state support, and his foster family's ability to keep providing him with one-on-one care — a task that Mrs. Levasseur said was already stretching them thin financially.

Despite the challenges, Mr. Rothstein emphasized that "on a philosophical level, we in society should be judged on what we're doing for those who need our support, because they can do great things."

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## More Information About Deafblindness

[DB-LINK](#) - Perkins School for the Blind, in partnership with the Teaching Research Institute and the Helen Keller National Center, operates DB-LINK at the National Consortium on Deaf-Blindness. DB-LINK is the largest collection of information related to deaf-blindness worldwide. Contact us by phone: 800-438-9376 by TTY: 800-854-7013 by fax: 503.838.8150 or by [email](mailto:email@nationaldb.org) at [info@nationaldb.org](mailto:info@nationaldb.org).

[The New England Consortium of Deafblind Projects \(NEC\)](#) - With a central office on Perkins' campus, we provide technical assistance to children who are deafblind in Connecticut, Maine, Massachusetts and New Hampshire, as well as to their families and educational programs. Contact us at 617-972-7515 or [NEC@Perkins.org](mailto:NEC@Perkins.org).

[Deafblindness: Educational Service Guidelines](#) - Available from Perkins Publications, this text is a best practice guide for educational administrators at the state, local, and program levels. Call 617-972-7308

## 2009 NE/AER Fall Conference



**Hartford Marriot**  
**200 Columbus Blvd.,**  
**Hartford, Connecticut**  
**November 4th - 6th, 2009**



### Opening Keynote Speaker: Dr. Raymond Mis

Dr. Raymond Mis, a gastroenterologist from Rhode Island, lost his central vision to a condition called optic nerve atrophy, and was eventually declared legally blind. His doctors and colleagues thought it would be impossible for him to continue his practice. "Loving the practice of gastroenterology, I refused to give up," said Dr. Mis.

Despite being legally blind, hearing impaired, and faced with the potential loss of his career, Dr. Mis overcame significant odds to continue practicing medicine. He voluntarily stopped performing endoscopic procedures but continued to see patients, and relied on his staff to read charts and medical records for him. Eight months later, his partner left the practice, leaving him to cope alone. Dr. Mis overcame these setbacks, eventually regaining his life, career, and independence back.

With the help of modern technology, Dr. Mis discovered a video monitor, which if he sat close enough to it, could correct his vision loss to 20/25. As part of a re-credentialing process, Dr. Mis had to perform 60 supervised procedures in order to be deemed a safe practitioner. On April 18, 2002, Dr. Mis became the first visually impaired gastroenterologist to receive accreditation by the State of Rhode Island and the Rhode Island Medical Society, paving the way for other professionals with physical limitations.

Currently approaching the completion of his memoir entitled, "Blind Sighted," Dr. Mis travels the country as an inspirational speaker sharing his story of courage and hope to people with disabilities. Additionally, he has delivered inspirational keynote speeches at medical conventions, various organizations, hospitals and nursing groups.

Dr. Mis teaches medicine at the New England College of Osteopathic Medicine and is chief of the gastroenterology department at Kent County Memorial Hospital in Warwick, RI. He was named one of the top gastroenterologists in the state by Rhode Island Magazine in 2000 and 2007 ■

To register contact: Lori Cornelius, BESB, 184 Windsor Ave., Windsor, CT 06095, (E-mail: [Lcvision@aol.com](mailto:Lcvision@aol.com) with questions) Fax: 860-602-4030, Must be received **ONE MONTH** prior to the registration deadline set by the event. Download registration form at <http://www.neaer.umb.edu/?page=conference>

## Watch your mail for our Annual Survey

*By Cheryl Harvey, Project Assistant*

Please watch the mail for our annual survey. We need your help in deciding what Technical Assistance you need. Our survey will ask a few questions and your responses will help determine our direction for the next year. Please take a minute and reply. I will also post the survey on our website at [www.necdbp.org](http://www.necdbp.org).



## Connecticut in the News

*Taken from the CPAC website*  
[www.cpacinc.org](http://www.cpacinc.org)

### 6th Annual CPAC Friends and Family Summer Picnic

On Saturday, July 18th CPAC will hold its annual friends and family summer picnic! Families are invited for food, fun and time at the beach at Camp Harkness in Waterford, Connecticut. (860) 739-3089 V/TDD Toll Free 1-800-445-CPAC

### Virtual Learning Academy Available This Summer for Students

This summer CREC will be offering an online opportunity for students wishing to recover

credits. The five-week online program will utilize the Virtual Learning Academy, an online tool currently being used in schools. Students will take the classes completely online using their home computer. CREC teachers will monitor student progress, grade their lessons, and provide a final transcript to the student's school. Students can take one, two or three courses, earning 1/2 credit. The program will run July 6th through August 7th.

Courses offered include:

- ◆ English/Language Arts I and II
- ◆ English/Language Arts III and IV
- ◆ Physical Science
- ◆ Biology

- ◆ World History
- ◆ US History
- ◆ Government
- ◆ Algebra I
- ◆ Algebra II
- ◆ Geometry

The cost to participate is based on the number of courses a student is enrolled in. Student must complete all assignments (18 units per course) in order to receive a numerical grade and course credit.

For more information and to register for summer school, please visit [www.crec.org](http://www.crec.org) Please contact Cara Hart at 860-524-4021 or [chart@crec.org](mailto:chart@crec.org) if you have any questions. ■

## Maine: Accessible Recreation, Arts & Leisure

*Taken from [www.Maine.gov](http://www.Maine.gov) website*

What do we mean by "accessible recreation, arts and leisure"? This site contains listings of facilities and organizations that have made an effort to create physical and/or programmatic accessibility to the greatest number of people — including people with disabilities, elderly, and others. Accessibility is often thought of in terms of wheelchair access, but can include much more than that. It means incorporating "universal" access and creating opportunities so that people with a wide range of needs (deaf/hard of hearing, blind/visually impaired, etc.) can also enjoy the wealth of leisure activities that Maine has to

offer.

This Accessible Recreation, Arts and Leisure guide presents information about recreational opportunities available to people with disabilities in Maine. The level of access and/or compliance with regulatory mandates for public accommodations has not been verified; the information has been provided by the listed organization. Calling ahead for specific accessibility information is highly recommended.

Accessible Activities (Go to the website and select an activity below to learn more)

- ◆ Beaches

- ◆ Boating
- ◆ Hiking and Camping
- ◆ Horseback Riding
- ◆ Hunting and Fishing
- ◆ Museums and Historic Sites
- ◆ Other Sports
- ◆ Skiing
- ◆ Spectator Sports/Entertainment
- ◆ Summer Camps
- ◆ Swimming Pools
- ◆ Transportation (Recreational) ■

## Maine Parent Federations 25th Anniversary Gala

*Taken from the Maine Parent Federation Website [www.MPF.org](http://www.MPF.org)*

October 2 & 3, 2009 Save the Date!  
**Maine Parent Federation's 25th Anniversary Gala & Celebrating the Family Conference** Wyndham Portland Airport Hotel, South Portland, ME

Keynote Address by Jack Levine, Founder of 4Generations Institute and President of Advocacy Resources. Friday evening dinner,

awards, silent auction, and dancing with The Tony Boffa Band!

Two full days of workshops on Early Childhood, Parent Involvement, Family Support, Special Education, and more.

**The Maine Parent Federation, Inc.** is a statewide private non-profit organization that provides information, advocacy, education, and training to parents and professionals to benefit all children. We promote individual aspirations and community inclusion for peo-

ple with disabilities. In existence since 1984, MPF is physically located in Augusta Maine, but assistance is available on a statewide basis. MPF services are offered at no cost to parents and a small fee for professionals.

Through our projects, individuals can receive information about: specific disabilities, parenting issues, education, services, support groups and other resources available to assist families and professionals within the home, school and community. Call 207-623-2144 ■

## New Hampshire in the News

*By Kim Conlon, NH Educational Consultant*

This past spring New Hampshire had a very successful 4 Part Training Series in Deafblindness that was offered in Con-

cord, NH. We had a 'bring your own chair' attitude as registrations kept coming in and the space was filled to capacity (and then some!) Topics included the impact of dual sensory impairments, etiologies, communication, assessment and curriculum (including literacy). For in-

formation on the training series during school year 2009-2010 in New Hampshire, please contact either ATECH Vision and Hearing Services, 603-226-2900 or the NEC office, 617-972-7515.■

## NH Consultant Heads to the Land of the Midnight Sun

*By: Kim Conlon, Educational Consultant, NH*

I wanted to take this opportunity to let everyone know that I am leaving The New England Consortium, ATECH Services and MICE Program as of June 2009 as educational consultant and re-locating with my family to Alaska. My husband received a wonderful job opportunity that we couldn't pass up (nor could we pass up the gorgeous scenery, endless daylight in summer, dog sledding and skiing in the winter, hiking,

boating ...) To all the families and school teams that I have come in contact with throughout my career both as a teacher at Perkins School for the Blind in the Deafblind Program and as an educational consultant in New Hampshire, I would like to say thank you for allowing me to share in your journey with your child/student. Every individual with dual sensory impairments that I have met has taught me something unique about deafblindness, themselves, myself and most of all, what is important in life. It is with great sadness that I am leaving New England and

all of my personal and professional relationships. Please know that a piece of every child with deafblindness will be traveling with me

*“So long to Kim—Thanks for all your expertise and support!”*

in the next great adventure of my life.■

## Northeast Passage-Innovative Therapeutic Recreation in NH

*Taken from the Northeast Passage Website [www.nepassage.org](http://www.nepassage.org)*

The mission of Northeast Passage is to create an environment where individuals with disabilities can recreate with the same freedom of choice, quality of life, and independence as their non-disabled peers.

We do this by developing, delivering, and evaluating innovative barrier-free recreation and health promotion programs. Our guiding principles are promoting client independence through education and problem solving, creating opportunities, and collaborating with others to create a strong network of accessible recreation.

### History

Northeast Passage (NEP) was founded in 1990 as a private non-profit organization. In March of 2000, after years of successful collaboration, NEP officially merged with the University of New Hampshire as the service branch of the Recreation Management and Policy Department within the College of Health and Human Services.

### Philosophy

Listen carefully to consumers needs, think creatively to solve problems, attend to details, work as a team and explore the possibilities! Check out their website for a schedule of events or call them at 603-862-0070 TTY NH Relay 800-735-2964 ME Relay 207-955-3323■



**Adaptive Kayaking**

## Massachusetts Deafblind Family Leadership and Advocacy Award

By Tracy Evans Luiselli

***Congratulations to Lorraine Wales for receiving the first Advocate award at the State House on May 14<sup>th</sup> for her work for all learners who are deaf-blind.***

It is with heartfelt gratitude that the Massachusetts Deafblind Coalition acknowledges Lorraine Wales and her son Michael Garvey. As a team, they have inspired other families and professionals to reach for the stars and create new op-

portunities for individuals who are deaf-blind, at home and in the community. Lorraine's quiet determination to be "at the table" and remind others about what matters most for a mom and her son in navigating the complex service delivery systems is a model for so many others on this journey. In fact, Lorraine's voice and advocacy has directly influenced the decisions of policy makers and legislators in Massachusetts. On so many occasions, Lorraine has been able to clearly communicate her wishes for Michael in a thoughtful and

effective manner. Lorraine and Michael – thanks so much for your dedication, will-

***“Optimism is the faith that leads to achievement. Nothing can be done without hope and confidence. (Helen Keller)***

ingness to help organize others, energy and humor.■

## Massachusetts in the News

By Susan DeCaluwe, MA Educational Consultant, NEC

This past winter and spring MADBP (MA Deafblind Project) worked diligently with parents of transition age students to contact their state senators and representatives' (during this very difficult fiscal period) to maintain the turning 22 monies allocated for students who are deafblind transitioning into adult services. Line item 4110-2000 was initially cut from the governors FY 2010 budget, but recommended to be restored by the House Ways and Means budget and maintained by the Senate Ways and Means budget. The line items once again are being reviewed by a Joint Committee of both members of the House and Senate and a final budget will be submitted to the governor for his final approval. The parents joined forces to create a portfolio of the faces

and stories of MA Deafblind Citizens to share with their representatives describing the impact of the line item 4110-2000.

Also, this past fall at the Murdock Middle HS in Winchendon and this past spring at the Murphy School in Boston, we had a very successful 4 Part Training Series in Deafblindness. Each series (FREE OF CHARGE) covered the topics of the impact of dual sensory (vision and hearing) impairments on learning, etiologies, communication, role of the intervener, assessment and curriculum. If you are interested in learning more about scheduling a deafblind training series in your area and obtain PDP's please contact Susan DeCaluwe at 617-972-7516 [Susan.DeCaluwe@perkins.org](mailto:Susan.DeCaluwe@perkins.org) or go to the [www.necdbp.org](http://www.necdbp.org) website for details.■

## Project Wild

Taken from the Project Wild website [www.mass.gov/dfwele/dfw/education/wild/project\\_wild.htm](http://www.mass.gov/dfwele/dfw/education/wild/project_wild.htm)



An interdisciplinary, conservation and environment education program that emphasizes wildlife, people and the environment. This national program provides supplemental curriculum materials containing over 100 activities for educators of youths in grades K-12.

The goal of Project WILD is to assist learners of any age in developing awareness, knowledge, skills and commitment that will

result in informed decisions, responsible behavior and constructive actions concerning wildlife, people and the environment. The curriculum/activity guide is available only through a 6-hour educator training workshop. Workshops can be scheduled to accommodate your group's or school's in-service training. In Massachusetts, Project WILD is sponsored by MassWildlife. Hours in Project WILD Workshops may be used toward obtaining PDPs. Click on MassWildlife Calendar for a current schedule.

For more info, contact Project WILD Coordinator, Pam Landry at [Pam.Landry@state.ma.us](mailto:Pam.Landry@state.ma.us) or call her at 508/389-6310.

Visit the National Project WILD website for further information.■

# Advocating for a Successful Transition

By Dave Power, Parent, March 14, 2009  
Envision Conference

Dave's PowerPoint Presentation for the Envision Conference at Perkins School for the Blind. Please feel free to use as a guide

## AGENDA

1. Start Early
2. Create a Vision
3. Research and Network
4. My Son David (Profile)
5. You're Never (Completely) Done

## START EARLY

	Months from Transition Date:
1. Create Your Vision	18
2. Talk to Families	12-18
3. Determine State Funding	15
4. Visit Private Agencies	12-15
5. Select Agency	6-12
6. Manage Transition Details	8

- ◆ Find creative partners who share your vision
- ◆ Pass on "one size fits all" programs

- ◆ Talk to Families (Experience with agencies) (future room mates)
- ◆ Use organizations and conferences

NAPVI-(National Association for Parents of Children with Visual Impairments) [www.spedex.com/napvi/](http://www.spedex.com/napvi/),  
NECDBP- (New England Consortium of Deafblind Projects) at [www.necdbp.org](http://www.necdbp.org) and Perkins School for the Blind at [www.perkins.org](http://www.perkins.org)



David Power and Dad, David with brothers and sisters and friends.

## DAVID

David will be active in a community that knows him...

- ◆ Doing volunteer work and things he enjoys, not too far from home...
- ◆ With sidewalk access to stores and public transportation

## CREATE YOUR VISION

- ◆ Person Centered Plan (PCP)
  - ◆ Daily Activities
  - ◆ Jobs/Volunteer Work
  - ◆ Roommates
  - ◆ Community
- ◆ PCP becomes your scorecard
- ◆ Stick with your vision

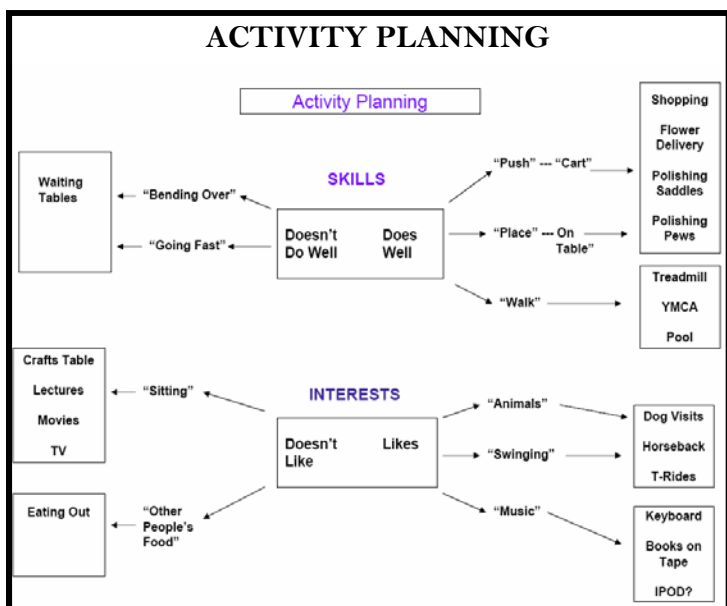
## RESEARCH AND NETWORK

- ◆ Communicate your vision, get help (other people have done this before you)
- ◆ Visit 5-10 private agencies (See DayHab Centers and Residences)

## YOU'RE NEVER (COMPLETELY) DONE

Recruiting and training staff

- ◆ Improving weekly programs
- ◆ Advocating for state agency funding
- ◆ Finding community jobs
- ◆ Helping others families♥



### DAVE'S WEEKLY SCHEDULE

DMP Weekly Schedule

	MON	TUES	WED	THURS	FRI	SAT	SUN
12 AM							
3 AM							
6 AM			Shared Living				
9 AM		Day HAB Program					
12 PM							
3 PM		Volunteer Work, Recreation					
6 PM							
9 PM			Shared Living				
12 AM							

## A Mechanism for Translating Websites

**By: Gail Leslie, National Consortium on Deaf-Blindness** [www.nationaldb.org](http://www.nationaldb.org)

In collaboration with the Statewide Parent Advocacy Network of New Jersey, SPAN, NCDB is able to provide access to a website translation tool from the NCDB website. The tool provides a mechanism for translating websites – English to Spanish or Spanish to English during a browsing session. The tool, Traducelo Ahora, is different from typical translation applications in that it allows users to simply follow the links in the site they want to visit and each page is translated automatically. Most applications require users to return to the original translating site to type

a new URL for each page to be translated. With Traducelo Ahora you can browse to another website and the translations continue. Links to most MSWord or Adobe Acrobat files can also be translated and it also provides for the translation of emails.

As you will see, to use the program requires that you sign up as a user.

But once that is done, Traducelo Ahora will then be available to you for translation at any time. It is important to note that you must use the SPAN password, State and City (Newark) as part of the sign up. This is per their collaborative relationship with IBM, who developed the tool.

Our thanks to Diana Autin and SPAN for sharing this resource. Feel free to also provide access to this tool from your own website pages. Please don't hesitate to call if you have questions.

You can find the instruction on our site at: <http://www.nationaldb.org/ViewInSpanish.php>

You can also get to the instructions from the NCDB home page by using either the link at the top of the page \*En Espanol?\*, or the link in the Site Resources, \*Traducir este sitio de web.\* for additional information contact Leslie at the Teaching Research Institute, (503) 838-8756 or [leslieg@wou.edu](mailto:leslieg@wou.edu) ■

## FREE Reproducible Language and Early Literacy Activities in English and Spanish

**Supporting Early Literacy in Natural Environments Taken from the** [www.wlearning.com](http://www.wlearning.com) website

**Activities for Caregivers and Young Children in English and Spanish**

Developed by Angela Notari-Syverson, Ph.D. and Kristin Rytter, Ph.D, with Judy Chal-loner, Faith Haertig Sadler, Young Sook Lim, Ph.D., Marilyn Sturm, and Rodd Hedlund (2005).

These materials include forty-six home and community activities for adults and children that encourage early language and literacy development in young children.

They are appropriate for children with dis-

abilities as well as children who are developing typically.

Each of the forty-six activities includes three pages: 1) An activity description, 2) Hints for making the activity fun and developmentally appropriate, and 3) A brief self-evaluation form that cues parents and other caregivers to notice their children's skills, and also cue adults to examine and grow their own interactions with children.

The materials are specifically designed to address the three key skills of 1) language development, 2) phonological awareness, and 3) general print awareness.

The files are in PDF format to allow easy and

secure downloading. Five files for each language (Spanish and English) include:

- Table of contents listing the 46 activities
- Level 1 activities (for developmentally younger children)
- Level 2 activities (focus on print)
- Level 3 activities (focus on using more complex language)
- Brief self-evaluation forms for each activity

Dr. Notari-Syverson and colleagues allow the materials to be reproduced and distributed as long as the materials are not sold.

The development of these materials was supported by Grant H324M020084 from the U.S. Department of Education, Office of Special Education Programs. ■

## Resources for Materials in Spanish

**Taken from the Texas School for the Blind and Visually Impaired website** <http://www.tsbvi.edu/Education/>

- Articles in the TSBVI newsletter (TX SenseAbilities, formerly See/Hear) are translated into Spanish and past issues are archived on the website at [www.tsbvi.edu](http://www.tsbvi.edu). You can also do a site search for specific topics.
- "Materials in Spanish for Families of and Interventionists Serving Young Children

Who are Blind, Visually Impaired, and Deaf-blind", in the Summer 2000 issue, <http://www.tsbvi.edu/Outreach/seehear/summer00/spanish.htm>, that lists resources.

- NICHCY (National Clearinghouse for Children & Youth with Disabilities) has several articles in Spanish online at [nichcy.org](http://nichcy.org)
- Watch Me Grow--This Spanish/English book contains month to month suggestions for assisting the development of a child who is

blind or visually impaired from birth to age three. Blind Children's Fund [http://www.blindchildrensfund.org/products/fund\\_materials.asp](http://www.blindchildrensfund.org/products/fund_materials.asp)

- Blind Children's Center, <http://www.blindchildrenscenter.org/index.htm> has several booklets available in Spanish.
- National Eye Institute <http://www.nei.nih.gov/health/espanol/> ■

# Activities for Caregivers and Young Children

Taken from [www.walearning.com](http://www.walearning.com) website and edited by NEC for parents and caregivers of children with vision and hearing losses

## GOING TO THE GROCERY STORE

Developed by Angela Notari-Syverson, Ph.D. and Kristin Rytter, Ph.D. with Judy Challoner, Faith Haertig Sadler, Young Sook Lim, Ph.D., Marilyn Sturm, and Rodd Hedlund (2005).

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When you go to the grocery store with your child, you can:

- ◆ Point to, read and sign items to your child.
- ◆ Show your child the things on your grocery list one at a time and have your child help you find them.
- ◆ Read, sign and point to the labels with large print.
- ◆ Read sign and point to the numbers on prices.

*Hints*

To help your child succeed, you can:

- ◆ Point to, read and sign for the food your child likes to eat.

- ◆ Read and sign and point to the labels of the things your child is interested in.

To make this activity more challenging, you can:

- ◆ Make a grocery list with your child before you go to the store.
- ◆ Have your child draw one or two things your child wants and help your child write the words under the picture.
- ◆ At the store, help your child read his/her grocery list and find the items. ■



## LISTENING TO DIFFERENT SOUNDS

Developed by Angela Notari-Syverson, Ph.D. and Kristin Rytter, Ph.D. with Judy Challoner, Faith Haertig Sadler, Young Sook Lim, Ph.D., Marilyn Sturm, and Rodd Hedlund (2005).

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Have your child listen for:

- ◆ Birds and insects
- ◆ Cars and airplanes
- ◆ Animals
- ◆ Leaves rustling in the wind
- ◆ Water



Talk about how these things sound.

To help your child succeed, you can:

- ◆ Have your child listen for things your child is touching.
- ◆ Have your child listen for things your child likes.
- ◆ Have your child listen for loud sounds (cars, trucks, dogs barking).

- ◆ Tell and sign for your child what the child is listening to.
- ◆ Do this activity in a familiar place (backyard).
- ◆ Choose a quiet place with just a few sounds.

*Hints*

To make this activity more challenging, you can:

- ◆ Have your child listen for quiet things (cats meowing, people walking).
- ◆ Have your child listen to things that your child cannot see. Ask your child to guess what is making the sound
- ◆ Have your child describe what he/she hears with a simple sentence. (The dog is barking. That's a big truck.).
- ◆ Ask your child to tell where sounds come from (down there, close to us). ■

## MAKING A TOUCH BOOK

Developed by Angela Notari-Syverson, Ph.D. and Kristin Rytter, Ph.D. with Judy Challoner, Faith Haertig Sadler, Young Sook Lim, Ph.D., Marilyn Sturm, and Rodd Hedlund (2005).

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- ◆ Cut cardboard into same sized pieces. Put three holes in the pieces on the left side.
- ◆ Tie the pieces together with yarn, so you will have a book.
- ◆ Put one thing your child likes on each page (rattle, rings, and keys).
- ◆ Talk and sign about the things while your child touches them.
- ◆ Have your child take the book to school and share with the teacher.



*Hints*

To help your child succeed, you can:

- ◆ Make only two pages.

- ◆ Put your hand under your child's hand and turn the pages with your child.
- ◆ Again, Hand under hand, help your child touch the things on the pages.
- ◆ Put food (M&M's, Cheerios, crackers) in baggies, put them on the pages and let your child eat the food.
- ◆ Take turns eating what is in the baggies.

To make this activity more challenging, you can:

- ◆ Put new things (cotton, aluminum foil, yarn) on the pages
- ◆ Have your child turn the pages him/herself
- ◆ Encourage your child to say what is on each page. ■

## Usher Syndrome

Taken from the Usher Syndrome website  
[www.usher-syndrome.org](http://www.usher-syndrome.org)

A diagnosis of Usher Syndrome is a traumatic event for a family. There often appears to be no hope for the loved one suffering from the disorder. But while it is true that there is currently no cure for Usher Syndrome and few widely accepted treatments for some of it's symptoms, there is still hope.

People with hearing loss have more options for communication than ever before. Sign language still remains a viable communication option and new technologies like the

cochlear implant and digital hearing aids offer access to quality sound to even the profoundly deaf. Researchers are making significant progress on the retinal degeneration experienced by most children with Usher syndrome as well. There is real hope that viable treatments will be found in the near future.

Hope here comes in many forms, however. The Coalition offers families with Usher Syndrome the opportunity to connect with other families. We have the best and latest information on Usher Syndrome and count many of the world's leading researchers among our

members. We invite families to directly par-

*“There is hope that viable treatments will be found in the near future.”*

ticipate in our efforts to search for a cure, to get involved in helping their children. Here you are neither alone nor helpless.

Here, there is hope.■

## Usher Syndrome—More Hope Than Ever

Take from the HEARSEEhope website:  
Research Grants: [info@hearseehope](mailto:info@hearseehope)

**Breaking Research News!** Gene Therapy provides vision to nearly blind young adults”. Three young adults with virtually no vision can now read several lines on an eye chart and see better in dimly lit settings thanks to an innovative gene therapy aiming to reverse blindness in a severe form of retinitis pigmentosa known as Leber congenital amaurosis or LCA. One person was even able to better navigate an obstacle course several weeks after receiving the therapy.

The three individuals are participating in a Phase I clinical trial at The Children's Hospital of Philadelphia.

This is an incredible milestone in curing blindness, and this advancement will help pave the way for the development of gene therapies to treat and cure a variety of retinal diseases including Usher syndrome.

Doctors working on Usher syndrome research are working to extend this incredible breakthrough to Usher syndrome. There is great hope that clinical trials for similar gene

therapy for Usher syndrome is right around the corner. Future funding is needed for this important research to continue.

### Summary of Research Grants Funded:

-Pilot Project of Population Genetic Studies of Usher syndrome (funded January 2006)

-Development of Methods of Usher Syndrome Gene Therapy (funded January 2007)

-Development of Improved Visual Field Testing as an Outcome Measure for treatment

## CHARGE Syndrome Conference

From the CHARGE Syndrome Website  
[info@chargesyndrome.org](mailto:info@chargesyndrome.org)

### 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.

### 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.

**CHARGE Conference:** Hilton Chicago/Indian Lakes Resort, IL on July 24-26, 2009. To register call 800-334-3417.

### CHARGE Accounts:

Browse our latest PDF newsletter in Adobe Acrobat format to read personal accounts, as well as the latest information about the 2009 conference, general updates, and an upcoming calendar of events. You can also view our newsletter archives.

[www.chargesyndrome.com](http://www.chargesyndrome.com) 141 Middle Neck Rd · Sands Point, NY 11050 · 800-442-7604 ■

## Building Partnerships Among Parents, Schools and Adult Service

*Recommendations from Dr. Jim Early, Walker School, Building Partnerships, March 14, 2009 Envision Conference at Perkins School for the Blind*

One factor that I have learned in my years in the field of special education administration is that for transition to be successful, whether it is at the early childhood level or transition from elementary to secondary education or to adult services, is that relationship building is the key ingredient to success. And let me emphasize this about relationship building, **it takes time and effort.**

I can not stress these two points enough, **time and effort** on everyone's part. And when one doesn't or is unwilling, then the transition process will be difficult and less successful. In looking at transition to the adult service systems, one must take an ecological approach.

That is, the whole child and all the facets of the student's life, family, community, friends, avocations and aspirations.

I see that there are four major principles that must be practiced to ensure a successful tran-

sition

- ◆ Collaboration –all the stakeholders working together
- ◆ Communication- open, forth-right, honest, frequent
- ◆ Cooperation- willingness to give and take, being responsible
- ◆ Commitment- To the process, to the student and to the other stakeholders

These four principles can be realized through effective relationship building where the process must be continuous, and ongoing.

By regulation the transition process should begin at age 14, but in actuality it needs to begin from the day the child enters the service system and continues to evolve into the adult service arena. Transition is not an event that can be quickly put in place, but rather "Transition" is:

- ◆ A lengthy process
- ◆ Requires adequate planned resources for the development of appropriate services and programming
- ◆ Should include ongoing case management and parent support

There are several steps that need to be taken to ensure successful transition that include:

- ◆ Identification of necessary community resources, which at times are scarce and limited.
- ◆ Determination of how the supports are to be implemented the "who", "what", "where", "when", "how" are the most important

***"In looking at transition to the adult service systems, one must take an ecological approach."***

- ◆ Development of a Plan "B" in case Plan A does not come to be.

Finally, advocacy must be maintained and even increased because entitlement programs and mandates are no longer absolute. Advocacy may be difficult to sustain, but it is absolutely necessary to ensure successful transition to adult services.■

## For Professionals: Two Thoughts About Invitations to Keep in Mind

*Deborah A. Chase, Ph.D., Massachusetts Licensed Psychologist, Nationally Certified School Psychologist*

Two important thoughts:

1. The invitation that you receive as a professional to work with a student is often called a referral. Perhaps it is to work with a very young child who may be at home or an older child or adolescent in a school setting. But I believe the real invitation here is not this referral or the release that is signed by the parent or guardian but the less overt one where permission is truly granted. It is in developing a relationship and not just with the child or young adult but with their parent (s) as well. It is within these relationships that the real permission to do your work is

granted. I believe that in order to embrace your work with the child you must first extend a hand to the parent.

2. A second invitation that comes to mind is the one that is extended to the Team Meeting. As a professional it may come first as an e-mail to check on the availability of your time and then possibly it is confirmed in print. The invitation to the parent or guardian does not come like this. Their invitation came much earlier, after learning that their child, for whom they had all sorts of hopes and dreams, is on a path they likely did not expect. For many parents this new path can be powerfully linked to loss and trauma and the absolute need to develop a new set of hopes and dreams. The professional chooses to attend the Team Meeting because of personal and professional choices that they have made. The

parent's decision to attend is extraordinarily different. It is not made through personal or professional choice, it is one that has the potential to launch them into a world that they may not have even known existed and for which they may or may not be prepared.

Debbie Chase is our Family Network Specialist and works with our Family Specialists in each state and is running the Family Phone Network (A series of conference calls on specific topics requested by our parents). Feel free to contact Debbie regarding future topics for discussion at [lifesp@verizon.net](mailto:lifesp@verizon.net)■

# Accessible Textbooks: A Guide for Parents of Children with Learning Disabilities

Taken from the Center for Applied Special Technology website [www.LDonline.org](http://www.LDonline.org)

## Introduction

As the parent of a student with learning disabilities, you want to do all that you can to enable your child to learn in school. In some cases, you need to be sure that teachers and school staff understand that the printed materials they rely on—textbooks—may be inappropriate for your child's use. Even if your child's reading level isn't as high as his or her classmates, they nevertheless need to understand the material that the other students are learning.

How can they do it? By using materials that work for them—materials that allow them to hear text spoken out loud, displayed in custom color combinations, in different fonts, in larger sizes, or in any of these combinations. This flexibility is a key factor in moving schools towards *universal design for learning*—learning environments that are designed to meet the needs of *all* students—including students with learning disabilities.

National policy-makers have realized that students with disabilities need access to the same materials as their fellow students. During the reauthorization of IDEA, the National Instructional Materials Accessibility Standard (NIMAS) was created. A central repository for publisher files, the National Instructional Materials Access Center (NIMAC), provides a nationwide system to supply accessible versions of core instructional materials—textbooks and related products—to qualifying students with print disabilities. Your school system is responsible for accessing the NIMAC and, as a parent, you can not receive files directly. However, sometimes parents have to take the lead in informing their school system of this type of resource.

## Supported reading software—Allowing your child to hear text

Today's technology allows words to be read aloud by a computer using synthetic speech. This occurs through the use of "supported reading software." Many software programs allow text to be highlighted as it is read. Some programs can automatically read a

whole page. Others offer study skill features such as looking up words in a dictionary or glossary, highlighting colors, or copying and pasting text.

You will need to try different software programs to figure out which one is good for your child. Their school should offer this technology to help your child and you need to put it in their IEP.

Regardless of the choices of your child's school, it may be helpful to introduce your child to supported reading software early, at home, so they can use it to understand complicated material as they learn to read.

Free NaturalReader and ReadPlease are good products to use on your home computer to test out whether or not your child would benefit from text-to-speech support. For Mac users, Tex-Edit Plus comes bundled with OS X system software and offers many features. Some of these supported reading products allow you to download synthetic speech on MP3 portable devices. To learn more about supported reading software and to compare features, see the Beyond the Text Project from the National Center on Accessible Media. This resource contains many options from high to low cost.

## Where can I get e-text?

You can try to get e-text yourself or request it through your school system. It is hoped that e-text will become available along with printed books, just as audio books are now available online and in bookstores. Today, you will need to do some hard work. Following are some ways to find e-text.

## Text publishers and commercial sources

More and more curriculum publishers are offering accessible e-text versions of their print materials. In the future, it is hoped that these options will regularly be offered for sale alongside their print counterparts.

For a sampling of web sites that offer e-texts for sale, visit the following:

Candida Martinelli's website *Simple-to-follow instructions for the computer novice on how to*

*download E-Texts and E-Books to your PC* explains how to locate, download, and use e-texts. She provides a list of Stores and Sites that sell e-text versions of print works. Even though her site does not specifically target educators, it provides an overview of e-texts available from commercial sites and tells you how to use them.

The NIMAS Development and Technical Assistance centers website also offers a *Mainstream Sources of Digital Electronic Text* listing, and these sites usually provide e-texts for sale.

Your child's school will often assign books that are available from bookstores and other commercial sources. Check Overdrive, ebooks.com, Amazon, and other online bookstores.

## Accessible media producers

Some national organizations are authorized to create e-text for qualifying students (see "Who is Eligible" from the National Library Service for the Blind and Physically Handicapped (NLS). The two most prominent organizations are:

## Bookshare.org

Bookshare.org produces e-text versions of print materials, available in the DAISY format (Digital Audio Information SYstem), sometimes referred to as "Digital Talking Books" (DTBs). DTBs are recorded using the exact words of the written version. They provide a way for the reader to navigate the book, such as to a particular part or section of the book. To "read" the book, a "DAISY-complaint" text to speech player is needed, which is provided free with Bookshare membership.

## Recording for the Blind & Dyslexic®

Recording for the Blind & Dyslexic®, distributes DTBs (AudioPlus) on CD-ROM. AudioPlus books are voice recordings that conform to the DAISY format. These products require specialized hardware for playback. The user needs a desktop or portable "player"-or

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## Accessible Textbooks - *Continued from page 14*

AudioPlus-compatible computer software—to "read" the books. E-text versions of textbooks, both with and without images, that can be read aloud using synthetic speech, will soon be offered, as well as their traditional recordings of human audio versions. RFB&D has gone beyond their tradition of specialized four-track recorded books on cassette tape. RFB&D recently developed a new web-based resource, Learning through Listening. Designed for educators, this site provides useful information on how to use these resources to support learning.

Both Bookshare.org and RFB&D charge a fee to individuals and institutions that use them. They are establishing collaborations with developers of supported reading software-products that can display and read e-text books aloud: Kurzweil, TextHelp, gh, Freedom Scientific, Don Johnston, and others—to increase product compatibility.

### -Hot Tip! DAISY Book Players

To use DAISY digital talking books, you need supported reading software that can read the DTB format. To find this software, check the comparison chart of e-book and digital talking book (DTB) hardware and software from the Beyond the Text Project at the National Center on Accessible Media, or contact software product manufacturers directly.

### -Hot Tip! Internet e-text

Sometimes, e-text can be found online, right on the Internet. After 95 years, most print publications emerge from copyright constraints and are often posted online in digital format. National Library Service has published a resource, Selected Sources for Electronic Texts 2005, combining commercial vendors, specialized repositories, and public domain e-text libraries. The University of Texas at Austin maintains an extensive, up-to-date, and comprehensive listing of Internet e-text sites, Electronic Books. Although recent textbooks would not be found online, there might be primary source material and other helpful information.

### Not all e-text is accessible

A PDF (Portable Document Format) document may be a picture of a printed page, which is not useable by supported reading software. In order to "read" text, supported reading software usually uses the same system that the computer uses to select text for cutting and pasting. So, as a general rule, if you can select the text, you will also be able to use assistive technology to "read" it. Only two supported reading software products are currently able to read and highlight most PDF documents. They are:

PDFAloud from TextHelp Systems,  
ReadOutLoud from Don Johnston, Inc., and  
PDF Equalizer from Premier Assistive Technology.

Some commercial electronic book products can read aloud (and otherwise manipulate) their respective proprietary file formats, without allowing users to copy it. Two of these are:

- ◆ Adobe Acrobat Reader, and
- ◆ Microsoft Reader

### Working through the school system

If your child finds supported reading software useful, then you need to acquire the text he or she needs in an accessible format.

Special education services

If your child is currently receiving special education services, their IEP team has the responsibility to determine if he or she requires alternate-format materials. It is their school's responsibility to provide materials. LD OnLine has extensive information on working with your child's IEP team to get the right services for your child. The NIMAS/NIMAC system may be a source that the school can use.



Regular education services

Your child may also be eligible to receive e-text as part of a plan under Section 504. They may be eligible for materials from national organizations such as RFB&D or Bookshare.org, either via an institutional or an individual membership.

### How the National Instructional Materials Accessibility Standard (NIMAS) can help

The authors of IDEA 2004 created the National Instructional Materials Accessibility Standard (NIMAS) and the National Instructional Materials Access Center (NIMAC) to assure that qualifying students with disabilities receive textbooks and other important materials in an accessible format at the same time as their fellow students.

The policies and technologies associated with the NIMAS/NIMAC system are complex and developing. There are variations in each state. Parents may consult the NIMAC database to determine if NIMAS files for a particular textbook are available, but these can only be accessed by users authorized by the state. Opened in December, 2006, the NIMAC provides public information about the availability of NIMAS filesets for a specific publication or series, and information about accessible, alternate-format, student-ready versions that may be available; where they are located, and how to obtain them.

### Here are the steps to using NIMAC:

Contact your local or regional special education or assistive technology specialist to assist you in acquiring accessible, student-ready versions of print instructional materials created from NIMAS filesets.

Contact your state agency for assistive technology to assist you in acquiring accessible, student-ready versions created from NIMAS filesets.

Contact your state's primary contact for NIMAS/NIMAC to determine which accessible media producers are eligible to receive NIMAS filesets from the NIMAC and to trans-

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## Accessible Textbooks—Continued from page 15

form them into accessible, student-ready versions.

Once state and local education agencies agree to coordinate with the NIMAC (all 50 states have indicated willingness to do so) they are then obligated to require publishers to deposit NIMAS filesets of print materials in the NIMAC or to purchase "specialized format" versions from publishers directly. Specialized formats include braille, audio, e-text, and large print versions. It is important to be aware of the fact that NIMAS files are not meant to be used by students, but instead provide the source files that are the basis for the subsequent creation of student-ready versions by organizations like RFB&D and Bookshare.org.

### -Hot Tip!

It is important to be aware that NIMAS files are not meant for classroom use, but provide the source files that are the foundation for subsequent creation of student-ready versions by Accessible Media Producers (AMPs). This intermediary step is important since the technology upon which NIMAS source files are based is designed to be flexible enough to allow the content to be "rendered" in many ways.

### The Importance of the IEP Process

According to the National Library Service, Library of Congress, students qualify for alternate-format materials when they are:

Persons certified by competent authority as having a reading disability resulting from organic dysfunction and of sufficient severity to prevent their reading printed material in a normal manner.

And authority is quantified as follows:

...in the case of reading disability from organic dysfunction, competent authority is defined as doctors of medicine and doctors of osteopathy who may consult with colleagues in associated disciplines.

In order to qualify a student for materials produced through the use of the NIMAS/

NIMAC system, their IEP team must a) determine that a student is unable to read print material in a normal manner, b) needs alternate-format materials derived from NIMAS source files and c) assure that the student is certified as print-disabled by a medical doctor or osteopath.

Once a student is qualified, their IEP team can then take advantage of NIMAS/NIMAC resources:

The NIMAC database can be searched to make sure NIMAS filesets exist

Once identified, the student's IEP team can request the assistance of state and/or regional NIMAS resources, or

Their team can acquire e-text versions from RFB&D or Bookshare.org or other locally-designated sources for use in the classroom.

The NIMAS centers at CAST have posted some suggested accessible instructional materials language online for inclusion in a student's IEP (if an IEP team makes the determination that a student requires accessible, alternate-format versions of textbooks and other instructional materials due to difficulties using print versions).

### -Hot Tip!

It should be noted that regardless of whether or not a student with learning disabilities or dyslexia is determined to be eligible for NIMAS-derived materials, the local school or district still has the responsibility for providing accessible versions to any student deemed in need of them.

This Quick Guide emphasizes accessible materials for student with reading disabilities and dyslexia, and how to identify, locate, and acquire those materials. Far from being the end goal, however, the increased availability of accessible instructional materials is, in fact, the first step towards *Universal Design for Learning*.

### A vision for the future: Universal design for learning

Universal Design for Learning (UDL) is not

"one size fits all," but precisely the opposite: multiple ways of accessing, expressing, and engaging with information and learning. Universal Design for Learning seeks to maintain high achievement expectations, including their associated challenges, while simultaneously decreasing the barriers that exist in all aspects of the traditional curriculum-goals, methods, materials, and assessment-through the application of three guiding principles.

The three principles of Universal Design for Learning—multiple representations of information, multiple means of expression, multiple means of engagement—provide benchmarks for each of the four components of the curriculum referenced above, and they are most often applied to instructional materials, and often (mistakenly) limited to accessibility. While accessibility is an essential prerequisite of UDL-oriented curriculum materials, it is vital to distinguish between access to information and access to learning. Accessible materials facilitate access to information, and UDL facilitates access to learning.

### Getting more information

This article is meant to provide an introduction to the process of acquiring e-text versions of instructional materials for students with Specific Learning Disability and dyslexia. For a more comprehensive review of the legislative framework, copyright constrictions, and a history of NIMAS/NIMAC, please refer to two articles: *The Promise of Accessible Textbooks* (2004) and *Accessible Textbooks in the Classroom* (2007).

For more information on how technology can help your child, go to Ask the Tech Expert, where Dr. Tracy Gray answers your questions.

Visit our section on Technology for more articles.

And for a guide to technology tools for learning, go to the TechMatrix.

Center for Applied Special Technology and LD OnLine, (2007). *A Parent's Guide to Making Textbooks Accessible and Usable for Students with Learning Disabilities*. ■

## National Websites for Families

*Developed by the Statewide Parent Advocacy Network 2008*

### U.S. Government Agencies & Government-Funded Technical Assistance Centers

#### U.S. Department of Education:

U.S. Department of Education: <http://www.ed.gov/index.jhtml>  
 U.S. Department of Education No Child Left Behind: <http://www.ed.gov/nclb/index/az/index.html>  
 U.S. Department of Education Office for Civil Rights: <http://www.ed.gov/about/offices/list/ocr>  
 U.S. Department of Education Office of English Language Acquisition: <http://www.ed.gov/about/offices/list/oela>  
 U.S. Department of Education Office of Safe and Drug Free Schools: <http://www.ed.gov/about/offices/list/osdfs>  
 U.S. Department of Education Office of Special Education Programs: <http://www.ed.gov/about/offices/list/osers/osep/index.html>  
 U.S. Department of Education Office of Vocational and Adult Education: <http://www.ed.gov/about/offices/list/ovae>

#### U.S. DOE Funded Technical Assistance & Dissemination Networks:

Accessing the General Education Curriculum: <http://www.ksaccesscenter.org/index.php>  
 Accessible Instructional Materials: <http://nimas.cast.org/>  
 Alliance for Parent Centers: [www.talliance.org](http://www.talliance.org)  
 College/Post secondary education for youth with disabilities: <http://www.heath.gwu.edu/>  
 Culturally Competent Education: [www.nccrest.org](http://www.nccrest.org)  
 Deaf-Blindness: <http://www.ncset.org/>  
 Dispute Resolution: <http://www.directionservice.org/cadre/>  
 Drop Out Prevention: <http://www.dropoutprevention.org/>  
 Early childhood: <http://www.nectac.org/>  
 Educational outcomes/student performance: <http://cehd.umn.edu/nceo/>  
 IDEA Partnership: [www.ideapartnership.org](http://www.ideapartnership.org)  
 Inclusion: <http://niusi.edreform.net/>  
 Juvenile Justice: <http://www.edjj.org/>  
 Learning Disabilities: <http://nrld.org/>  
 Literacy/Reading: <http://readingrockets.org/>  
 National Information Center for Children and Youth with Disabilities: [www.nichcy.org](http://www.nichcy.org)  
 Positive Behavior Supports: [www.pbis.org](http://www.pbis.org)  
 Post-School outcomes: <http://psocenter.org/>  
 Secondary Education and Transition to Adult Life: <http://www.ncset.org/> & <http://www.nsttac.org/>  
 Special Education Policy: <http://www.projectforum.org/>  
 Student Achievement & Progress Monitoring: <http://www.studentprogress.org/>  
 Technology: <http://www.fctd.info/>

#### U.S. Department of Health and Human Services:

U.S. Department of Health and Human services Home Page: <http://www.hhs.gov/>  
 Knowledge Path for Children/Youth with Special Health Needs: <http://www.mchlibrary.info/>

KnowledgePaths/kp\_CSHCN.html

#### Child Abuse & Neglect/Family Strengthening:

Child Abuse: <http://www.nlm.nih.gov/medlineplus/childabuse.html>  
 Communication Building with your Latino/Hispanic Youth: <http://ncadi.samhsa.gov/initiatives/hisplatinohisplatin.aspx>  
 Parenting Tips: <http://www.nlm.nih.gov/medlineplus/parenting.html>  
 Services for Families: [http://www.acf.hhs.gov/acf\\_services.html#walia](http://www.acf.hhs.gov/acf_services.html#walia)

#### Child Care:

National Child Care Information Center: <http://www.nccic.acf.hhs.gov/index.html>

#### Disabilities:

Learning Disabilities: <http://www.nlm.nih.gov/medlineplus/learningdisorders.html>

#### Government Benefits:

Benefits for Children with Disabilities: <http://www.ssa.gov/pubs/10026.html>  
 Check your Eligibility for Government Benefits: [http://www.govbenefits.gov/govbenefits\\_en.portal](http://www.govbenefits.gov/govbenefits_en.portal)

#### Health Care:

Centers for Disease Control and Prevention: <http://www.cdc.gov/az/a.html>  
 Child and Teen Health: <http://www.nlm.nih.gov/medlineplus/childrenandteenagers.html>  
 Childhood Immunizations: <http://www.nlm.nih.gov/medlineplus/childhoodimmunization.html>  
 Kid Website: <http://www.hhs.gov/kids/index.html>  
 Find a Clinic, Free or Low Cost Health Care: <http://ask.hrsa.gov/pc/>  
 Health Info for Teens: <http://www.nlm.nih.gov/medlineplus/teenspage.html>  
 Parents and Keeping your Children Healthy: <http://www.healthfinder.gov/justforyou/justforyou.asp?KeywordID=183&branch=1>  
 Newborn and Infant Hearing Screening: <http://www.cdc.gov/ncbddd/ehdi/ddscreen.htm>  
 Preventive Healthcare for Children: <http://www.ahrq.gov/ppip/childguide/>

#### Health Insurance:

Medicaid: <http://www.cms.hhs.gov/home/medicaid.asp>  
 State Children's Health Insurance Program: <http://www.insurekidsnow.gov/>

#### Mental Health:

Bullying Prevention: <http://stopbullyingnow.hrsa.gov/index.asp?area=main>  
 Center for Mental Health Services: <http://mentalhealth.samhsa.gov/cmhs/>  
 Mental Health: <http://mentalhealth.samhsa.gov/cornerstone/>

#### Oral Health:

Children's Dental/Oral Health: <http://www.nlm.nih.gov/medlineplus/childdentalhealth.html>

#### Substance Abuse:

Center for Substance Abuse Prevention: <http://prevention.samhsa.gov/capacity/prevedutools.aspx>  
 Preventing Drug and Alcohol Abuse: <http://ncadi.samhsa.gov/>

#### U.S. DHHS Maternal & Child Health Bureau Funded Technical Assistance Projects:

Bright Futures (American Academy of Pediatrics): <http://brightfutures.aap.org/web/>  
 Champions for Inclusive Communities: <http://www.championsinc.org/>  
 Healthy & Ready to Work/Transition to Adult Life: [www.hrtw.org](http://www.hrtw.org)  
 National Center for Cultural Competence: <http://www11.georgetown.edu/research/gucchd/nccc/>  
 National Center for Family-Professional Partnerships: [www.familyvoices.org](http://www.familyvoices.org)

#### "Across Disability" Organizations:

Family Voices (health issues): [www.familyvoices.org](http://www.familyvoices.org)  
 Kids As Self-Advocates (KASA): <http://www.fvkasa.org/>  
 National Council on Disability: [www.ncd.gov](http://www.ncd.gov)

#### National Disability Specific Organizations:

American Association of the Deaf-Blind: <http://www.aadb.org/>  
 The Arc (formerly Association for Retarded Citizens): <http://www.thearcinc.org/>  
 Autism Society of America: <http://www.autism-society.org/site/PageServer>  
 Children & Adults with Attention Deficit Hyperactivity Disorder: <http://www.chadd.org/>  
 Epilepsy Foundation: <http://www.epilepsyfoundation.org/>  
 Federation of Families for Children's Mental Health: [www.ffcmh.org](http://www.ffcmh.org)  
 The Learning Disabilities Association of America: <http://www.ldanatl.org/>  
 National Association of the Deaf: <http://www.nad.org/site/pp.asp?c=foINKQMBF&b=91587>  
 National Federation of the Blind: <http://www.nfb.org/nfb/Default.asp>  
 Spina Bifida Association: <http://www.sbaa.org/>  
 United Cerebral Palsy of America: <http://www.ucp.org/>

#### Other National Parent Resources:

Beach Center on Families and Disability: <http://www.beachcenter.org/>  
 Fiesta Educativa: <http://www.fiestaeducativa.org/>  
 National Coalition for Parent Involvement in Education: [www.ncpie.org](http://www.ncpie.org)  
 National Council of La Raza: <http://www.nclr.org/>  
 National Family Caregivers Association: <http://www.nfacares.org/>  
 Parents Anonymous (parent support to avoid child abuse): [www.parentsanonymous.org](http://www.parentsanonymous.org)  
 Parent to Parent USA: <http://www.p2pusa.org/>  
 Prevent Child Abuse: [www.pca.org](http://www.pca.org) ■

## NEW ENGLAND CONSORTIUM OF DEAFBLIND PROJECTS

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

Phone: 617-972-7515 Fax: 617-972-7354  
E-mail: [NEC@Perkins.org](mailto:NEC@Perkins.org)

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

### MA Deafblind Project

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

### CT Deafblind Project

BESB-Board of Ed Services for the Blind  
184 Windsor Ave  
Windsor, CT 06095  
800-842-4510  
Karen Olson  
[karen.olson@ct.gov](mailto:karen.olson@ct.gov)

### 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](mailto:kathy.thonis@crotchedmountain.org)

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

PO Box 2274  
Concord, NH 03302  
603-228-1028  
Jan Halley  
[miceprogram@juno.com](mailto:miceprogram@juno.com)

### ME Deafblind Project

Catholic Charities, 1066 Kenduskeag Ave., Bangor, ME 04401  
207-941-2855 Jean Small, [jsmall@ccmaine.org](mailto:jsmall@ccmaine.org)

## Save The Dates

July 18	CPAC Annual Picnic – CT <a href="http://www.cpacinc.org">www.cpacinc.org</a>
July 24-26	CHARGE Conference, Chicago, IL <a href="mailto:info@chargesyndrome.org">info@chargesyndrome.org</a>
Aug 8	Fishing Derby—TBD <a href="http://www.necdbp.org">www.necdbp.org</a>
TBD	Family Phone Conferences <a href="http://www.necdbp.org">www.necdbp.org</a>
TBD	4PT Deafblind Training Series <a href="http://www.necdbp.org">www.necdbp.org</a>
Oct 3	Apple Picking (Rain Date Oct 10) – TBD <a href="http://www.necdbp.org">www.necdbp.org</a>
Oct 3-4	Maine Parent Federation – 25 <sup>th</sup> Gala <a href="http://www.mpf.org">www.mpf.org</a>
Oct 24	Discover Conference – Watertown, MA <a href="http://www.perkins.org">www.perkins.org</a>
Nov 4-6	NE/AER Conference—Hartford, CT <a href="http://www.neaer.umb.edu">www.neaer.umb.edu</a>

For more detailed information regarding any event check out our website at [www.necdbp.org](http://www.necdbp.org) and go to the calendar section.

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