

in touch



Winter 2004

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

Best Wishes from NEC!

Best wishes for a happy and healthy 2004 from all of us at the New England Center Deafblind Project (NEC) and our affiliated agencies (Board of Education Services for the Blind – CT; Catholic Charities – ME; Perkins School for the Blind – MA; and ATEC/ASSETT – NH). In October of 2003 the New England Center Deafblind Project was awarded continuation of our grant for five additional years, spanning the period from October 1, 2003 to September 30, 2008. We are pleased with this award because a critical requirement for funding was a greater emphasis on accountability and efficacy evaluation. It is clear that while the federal government values the work conducted by deafblind projects across the country, we are being asked to do a better job of documenting positive impact on children who are deafblind, their families, and service providers.

A major task for NEC over the next five years will be to conduct technical assistance and training activities to a wide range of children and programs, while also documenting and evaluating these efforts on an ongoing basis. The six major areas of training and consultation are: (1) Early identification and referral, (2) The impact of deafblindness on learning, (3) Teaching strategies that develop communication abilities, (4) Vision and hearing issues related to assessment and interventions, (5) Promoting successful transition (preschool and youth), and (6) Assessment and program planning (relative to the IFSP, IEP, ITP process).

While we have numerous objectives and activities in this new grant cycle, the identification of children who are deafblind in the four state region is a critical and ongoing task for the New England Center Deafblind Project. **Why is it important to identify a child who has combined vision and hearing loss as “deafblind”?** Here are some key reasons:

1. It is our belief, and that of many in the national fields of special education (early childhood special education, teachers of the visually impaired, teachers of the deaf and hard of hearing, national parent leaders), that children who have combined vision and hearing loss benefit from specialized instruction by professionals trained in the area of deafblindness. Generally, children who are deafblind have unique communication needs and require interventions that are best developed by professionals who have specialty training and expertise.

2. The federal government recognizes the unique needs of learners who are deafblind and therefore directs financial support to deafblind projects across the country. The New England Center offers technical assistance (training and consultation) for service providers working with children who are deafblind in Connecticut, Maine, Massachusetts and New Hampshire at **no cost** to the local school system.

3. Within each state and via multistate trainings, NEC and its affiliated agencies strive to bring families and service providers together to share information and experiences, and to strategize ways to improve learning and life encounters for children who are deafblind. Many service providers report that these connections are critical in assisting them in their work with children who are deafblind. Also, families across the four states have indicated that their connections to other families and children who have similar issues have been invaluable in supporting their child who is deafblind.

We hope the information contained in this newsletter keeps you apprised of recent developments at the NEC, and new directions we anticipate over the coming years. As always, your comments, feedback, and inquiries are welcome. Please be advised that we will be sending you a new survey this Spring, with the objectives of gaining greater knowledge about your service needs and documenting our census more precisely. We look forward to your responses and collaborating with you.



Office of Special
Education Programs

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

The Journey

by Delma Boyce

Family Specialist (Massachusetts)

As a parent of an adult who is deafblind, I have learned many things. Perhaps the most important to me is that my advocacy efforts around my daughter's communication needs are never-ending but almost always fruitful. I have often had to be strident in my desire for my daughter to have competent communication partners, requiring that people who live and work with her know sign language and the many ways she communicates her needs, desires and frustrations.

I wrote this article one morning soon after my daughter moved into her first group home. Staff were new to her and she to them. Seeing their struggles with communication, I realized anew how vital communication is and how we need to continue the struggle to make our children understood.

Take a journey now with me . . .

Think of living in a world mysterious, strange, confusing - a world ruled by foreigners. You can tell they're foreigners because they don't speak your language. You've tried your signs, gestures, behaviors - they didn't get it, they definitely are foreigners. And they're very powerful; these foreigners: they're definitely in charge.

These rulers from a foreign land wake you up in the morning. They don't tell you why you need to get up; they just tell you to get up. They help you shower and get dressed without talking to you at all (*although they talk to the other foreigners while they help you.*) They make you brush your teeth and brush your hair, and then they set food in front of you without telling you what it is (It's not foreign good, though, because you've seen it before: maybe it just doesn't have a name?) While you eat, they continue to talk to each other in that

foreign language only they can understand, then suddenly one of them signs to you to "clean up." Wow! You get really excited. Maybe they DO know your language. So you sign "more" because you'd really like some more to eat, but one of the foreign rulers signs "finished," and because they're the rulers you have to be finished. How come when you sign you don't get what you ask for, but you have to do everything they say?

This is all very confusing.

And, who are they anyway? They've worked with you before, but you don't know their names. Do they have names? Or maybe they just didn't tell you because someone said you were "low functioning" and you wouldn't understand anyway. I wonder how they could know that when they don't even know your language? They seem to know a few words, but know enough to understand you at all. And, you wonder, do they know you have a name? You've never seen any of them use your name-sign. You don't know how to tell them your name, but you understand that your name-sign is you, and you wish someone would tell them your name, because without a name you're just kind of "anonymous" --a generic deafblind person that they've been hired to work with.

Why that foreigner over there didn't even sign "hello" to you when she came to work; she just chatted with the other foreigners and then turned the television on. And, you really wish if they were going to live and work in "deafblind world" they'd learn your language. How did they get the job anyway? Maybe it should be a rule that if they're going to work with you they have to learn your language? Everyone's lives would be easier. Your needs and wants could be better understood; you'd be calmer, happier. You'd feel better about yourself. You'd like the foreigners better, too. Your behavior would improve. Your job performance would improve. It's a fact; past data on you and others prove it.

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You'd love to be able to communicate with these foreigners. You see them all the time. If they could only speak your language, they could get to know you better. Because they don't know you really. They don't know that you can be so much fun- that you have a great smile, an infectious giggle, the irresistible charm of a three year old woman-child. They don't know yet how much they can teach you, how much fun it can be, how loving you can be when you're understood and accepted how much you need them, and how much they can learn from you. They don't know how rewarding their jobs can be, how important and terrific they'll feel when they see you grow and learn---when they can talk to you, and you to them. They don't yet know that anyone can learn, anyone can grow.

They don't know that they can look back with a sense of accomplishment and joy and satisfaction, because they've learned to communicate to you and with you, and together you've built trust and ability and an atmosphere where growth and learning can take place for everyone.

They don't seem to know (well, some of them surely do, but perhaps we all need to be reminded from time-to-time) that in the midst of all the frustration and problems, and bad days, and rotten pay, and lack of appreciation- communication can make all the difference in the world. Science tells us that all creatures communicate, and that without communication, human spirits shrink and wither. Without it life can be very lonely, empty of the connection language brings-empty of what we all take for granted every day. Communication is our connection to others in our world. Can you imagine living your life in a world where no one talks to you, where others only speak to you when they're telling you what you have to do? What a lonely world it must be to live in a world where so few people know your language, You can't express your needs, your wants, your feelings. You get so angry, so frustrated, so sad. Life can be very empty without someone to talk to.

Dolly Boyce, ALL of the "Dollies" are worth every effort to try to learn their language, to make them full members of the world they live in. They are worth all the work, the unspeakable pain, the indescribable joy--worth all we've faced on the journey of their lives to here-and beyond. They are unique and wonderful human beings. They deserve our respect; they deserve dignity and acceptance. They need us to care enough to strive to learn their language, their communication, in all of its complexities and twists and turns. It is a big task, an ongoing, ever-changing task and it requires care and commitment. We need caring, committed communicators on our journey.

If Dolly could talk, she would say these things to you. Because she and her fellow travelers do not have the "voice" to tell you these things, today I lend them mine. I know that if they could, they would tell me to tell you how much they need communication, how important it is -how it's a life-altering basic human need.

Good luck in your journey.

Delma Boyce
Family Specialist

A Tribute to Joey

Joey Wollack (pictured below) died at home one month after this picture was taken on December 8, 2003. Our thoughts and prayers go out to his parents Joe and Denise, his family, and all those touched by his life.

Joey had a message for us that Denise wanted to share:

*"To everyone who ever loved me,
I loved you back.*

*And because of your love,
I had the time of my life!"*

- Love, Joey Wollack



Collaborative Assessment of Students who are Blind or Visually Impaired

*PaTTAN Teleconference on Assessment -
February 27, 2004 Time: 9:00 a.m. - 3:30 p.m.*

Early Intervention-VI Infants/Toddlers

The Pennsylvania Department of Education, Bureau of Special Education and the Pennsylvania College of Optometry are pleased to announce the following teleconference opportunity:

Title: Collaborative Assessment of Students Who Are Blind or Visually Impaired

When: Friday February 27, 2004

Time: 9:00 a.m.-3:30 p.m. EST

Locations: Three PaTTAN offices (Harrisburg, King of Prussia, and Pittsburgh [gate code: 47087#]) and various sites across Pennsylvania and the US. Check on-line at www.pattan.k12.pa.us for the list of downlink sites.

Description

Children and youth who are blind or visually impaired need educational assessment in all areas of the expanded core curriculum in order for their teachers, specialists, psychologists, and parents to create their individual education plans. In this session the expanded core curriculum for students who are blind or visually impaired will be presented, along with suggestions and procedures for assessing all aspects of these areas. Participants will receive materials to aid them in collaborating with families and professionals of various disciplines in the assessment of students who are blind or visually impaired.

Audience

- Teachers, specialists, paraeducators and supervisors in the field of education of children and youth who are blind or visually impaired
- Families of students who are visually impaired
- Speech and language pathologists
- School psychologists
- Special education teachers and related services

providers

- Others who are interested in the educational assessment of students who are blind or visually impaired



Learner Outcomes

As a result of participating in this teleconference, each learner will be able to:

- List the areas included in the expanded core curriculum for students who are blind or visually impaired.
- Select assessment tools for use for each area of the expanded core curriculum which are appropriate for a variety of students who are visually impaired.
- Develop strategies to increase collaboration with families and professionals inside and outside of the field of education for students who are visually impaired.
- Use a variety of activities to assess students who are blind or visually impaired.
- Use data gathered through assessment to develop educational plans and curriculum materials.

Presenters

The presenters are all members of the Assessment Team of the California School for the Blind.

-Lizbeth Barclay, M.A., is an Orientation and Mobility Specialist and teacher of students who are Visually Impaired.

-Stephen Goodman, M.A., M.S., is Director of Pupil Personnel Services, and Psychologist.

-Frances K. Liefert, M.A., is an Orientation and Mobility Specialist and a teacher of Visually Impaired Students.

-Marsha A. Silver, M.S., is a Speech-Language Pathologist.

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Agenda

9:00 - 9:15 am Introduction: Purpose of Assessment, Assessment and Collaboration, Expanded Core Curriculum as a Foundation for Assessment
9:15 - 10:30 am Ways to Facilitate Family Involvement and Preparation for Assessment
10:30 - 10:45 am Break
10:45 am -12:00 pm Assessment and the Core Curriculum, Assessment and the Expanded Core Curriculum, Presenting Assessment Results
12:00 - 1:00 pm Lunch (on your own*)
1:00 - 1:30 pm Assessment Results (continued)
1:30 - 2:15 pm Setting Program Goals and Developing Curriculum
2:15 - 2:30 pm Break
2:30 - 3:15 pm Developing Curriculum
3:15 - 3:30 pm Question & Answer Period, Wrap-up *Lunch will be provided to participants at WQED Pittsburgh.



Continuing Education Credits

Five (5) Act 48 clock hours are available to individuals who hold a valid PA Professional Educator Certificate.

The Pennsylvania Training and Technical Assistance Network is approved by the Pennsylvania State Board of Psychology to offer continuing education for psychologists. PaTTAN maintains responsibility for the program. This workshop is offered for 5 CE hours.

Commission on Rehabilitation Counseling Certification (CRCC): Continuing Education credits for professions with Commission on Rehabilitation Counselor Certification (CRCC) credentials will be offered for attendance of this program. (CRCC) Continuing Education

Certificates will be available upon successful

completion of the program for interested participants.

Registration

You may register directly on-line by visiting www.pattan.k12.pa.us and entering the Registration On-line page.

For More Information: Questions regarding downlink sites, registration, or satellite coordinates, please email PaTTAN Distance Learning at lc@pattan.k12.pa.us. For individuals who are deaf or hard of hearing, PaTTAN Distance Learning can be reached at 412-826-2338 (TTY only).

This teleconference is available to Pennsylvania participants at no cost. This program is being broadcast live from WQED Pittsburgh. There is a \$250 registration fee for downlink sites outside Pennsylvania. Please make checks or purchase orders payable to: PaTTAN, Attention: Distance Learning, 3190 William Pitt Way, Pittsburgh, PA 15238.

For content information about this event contact: Debby Holzapfel at 800-446-5607, ext. 6843 (PA only) or 412-826-2336. If you have special needs as addressed by the Americans with Disabilities Act and need assistance at this teleconference, please contact PaTTAN Distance Learning at dlcregistration@pattan.k12.pa.us. Reasonable efforts will be made to accommodate you.



Videotapes

To obtain a videotape and handout of this teleconference, please email Distance Learning for ordering information at dlc@pattan.k12.pa.us. Please provide your fax number. Allow 4 to 6 weeks for delivery. Please do not reply directly to this automated email. Contact PaTTAN Distance Learning at dlc@pattan.k12.pa.us for further information.

Where are the Parents?

By Sue Stuyvesant

(Article taken from the internet.)

A question was asked by an official as to why there weren't more parents (of special need kids) involved in the local PTA and other issues that have come up that directly involve our kids.

Where are the parents?

They are on the phone to doctors and hospitals and fighting with insurance companies, wading through the red tape in order that their child's medical needs can be properly addressed. They are buried under a mountain of paperwork and medical bills, trying to make sense of a system that seems designed to confuse and intimidate all but the very savvy.

Where are the parents?

They are at home, diapering their 15 year-old son, or trying to lift their 100 lb daughter onto the toilet. They are spending an hour at each meal to feed a child who cannot chew, or laboriously and carefully feeding their child through a g-tube. They are administering medications, changing catheters and switching oxygen tanks.

Where are the parents?

They are sitting, bleary eyed and exhausted, in hospital emergency rooms, waiting for test results to come back and wondering: is this the time when my child doesn't pull through? They are sitting patiently, in hospital rooms as their child recovers from yet another surgery to lengthen hamstrings or straighten backs or repair a faulty internal organ. They are waiting in long lines in county clinics because no insurance company will touch their child.

Where are the parents?

They are sleeping in shifts because their child won't sleep more than 2 or 3 hours a night, and must constantly be watched, lest he do himself, or another

member of the family, harm. They are sitting at home with their child because family and friends are either too intimidated or too unwilling to help with child care and the state agencies that are designed to help are suffering cut backs of their own.

Where are the parents?

They are trying to spend time with their non disabled children, as they try to make up for the extra time and effort that is critical to keeping their disabled child alive. They are struggling to keep a marriage together, because adversity does not always bring you closer. They are working 2 and sometimes 3 jobs in order to keep up with the extra expenses. And sometimes they are a single parent struggling to do it all by themselves.

Where are the parents?

They are trying to survive in a society that pays lip service to helping those in need, as long as it doesn't cost them anything. They are trying to patch their broken dreams together so that they might have some sort of normal life for their children and their families.

Where are the parents?

They are busy, trying to survive. . .



First Annual Beach Party a Success!

*From Janette Peracchio and Andrea Garewski,
CT Family Specialists*

The first annual beach party for the CT parents group, (CT DB FUN) was a great hit. Several families met at the Eastern Point Beach in Groton, CT July 19th for fun in the sun (and shade). Alice and Merisha Burton invited the group to their town beach and the families brought picnic lunches and a dish to share. The facilities were first class, the weather was perfect and the company was superb.

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There were plenty of activities for everyone to enjoy. The moms networked, the dads connected, and the kids schmoozed. Can you tell that we all enjoyed the day? Special thanks go to Alice and Merisha for being such gracious hosts.



From left to right, Jeff, Andrew, Merisha, Amy, Sara, Katie, Jacek and Marcie at the July 19th, CT Beach Day -

We took some time to discuss the IDEA disability category definitions; deafblind vs. multi-handicapped. Our children should be classified as deafblind on all IEP forms to qualify for appropriate services that address their dual sensory educational needs. This is especially important as they become teenagers and begin transitioning to adult activities. Being classified as multihandicapped is OK for a secondary classification, but it is not as beneficial for them as their primary classification. We will be happy to send you information on category definitions if you call 1-800-842-4510 ext. 4128. Leave your name and mailing address. Plans are underway to make this an annual event and it will be held next year on Sunday Sept. 12th, 2004. **SAVE THE DATE!**



Connecticut Moms Enjoy A Spring Fling

From Janette Peracchio and Andrea Garewski, CT Family Specialists

Several moms from the CT Deafblind Families United Network (CT DB FUN) got together on Sunday afternoon in April 2003 to network and enjoy some time together. We met at a movie theater in a shopping plaza so the moms had a choice of activities to choose from. Some went to the movies, others went shopping, and we all met back for a

meal together. It was a great chance to catch up with each other and discuss how our kids were doing (of course), and plan our next CT DB FUN gathering.

One mom volunteered to host the summer picnic at her private town beach at the CT shore in July 2003. We talked about the CT legislature and budget cuts in our state. In addition, the parents and children who testified at the legislature in March were praised for their heartwarming testimonies. Parents and children who visit our capitol and legislature always have such a great impact on Senators and Representatives. Their stories were told and it made a huge difference in holding onto services for our children.

The Mom's Spring Fling participants also received a childcare stipend from our treasury to help defray costs for childcare that day. A fun time was had by all and we look forward to our picnic in July.

Annual CT Fall Family Fling

From Janette Peracchio and Andrea Garewski, CT Family Specialists

Despite overcast skies, the Connecticut Deafblind Families United Network (CT DB FUN) held its annual Fall Family Fling on Sunday, November 2, 2003 in Coventry, CT. The group enjoyed a hayride at The Pumpkin Patch, while singing songs and reading stories with "Mrs. Pumpkin". Later in the day, the group was treated to a fascinating dairy farm tour at Hytone Farms, compliments of "Farmer Bill" (Sara's dad). A fun day in the country was had by all!

The group's planning committee meets every January to schedule three major events for the upcoming year. The events held are the "Spring Fling", the Summer Family Picnic", and the "Fall Family Fling". We invite and encourage any new families to attend. Anyone interested please contact us at - 860-602-4128.



From left to right, Front row: Madison. Middle row: Amy, Joey, Merisha. Back row: Sean, Sara and Katie at the November 2nd, Hayride -

NTAC Topical Workshop on Transitioning

From Janette Peracchio, CT Family Specialist

I was very fortunate to attend the workshop on transition because my 21 year old daughter, Sara, is in the process of moving from High School to the adult world. This workshop was extremely relevant to the stage we are presently going through. I always knew transition planning was important for Sara's future, and this workshop gave me tools to make that happen.

Five topics covered at the workshop included IDEA regulations on transition; how to transition youth with disabilities to adult life; how to get the educational support in transitioning students; what to look for in post-school outcome studies; and how to provide good transition practices in our states.

An overview of Transition was given by Dr. Rick Blumberg, as well as a discussion of the Best practices for smooth transitions for all students. Dr. Jerry Petroff reviewed our Assumptions and Beliefs about deafblind children and how to make smooth transitions happen for them.

Things that were reinforced in my mind include:

- ◆ Transition is not just a job. It should/can include sports and fitness, health, recreation, clubs, travel friends, pets, further education - either academic or community based.

- ◆ A transition team can make things happen: share work, overcome barriers, share ideas, open doors, search for community resources, foster social relationships in the community.

- ◆ During the last few years of high school students often need an increased level of services (OT, PT, Speech) so students can be integrated into the larger community. Parents tend to want to keep their child's world small and safe when actually students need more access to the world and to develop interdependent relationships.

- ◆ Most importantly - Parents and siblings are the constant for our children-we cannot be absent in this critical planning stage. We need to make our hopes and dreams known. Very often, we just want for our children what the other kids are doing, at every stage in their lives.

Please ask yourself these two very important questions:

1. Is my child's school preparing him/her for his/her life as an adult?
2. How can WE make this happen?



The Sibling Support Project is now offering Workshops on Sibling Issues and Training on the Sibshop Model

Brothers and sisters are too important to ignore, if for only these reasons:

- ◆ Siblings will be in the lives of family members with special needs longer than anyone. Brothers and sisters will be there after parents are gone and special education services are a distant memory. If they are provided with support and information, they can help their sibs live dignified lives from childhood to their senior years.

- ◆ Throughout their lives, brothers and sisters share many of the concerns that parents of children with special needs experience, including isolation, a need for information, guilt, concerns about the future, and care giving demands. Brothers and sisters also face issues that are uniquely theirs including resentment, peer issues, embarrassment, and pressure to achieve.

- ◆ No classmate in an inclusive classroom will have a greater impact on the social development of a child with a disability than brothers and sisters will. They will be their siblings'

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lifelong “typically developing role models.”

The Sibling Support Project is the only project dedicated to the concerns of brothers and sisters of people with special health, developmental and mental health concerns.

Our books for families can be found at web site:
<http://www.amazon.com/exec/obidos/ASIN/>

**[1557661693/qid=981224290/sr=1-1/
ref=sc_b_1/107-8353851-
4551735#Sibshops>Sibshops](http://www.amazon.com/exec/obidos/ASIN/1557661693/qid=981224290/sr=1-1/ref=sc_b_1/107-8353851-4551735#Sibshops>Sibshops)**

**[0933149980/ref=sim_books/107-8353851-
4551735#Views from our shoes](http://www.amazon.com/exec/obidos/ASIN/0933149980/ref=sim_books/107-8353851-4551735#Views from our shoes)**

**[0295975474/ref=sim_books/107-8353851-
4551735#Uncommon Fathers](http://www.amazon.com/exec/obidos/ASIN/0295975474/ref=sim_books/107-8353851-4551735#Uncommon Fathers)**

include (all above in bold, no spaces)

The Sibling Support Project is pleased to announce SibNet and SibKids

The Sibling Support Project of the Arc of the United States is pleased to announce SibNet and SibKids. SibNet and SibKids are the internet’s only listservs for and about brothers and sisters of people with special health, development, and emotional needs.

Both SibKids (for younger brothers and sisters) and SibNet (for older siblings) allow brothers and sisters an opportunity to connect with their peers from around the world. Both listservs have members from the US, Canada, Australia, England, Japan and elsewhere. SibNet (started in 1996) and SibKids (started in 1997) are remarkably warm, thoughtful, and informative communities where young and adult brothers and sisters share information and discuss issues of common interest.

Anyone who has email can subscribe to SibKids and SibNet. For a no-cost subscription and to learn more about SibKids and SibNet, please visit the Sibling Support Project’s Web Page (see address below). Finally, if you have further questions about SibKids, SibNet, our sibships or the work of the Sibling Support Project, please contact:

Don Meyer, Director - sibling Support Project of
the Arc of the United States

6512 23rd Ave NW, #213, Seattle, WA 98117

Telephone: 206-297-6368

email: donmeyer@siblingsupport.org,

Web: www.thearc.org/siblingsupport/



Ear & Eye Facts

From: American Health, December 1994

Ear Facts:

The sound of your own voice is conducted to your inner ear internally, through your skull, as well as from outside. That’s why when you hear your voice coming entirely from an outside source, such as a tape recording, it sounds unfamiliar. The stirrup, in the middle ear, is the smallest bone in the body, smaller than a grain of rice.

Eye Facts:

Ten percent of men have some form of color blindness, an inherited trait that occurs because one type of cone is either missing or functioning poorly. For perfect vision, the lens must focus an image directly on the retina. Nearsightedness (myopia) occurs when the image falls in front of the retina, and farsightedness (hyperopia) when the image falls beyond the retina. Another cause of blurred vision, astigmatism, results from an imperfect curvature of the cornea.

Images land on the retina upside-down, and the brain automatically converts them to right side up. In experiments with volunteers wearing glasses that intentionally invert images, the brain adjusts to see them right side up within a few days.

A Selected List of Childrens Books Featuring Characters with Visual Impairment

This is a list of SOME children's books containing characters with visual impairment . . .

* only denotes recommended reading.

Taking Hold- My Journey Into Blindness (ages - 12-16) * **this is the equivalent of 2 children's books as it is at the junior high level**, By: Alexander, S. H. Simon & Shuster. Copyright 1995, ISBN: 0027004023

On My Own- The Journey Continues (ages - 12-16) * **this is the equivalent of 2 children's books as it is at the junior high level**, By: Alexander, S. H., Farrar Straus & Giroux, Copyright 1997, ISBN: 0374356416

*Mom Can't See Me (ages - early elementary), By: Alexander, S. H., Copyright 1990

*Mom's best friend (ages - early elementary), By: Alexander, S. H., New York: Macmillan Publishing Company, Copyright 1992

The Blind Men and the Elephant (ages – elementary), By: Backstein, K., Scholastic Inc., Copyright 1992

*Sing to the Stars (ages - elementary), By: Barrett, M. B., Little Brown & Co., Copyright 1994

Tangerine (ages 12-16) * **this is the equivalent of 2 children's books as it is at the junior high level**, By: Bloor, E., Apple Signature of Scholastic, Copyright 1997, ISBN: 0-590-43277-x

*Arthur's Eyes (ages – preschool / elementary), By: Brown, M., Chicago. Little Brown & Co., Copyright 1979

Gift of Gold (ages 12-16) * **this is the equivalent of 2 children's books as it is at the junior high level**, By: Butler, B., New York: Simon and Schuster., Copyright 1973, ISBN: 671-29742-2

Light A Single Candle (ages 12-16) * **this is the equivalent of 2 children's books as it is at the junior high level** By: Butler. B. Simon and Schuster, New York, Copyright 1970. ISBN: 671-29758-9

**Seeing Things My Way (ages - elementary / preschool) By: Carter, A. R. Albert Whitman & Company, Copyright 1998

See You Tomorrow Charles (ages - elementary) By: Cohen, M. Greenwillow Books, Copyright 1983

*See The Ocean (ages - preschool / early elementary) By: Condra, E. Ideals Children's Books, Copyright 1994, ISBN: 1571020055

Louie Braille - The Boy Who Invented Books for the Blind (ages – elementary) By: Davidson, M. Scholastic Trade, Copyright 1991, ISBN: 059044350X

Sees Behind Trees (ages 9-13) By: Dorris, M. Hyperion, Copyright 1997, ISBN: 0-7868-0224-3

The Seeing Summer (ages – elementary) By: Eyerly, J. J.B. Lippincott., Copyright 1981

Out of Darkness: The Story of Louis Braille (ages – elementary) By: Freedman, R. Houghton Mifflin, Copyright 1997

*Jenny's Magic Wand (ages - elementary) Hermann, H. & B. Franklin Watts, Inc., 1988

Helen Keller: Courage in the Dark (ages – elementary) By: Hurwitz, J. , Kent, D. & Quinlan, K. A. Copyright 1997

*Best Friends (ages - preschool / elementary) By: Hill, S. Creative Teaching Press Inc., Copyright 1998

*The Unfrightened Dark (ages 13-17) * **this is the equivalent of 2 children's books as it is at the junior high level** By: Holland, I. Ballantine Fawcett Juniper, Copyright 1990, ISBN: 0-449-70383-5

*The Window (ages 13-17) * **this is the equivalent of 2 children's books as it is at the junior high level** By: Ingold, J. Harcourt Brace, Copyright 1996, ISBN: 0-15-201264-8

Mandy Sue Day (ages - elementary) By: Karim, R. Clarion Books, Copyright 1994

Apt. 3 (ages - preschool) By: Keats, E. J. New York: Aladin Books of Macmillan Publishing, Copyright 1971

Through Otis' Eyes - A Lesson Learned from a Guide Dog Puppy (ages - preschool / early elementary) By: Kennedy, P. B. Howell Book House, Copyright 1997, ISBN: 0876054734

Naomi Knows its Springtime (ages - elementary) By: Kroll, V. L. Boyds Mill Press, Copyright 1993

Women Of Our Time - Helen Keller, A Light for the Blind (ages – elementary) By: Kudlinski, K. V. Penguin Books,

(Continued to page 11)

(Continued from page 10)

New York, Copyright 1989

Blindness - Understanding Illness (ages 9-12) By: Landau, E. Twenty First Century Books, Copyright 1995, ISBN: 0805029923

A Cane in Her Hand (ages - elementary) By: Litchfield, A. B. Chicago: Albert Whitman and Company

Stars Come out Within (ages - elementary) By: Little, J. Viking Press, Copyright 1991

*From Anna (ages - elementary) By: Little J. New York: Harper Trophy of Harper Collins Publishing, Copyright 1972

*Listen for the Singing (ages 8 - 12) By: Little, J. Harper Trophy of Harper Collins Publishing, Copyright 1977

*Listen for the Fig Tree (ages 13-18) * **this is the equivalent of 2 children's books as it is at the junior high level** By: Mathis, S. B. ISBN: 670-43016-1

*Listen for the Bus (ages - preschool / elementary) By: McMahon, P. Boyds Mill Press, Copyright 1995

*Can You Feel the Thunder (ages 12 -16) * **this is the equivalent of 2 children's books as it is at the junior high level** By: McElfresh, Lynn E Atheneum Books for Young Readers, Copyright 1999, ISBN: 0-689-82324-x

*Through Grandpa's Eyes (ages - preschool / early elementary) By: MacLacblan, P. Harper Trophy of Harper Collins Publishing, Copyright 1980

Knots on a Counting Rope (ages preschool / early elementary) By: Martin, B. & Archambault, J. Henry Holt and Company, Copyright 1987

Blind Flight (ages 12-16) * **this is the equivalent of 2 children's books as it is at the junior high level** By: Milton, H. Franklin Watts, Copyright 1980, ISBN: 0-531-04108-5

*Lucy's Picture (ages - preschool / elementary) By: Moon, N. Dial Books for Young Readers, Copyright 1994

*Jennifer Jean the Cross-Eyed Queen (ages - elementary) By: Naylor, P. R. Carolthoda Books, Copyright 1994
Carver (ages - elementary) By: Radin, R. Y. Macmillan Publishing Company, 1991

Spectacles (ages - elementary) By: Raskin, E. Antheum,

Copyright 1980

Wild Horse Summer (ages 9-12) By: Ryden, H. Clarion Books, Copyright 1997, ISBN: 0395775191

Into the Dark (ages 13-17) * **this is the equivalent of 2 children's books as it is at the junior high level** By: Stine, R. L. Archway of Pocket Books, Copyright 1997, 1997 ISBN: 0-671-52966-8

*Glasses, Who Needs 'em (ages - elementary) By: Smith, L. Puffin Books, Copyright 1991

The Cay. (ages 12-16) * **this is the equivalent of 2 children's books as it is at the junior high level** By: Taylor, T. Doubleday, Copyright 1987, ISBN: 0-3850-7906-0

The Seeing Stick (ages - elementary) By: Yolen, J. Thomas Y. Crowell, Co., Copyright 1977

Crystal Moonlight (ages - elementary) By: Weldman, D. K. Rebecca House, Copyright 1990

My Sister Katie - How She Sees God's World (ages - preschool / early elementary) By: Wright, C. Minneapolis: Augsburg., Copyright 1990



Congratulations!!!

Last year, the Massachusetts Deafblind Family Alliance (MDBFA) work diligently in advocating that services for youth who are deafblind and turning 22 were maintained in the Governor's budget. Recently, the budget was passed and included a \$74, 000 increase over last year's budget, insuring that Turning 22 Services for the blind would certainly be continued. Many thanks to the families who called their legislators and made their voices heard. Your involvement and attention to legislative issues relative to the services and needs of deafblind children, youth, and adults really does make a difference!!

Your Help is Needed in Updating our Database

The NEC would like to ask all of you to please forward any and all changes to your name/address/phone or email to the center attention: Cheryl Harvey, Project Assistant, Thank you.

Trainings in Massachusetts for Families

(Edited from The Family network, A family support newsletter designed to inform families of upcoming events throughout the region. Jan Issue)

IEP Clinics (Time TBA)

February 12, 2004

March 18, 2004

April 15, 2004

Deb Crane, Educational Advocate, will provide a private one hour consultation to parents whose children are eligible for DMR services. Held at EMARC, Reading. Call for an appointment Deb Crane, 781-942-4888 X4019.

Let's Get Organized

March 9, 2004 7-9 pm

What to do with all that paper! Doctor's reports, therapy progress, IEP's, insurance info-Bring your records - you can organize them that evening! Supplies are included. Held at EMARC, Reading. Contact Vici Riel Smith 781-944-4888 X4021

Visions of Community:

A conference for families of children with special needs and the professionals who serve them.

March 20, 2004

8:00 - 4:00 pm

World Trade Center, Boston

Call 1-800-331-0688 or

www.fcsn.org

Basic Rights

March 24, 2004 - 7-9:30 pm

Holly Neal, Parent Training/ Advocate from the Federation for Children with Special Needs will review basic rights on IEP's and will share updates, information or

changes in our child's IEP. Held at Courtyard at Marriott, Andover Contact Eileen Lee, 978-738-0070 FFE3@aol.com

Links to Curriculum Frameworks

March 25, 2004-9:00 - 12:00 noon

Assistive Technology can help students with disabilities demonstrate their knowledge and develop skills. Held at Easter Seals, Worcester. contact Thao Duong at 800-922-8290 X328 or www.EasterSealsMA.org.

Preparing for the Team

Meeting How to be a Proactive Member

March 30, 2004 7-9 pm

A list of tried and true strategies on how to make the most out of your child's IEP meeting. Held at EMARC, Reading. Contact Deb Crane 781-942-4888 X4019.

Transition to College and Work

April 6, 2004

State and federal laws that require the IEP to address goals such as transition to college, competitive employment and independent living to assist students 14 and older with planning transition to adult living. Held at the MerdochMiddle School, Chelmsford. Email register@fcsn.org or call 800-331-0688.

Peabody Parents of Children with Special Needs

April 6, 2004 - 7:00 pm

Neuro-psychologist Dr. Jan Schwartz will discuss ways to "build partnerships between home and school". Held at Higgins Middle School, Peabody, Call Rosemary Piaker 978-531-8005, PPCSNRosemary@aol.com

Say it with Pictures!

Using Visual Strategies to Enhance Communication

April 7th, 14th, 2004

Enhance kid's communication

skills through the use of environmental cues, pictures and using programs developed by Speech and Language Pathologist Linda Hodgdon and others. Held at EMARC office, Reading. Contact Kerry Mahoney 781-942-4888 x 4015.

How to Work with the Medical Dept. in your Child's School

April 28, 2004 - 7-9:30 pm

How to generate a Health Care Plan that reflects all of your child's medical needs while attending school. Held at Courtyard Marriott, Andover Contact Eileen Lee, 978-738-0070 FFE3@aol.com.

The Following Workshop Presentations are available for you to schedule for PAC and advocacy groups:

Planning for the Future in Changing Times

A free workshop for Families Presented by: Cynthia R. Haddad, CFP Sibling and Advocate 781-893-0909 or www.specialneedsplanning.com

- How will the budget deficit effect our family members security?
- What parents and siblings can do today to provide financial security for tomorrow.
- Common mistakes families make in planning and how to avoid them.
- Protecting and maximizing Government benefits.
- Strategies to fund a Special Needs Trust.
- Purpose of The Letter of Intent Call or go to website for more information and dates. **Contact Andrea at 1-800-672-7084 or e-mail pfrr@fcsn.org for the**

following workshops:

Residential Schools-Know Your Rights

This workshop gives an overview of the rights of consumers and their children in residential schools. Topics covered include but are not limited to, laws, regulations, oversight, complain processes, state agencies, access to the general curriculum, MCAS, custody, and much more. We will discuss effective communication strategies when dealing with staff and others at a residential school.

If appropriate, we will also cover the establishment of PAC's at 766 approved residential schools.

Residential Schools and The Maze of State Agencies

DOE, DSS, OCCS, DMH, DMR, CHINS, and DYS, what's it all mean? This workshop gives information and insight into the different state agencies, their roles and responsibilities, cost share, and custody. Also, explains community based resources, how to find them and obtain them.

Preparing for Transition from Residential School to Home/Community

This presentation gives parents and others ideas and insight into how to transition a child from residential school to home. Topics include: ideas of when to begin transition process, how to collaborate services needed with state agencies to obtain appropriate services, how to get support from others, and much more.

A Parents Perspective

This presentation is for child-care workers, teachers, administrators and others who work in the residential school field. It offers insight into the challenges parents face when having to place the life of their child in other's hands. Tips for developing collaborative relationships with families is also covered.

The following Mass. Advocacy Center courses are available for you to reserve for your P.A.C. and support groups.

Email or call Johanne Pino at 617-357-8431 ext.234

pinoj@powerinter.net for more information:

- MCAS and Students With Special Needs (Disabilities)
- Discipline for Children with Disabilities
- Autism Spectrum Disorder (ASD)

**Massachusetts Families
Organizing for Change
11th Family Leadership Series
January 30, 31, February 27, 28,
April 2,3, 2004**

**Will be held at the Holiday Inn in
Peabody. Registration required.
Contact Susan Nadworny 781-665-
5179 or**

**Snadw@aol.com for application
and details**

**Check the Federation website for
other workshops in your area
www.fcsn.org**



Legal and Future Care Planning Training

Topics: Negotiating the Social Security Maze, Preserving Eligibility for Government Benefits including MassHealth through proper estate planning, Guardianship and Less Restrictive Alternatives, The Implications for Consent, Health Care Proxies and Advance Directives, Selecting a Knowledgeable Attorney.

**Saturday, February 28, 2004
Minute Man Arc for Human
Services 1269 Main St., Concord,
MA**

Family members - \$20

Professionals - \$40

10% discount for local Arc Members

To Register: 978-371-1515 ext 122

Welcome to . . .

Cheryl Harvey our new Project Assistant.

Djene Morris is our new Family Specialist in Massachusetts, also working with Delma Boyce.

Glenda Longe is the new Family Specialist in ME

Ann Dillon is the new Family Specialist in NH.

**More Information for
Parents taken from:**

Parents' PLACE

(Parents Learning About Children's Education, as service for parents of kids in MA public schools)

is a Parent Information and Resource Center (PIRC) funded by the U.S. Department of Education to help families and educators advance children's success in school. for more information, call toll free 877-471-0980 or online at www.pplace.org

TRAINING IN NH

ATECH SERVICES ASSETT SPRING 2004 PROFESSIONAL DEVELOPMENT OPPORTUNITIES

Location: All the workshops will be held in the ASSETT Conference Room, 2nd floor of the Dolloff Building, 117 Pleasant Street in Concord, NH. PARENTS AND STUDENTS ARE INVITED TO ATTEND ANY OF THE WORKSHOPS AT NO COST. **For more information regarding these workshops: Please call (603) 226-2900 or visit our website at www.nhassistivetechology.org**

DEAF & HARD OF HEARING

1. Working Effectively with Students who are Deaf or Hard of Hearing **Dates: February 13, 2004, OR March 19, 2004, OR May 14, 2004**

BLIND AND LOW VISION

3. Piecing Together the World: Vision and Language Development in Children who are Visually Impaired, March 5, 2004
4. Literacy for Students who are Blind or Visually Impaired April 15, 2004
5. Helping Visually Impaired Students Get Organized May 11, 2004
6. Invitation for (AAC) Users, March 9, 2004
9. DynaVox: Selection Methods, March 10, 2004
10. DynaVox: Using the DynaVox to Communicate, April 14
11. DynaVox: Information Management, May 12, 2004

TRANSITION

12. Technology Solutions to Support Transition: PowerPoint and Photo Story, March 12, 2004

ASSISTIVE TECHNOLOGY (AT)

The workshops listed below will be presented by Therese Willkomm, Ph.D., ATP. These workshops can also be customized to be held at your school, agency, or place of business. **Please call 603-226-2900 for more information. AOTA CEU's will be provided for all AT workshops. ATECH Services is an AOTA Approved Provider.**

13. Assistive Technology and School-to-Work, February 24, 2004
14. Creating a Universally Designed Classroom, March 16, 2004-
15. Assistive Technology Solutions in Minutes: An All Day Hands-on Fabrication Workshop, March 30, 2004
16. Making Your Website Accessible, April 13, 2004
17. Switch Making, Mounting, and Modifying, April 27, 2004
18. Electronic Memory and Prompting Aids, May 20, 2004
19. Assistive Technology and the Workplace-Rapid Solutions at a Low Cost, June 1, 2004

AUDITORY PROCESSING DISORDER

20. Demystifying Auditory Processing & Auditory Processing Disorders, March 8, 2004

COMPUTER ACCESS

21. IntelliTools for Beginners, February 17, 2004
22. IntelliTools Intermediate, March 23, 2004

Other Workshops Offered by ATECH Services

Call 603-226-2900 to set up dates, times and locations

23. Basic Switch Making
24. Creative Problem Solving and Worksite Accommodations
25. Assistive Technology Solutions for Home, School, Work, and Play
26. Electronic Aids for Daily Living
27. Computer Access Hardware and Software for Physical Disabilities

28. Computer Access Software Training
29. Adapting Music, A Workshop for People with Disabilities
30. The Principles of Communication Devices and Strategies
31. Breaking the Cycle of Underestimating the Potential for Communication
32. The Role of the Communication Partner
33. The Importance of Seating and Positioning
34. Mobility
35. Commercial Products and Custom Modifications for Activities of Daily Living and Work Activities
36. Solutions for Home Access-Modifications vs. Renovations
37. Solutions for Home Safety
38. Bridging the Gap Between Home and School
39. Products & Techniques to Prevent Injuries to Direct Care Staff



Announcing Professional Development Opportunities for Spring '04 Registration Form

Name: _____

School: _____

Address: _____ City: _____ State: _____

Zip: _____ Work Phone: _____

Home Phone: _____

Email Address: _____

I am a teacher paraprofessional student parent other

Workshop Number: _____ Date: _____

Workshop Title: _____

Number of Participants: _____

ASSETT Student(s) who will Benefit: _____

In order to fully participate in this workshop, I need the following accommodations:

Braille Materials Large Print Materials

Sign Language Interpreter ASL PSE

Other (please explain): _____

If you have any questions please call us at (603)226-2900 V/TDD or fax us at (603)226-2907.

“Save the Dates”

Upcoming Trainings, Workshops, and Events

Please visit www.necdbp.org and click on “Events” for detailed event descriptions and schedule updates

Date	Event	Location
March 17 th	ME Instate Planning Committee Meeting (9:00 - 12:00 pm)	Augusta, ME
April 4 th	CT Spring Fling - Adult Caregivers Day Out. Shopping, movie and lunch.	Westbrook Shopping Outlet
April 7 th - 8 th	NEC Hearing Workshop	Hilton Building, Perkins School for the Blind, Watertown, MA
May 1 st	New England Regional Seminar for Children Visually Impaired and their Family including Deafblind, Birth to Age 7 years Lunch and childcare provided	Hilton Building, Perkins School for the Blind, Watertown, MA
May 19 th & May 20 th	NEC Multistate Meeting 9:00 - 4:00 pm, 8:30 - 12:00 pm	Hilton Building, Perkins School for the Blind, Watertown, MA
May 20 th	NEC Advisory Committee Meeting (1-3 :00 pm)	Hilton Building, Perkins School for the Blind, Watertown, MA
May (TBA)	Introductory Level Training for Those Working with Children who are Blind or Visually Impaired with Additional Disabilities. Call 207-941-2855 for more info.	Portland, ME
June 2 nd	Teaching Children with Visual Impairments and Additional Disabilities. Call 207-596-6209 or 207-941-2855 for more info.	Orono, ME
June 19 th – 23 rd	Perkins Outreach - Summer Institute	(TBA)
June 27 th - July 1 st	NEC - Summer Institute	(TBA)
July (TBA)	NEC - CVI Training with Dr. Christine Roman	Hilton Building, Perkins School for the Blind, Watertown, MA
September 12 th	CT Summer Family Picnic - Rain or Shine -	Eastern Beach, Groton CT
October (TBA)	NEC Family Harvest Day	(TBA)
November 7 th or 14 th (not yet set)	Holiday Gathering, Pot Luck, Crafts for kids, CT DB FUN Meeting	(TBA)

New England Center Deafblind Project Contact Information

NEC

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

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

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

Cheryl Harvey
Project Assistant
(617) 972-7515
NEC@perkins.org

Connecticut

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

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

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

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

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

Maine

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

Glenda Longe

Family Specialist (ME)
(207) 596-6209
glelonge@tdstelme.net

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

Massachusetts

175 North Beacon Street
Watertown, MA 02472
Susan DeCaluwe
Education Consultant (MA)
(617) 972-7516
Susan.DeCaluwe@perkins.org

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

Delma Boyce
Family Specialist (MA)
(617) 972-7543
dollysmom2@aol.com

Djenne Morris
Family Specialist (MA)
(617) 972-7543
djenne.morris@verizon.net

New Hampshire

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

Evelyn Kelso, ASSETT
Education Consultant (NH)
(603) 226-2900
ekelso@nhaat.mv.com

Ann Dillon, ASSETT
Family Specialist (NH)
(603) 226-2900
aedillon@cisunix.unh.edu

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

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

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