in touch

Winter 2002

The Newsletter of the New England Center Deafblind Project
175 North Beacon Street • Watertown, Massachusetts 02472 • tel: 617-972-7515

Happy New Year!

Here we are in the year 2002 and so much has happened since our last summer newsletter. We hope that this year brings peace and good health to you and your family. Those of us at the New England Center and our affiliated agencies have hardly had the time to reflect on the previous year. However, the following provides a brief synopsis: CHARGE conference at Perkins/New England Center In February, 2001; Transition Workshop, NEC Summer Institute: Critical Issues in the Assessment of children with Multiple disbilies or Who are Deafblind. Our most recent activity was the famous NEC Family Weekend at the Seacrest Resort in Falmouth, Massachusetts (October 26th – 28th). It's fair to say that a good time was had by all. Most importantly, Harry Anderson from the American Association of the Deafblind and Dr. Jerry Petroff both provided guidance regarding ways that families can facilitate self-determination for their children.

While we are planning for the future, including a workshop on vision assessment and cortical vision impairment with Dr. Christine Roman in March 2002, we are also evaluating ways we can better support parents and families regarding the education of their child who is deafblind. While this newsletter includes some ideas and suggestions for families and professionals, please know that we welcome your input, ideas and suggestions for how best to provide training and information to families and program staff. Please don't hesitate to call us or send an email message if your have recommendations. Also, if you need to register a child with the New England Center or have questions regarding our trainings, please call us at 617-972-9715 or email us at nec@nec.perkins.pvt.k12.ma.us. Best wishes in our new year!!

There are only two lasting bequests we can hope to give our children. One of these is roots; the other is wings.
-HODDING CARTER

NEC Massachusetts Family Check-In

Within the next 2 months, Families in MA will receive a check-in call from a NEC representative. The purpose of this call is to check-in and see how NEC might best assist you, your child, or your child's program (relative to deafblind issues).
If the call is not convenient for you, please

Cortical Visual Impairment (CVI)

Mary T. Morse, Ph.D.

There are many causes for deafblindness. Some of these causes may be genetic, others due to a prenatal or postnatal virus, an accident or other reasons. If the cause affects the neurological system, then in may be possible that the individual may have either a primary or secondary condition known as Cortical Visual Impairment (CVI). CVI may be a primary visual condition or it may co-occur with other visual handicaps.

CVI is the most common visual condition found in children in the United States and is considered both a visual and neurological disability. In some individuals with CVI, other neurological problems are considered "mild" but, in most individuals, they are multiple and complex. CVI is, perhaps, one of the most difficult visual conditions for parents, teachers, and others to understand.
Under typical conditions, the child's eyes look fine. Indeed, they're eyes are often quite beautiful. A great many of the children appear, at times, to see, but at other times, just seem to gaze into space. Other children may never appear to use their vision but have trouble with some particular aspect of their visual world.

Why is this visual disability so difficult to understand?

The ocular structures of the eye capture the visual image, but it is the brain that makes sense of this information. Although the occipital lobe of the brain (in the very back of the head) is a very important visual center, this center must work cooperatively with other parts of the brain in order to make sense of visual stimuli. The location and extent of an insult to the brain determines which functional behaviors will be affected. That is one of the reasons why there is such variation between persons who have the same diagnosis.

Some Commonly Known Characteristics of CVI

- Individuals with CVI demonstrate wide variations in the functional use of vision. Some individuals demonstrate no visual responses at any time, while others have considerable use of vision. For those who show some visual responses during infancy, the prognosis for increased funtional use of vision is good. Indeed, many may use vision as their primary

- Individuals with CVI demonstrate wide variability in their ability to efficiently use vision on a consistent basis. Some people may/may not recognize objects in general or certain categories of objects (e.g. animals, automobiles, the human face).

- Persons with CVI may have wide variation in regard to additional disabilities with the possibility of other ocular handicaps, medical and health problems, seizures, hearing, communication, self-care skills, feeding, cognition, type of visual and auditory stimuli understood, interpersonal relationships, and learning potential.

- There is a wide variability within individual persons and between individuals in managing multi-sensory demands and planning/ implementing motor responses. Many, but not all, tend to use peripheral vision more than central vision and many have possible depth perception difficulties. There is also a tendancy to look away when reaching.

- Another aspect of CVI that parents, teachers and others find difficult to understand is that

processing problems, from a mild to a severe degree. Usually (but not always) this means the mechanisms for hearing are normal but the understanding of what is heard is at risk. As with visual processing, it takes a considerable portion of the brain to make sense of the auditory message. Believing that central auditory processing difficulties exist is hard to understand because most individuals with CVI are reported to be very interested in sounds. They even may give the appearance of understanding most of the sounds they hear. However, caution is suggested in assuming that smiles and attention automatically mean understanding of what is said. Many persons respond more to the melody, intonations, emotion and/or routine of what is said than to the actual words that are spoken. The degree of difficulty in understanding language varies widely and depends on the location and extent of the brain insult.

Characteristics of CVI not Commonly Addressed

Some individuals with CVI do not have obvious additional disabilities. These individuals may be able to walk, care for themselves, talk, and have visually-based difficulties with specific stimuli and skills that are of neurological origin. These individuals may have difficulty or the inability:
- to recognize objects
- to recognize and discriminate one human face from another (remember: all faces are structurally the same), or to point to various parts of their own body
- to recognize a human face as more than an object unless it moves or talks
- to organize oneself spatially and to comfortably move through even a very familiar environment and to distinguish left from right
- to recognize colors or visual symbols which may include print, photos, and/or line drawings

Prosopagnosia and Facial Agnosia

A particular sub-set of individuals with CVI may have difficulty or the inability to recognize familiar faces (*Prosopagnosia)* or difficulty to recognize any face, familiar or not (*Facial Agnosia)*. Processing the human face is an extraordinarily complex visual, neurological, social, and communicative process. These individuals may have several of the following characteristics:

the condition and may have variations in brain imaging results.

- Will show variations even within this sub-group of persons with CVI. For example, may/ may not have associated agnosias (not recognize objects and/or certain categories of objects and/or two dimensional visual representations and/or certain categories of two dimensional visual representations).

- May avoid visually fixating on the human face OR may stare intently at the human face OR may look toward only one part of the face (e.g. mouth) rather than the facial configuration

- May be able to name and/or point to various parts of the face but not recognize and identify the total configuration. Many may recognize some faces from one orientation, within context, but not be able to generalize that face to other orientations or situations.
- A seemingly common characteristic is that many children may want to touch people--especially their faces.

- May not understand totality of language but brighten considerably when language is combined with emphasized

difficulty in using pronouns. Still others may use language but tend, at times, to "talk to the air." It is not uncommon for persons with this condition to have difficulty in discriminating one voice from another. Many may have excellent short term auditory memory.

- May not realize a person is present unless the person says something or moves. Even then, some may treat people as objects. If they do recognize a person is present, they may focus on a specific aspect of a person for identification.

Needless to say, persons who have difficulty with facial recognition usually have difficulty relating to peers. They may appear to prefer objects to people. To add to the confusion, some persons may/ may not have difficulty interpreting some/all types of two dimensional visual representation. Many may show definite ability to learn--especially colors, shapes, and repeating the alphabet. Some may be able to recognize pictorial representations of faces but not be able to do so with a tangible face. Many of these same children may have difficulty modulating their states of arousal and frequently are said to be inattentive and

For many students who are deafblind, vision is their primary information gathering sensory modality. some of these same students also may have cortical visual impairment. Determining if this is a secondary condition is present and, if so, the nature of the condition, is critical in determining appropriate teaching means.

Some Diagnostic Strategies for Suspected Facial Recognition Problems

What is the Visual Diagnosis? Be especially sensitive to CVI, hemianopsia, optic nerve atrophy and/or optic nerve hypoplasia

What is the cause of the condition? Be especially sensitive, but not limited, to strokes, meningitis, toxic shocks, right brain insults, occipital insults.

Have any types of brain imaging procedures been done? What are the possible implications of the results? The diagnosis is difficult and involves both sophisticated perceptual tests and sophisticated imaging techniques.

Parent reporting: For example, "doesn't recognize..." or "loves

School reporting: Plays alone; likes to be in corner or under table; shows no reaction when parent comes to school; ignores peers; touches peers a lot and sometimes "hurts" them; looks at objects more than people; "nothing wrong with his vision, he can see everything;" does not make eye contact; stares intently at people; little "peculiarities" in his/her language; tends to touch others a lot.

Mary Morse, Ph.D. is an Education Consultant for Children with Special Needs. To obtain Mary's "Initial Reading List to Begin the Process of Understanding CVI" please contact the New England Center Deafblind Project.

Key Ingredients in Developing a Behavioral Support Plan for a Child who is Deafblind

Tracy Evans Luisellsi, Ed.D.

Some children who are deafblind have challenging behaviors that pose serious problems for their families and interfere with community experiences. For example, a

extremely loud and more frequent than the tantrums of a typical young child. If a child has few adaptive and communication skills, the likelihood of challenging behaviors is often far greater. A behavior support plan may be developed to delineate specific procedures for how best to respond to problem issues and develop competing and more positive ways the child can interact and engage in activities (Sugai et al., 2000). Unfortunately, many families are not informed about what constitutes "best practices" approaches to behavioral intervention. The following list informs parents and families what to look for when a behavior support plan is proposed by the child's team:

1. Typically, a behavioral consultant is responsible for developing the behavioral support plan. Consideration should be given to the training level and background of the individual who will provide consultation or who will develop the plan. Generally, the behavioral consultant should be knowledgeable in the field of deafblindness or sensory impairments, as well as applied behavior analysis (ABA) and developmental disabilities. Many states now recognize board for a parent to review the certification status of the consultant (available through www.bacb.com).

2. In developing a behavior support plan, the consultant conducts a "functional behavioral assessment" (FBA), or process of identifying the factors that are most likely to reinforce or "cause" problem issues. During this process, the behavioral consultant should conduct several key steps: (a) conduct initial interviews with team members, including the child's parents or caregivers, (b) observe the child in school and/ or home setting or setting in which the behavior most likely occurs, (c) identify the child's likes and dislikes, (d) define the behaviors that will be the focus of intervention, (e) develop a written support plan, (f) review the plan on an ongoing basis, (g) be available to the educational team for questions or assistance in problem solving; (g) give feedback to team members concerning implementation of the behavior support plan and the need for modifications as warranted.

3. Data on the occurrence of target behaviors should be sent home on a regular basis to inform parents of progress. Ideally, these data should be understand and interpret. Data collection procedures usually are conducted by the child's teacher or a designated team member.

4. Best practices in the fields of applied behavior analysis and developmental disabilities require that a behavior support plan include strategies or procedures that facilitate the development of communication skills. The intent of these strategies is to teach the child who is deafblind appropriate and alternative ways to gain attention, make choices, and terminate activities. Most important, behavior intervention procedures should not be employed without this critical ingredient.

5. In some cases, certain challenging behaviors such as aggression and self-injury may be so serious that the child cannot be supported effectively in the ideal inclusive setting. Also, professionals in the setting have to be able to apply procedures with consistency and reliability, otherwise the plan should not be undertaken. Prior to transition from one classroom or program to the next, the team should consider whether the receiving staff or program are able to implement the behavior support plan accordingly.

to the implementation of a behavior support plan.

Lastly, in order for a behavior support plan to be most effective parents and families need to be directly involved in the development and evaluation of their child's behavior support plan. If information is unclear they should request clarification. Furthermore, when a behavior support plan is implemented at home, parents should always have access to the consultant to present the "pros and cons" of intervention and to express their concerns on any issue.

Sugai, G., Gorner, R.H., Dunlap, G., Hieneman, M., Lewis, T.J., Nelson, C.M., Scott, T., Liaupsin, C., Sailor, W., Turnbull, A.P., Turnbull, H.R., Wickham, D., Wilcox, B., Ruef, M. (2000). Applying positive behavior support and functional behavioral assessment in schools. (*Journal of Positive Behavior Interventions*), 2(3), 131-143.

Tracy Evans Luiselli is the Project Coordinator for the New England Center Deafblind Project.

AND PHYSICAL EDUCATION INVOLVEMMENT

Dear Parents,
As you know, it is often difficult to know what to do with your children during free time in your home, in the community, or in their physical education class. Whether your child is 1, 11, or 21, this is an ongoing question. Many of you do have some very functional, active, safe and interactive activities that you have set up in your home and community. There are also some successful physical education programs that are successfuland positive. I have seen activities that require little supervision, to activities that can be done with siblings, peers, neighbors and friends. In order to share information about activities that have been successful for you and your child, please fill out the following questionnaire and send it back to me (via mail or fax) so I can share the results and help families and children be come more active in the home. Thank you very much for your help in this worthwhile endeavor. If you would like a copy of the results, please include your name and address. If you have any questions, please do not hesitate to contact me.

Sincerely,
Lauren J. Lieberman, Ph.D
SUNY Brockport, Department of Physical Education
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Please fill out the following questionnaire and return to Lauren Lieberman at the address to the left. Thanks!

Name of child(optional): ______________________________
Age of child: _____ Gender: _____
Disability: ______________________________
Vision level: _____ Age of onset: _____
Add'l Disabilities: ____________________________________
Hearing level: _____ Age of onset: _____
Number of siblings: _____
Ages: _____ _____ _____ _____ _____ _____ _____ _____
Schooling:
Inclusive: _____
Type of classroom:

1 2 3 4 5

Satisfied Neutral Unsatisfied

Inclusive _____ What modifications are made, if any: ____________________________

Segregated _____ Small group _____ 1:1 _____ Other? _____

What modifications, if any: ____

Please rate your satisfaction with your child's current recreation at home:

1 2 3 4 5

Satisfied Neutral Unsatisfied

How much free time (hrs) does your child have during the week? _____ Weekend? _____

Please list and describe indoor activities that have been successful for your child

____

____

Please list and describe indoor activities that have been successful for your child

____

____

What assistive devices are necessary for your child's involvement?

____

Who is your child most likely to spend free time with?

Parents__ Neighbors__ Relatives__ Siblings__ Peers__ Sitter__ Other________________

Who is your child most likely to interact with during play at home?

Parents__ Neighbors__ Relatives__ Siblings__ Peers__ Sitter__ Other________________

What equipment or toy does your child enjoy interacting or playing with most (independent or with peers). Please also indicate store or catalogue information.

____

What activities would you like your child to participate in in the home?

____

What environment in your home does your child like best?

____

Please rate your satisfaction with your child's current recreation outside the home

1 2 3 4 5

Satisfied Neutral Unsatisfied

What recreational activities is your child currently involved in?

____

____

What recreational activities would your child like to be involved in?

____

____

What are the major barriers to participating in preferred recreational activities?

____

____

What agencies or organizations have been supportive as far as finanace or resources to assist your child in recreation?

New England Center Deafblind Project
Family Weekend 2001

On October 26th, 27th, and 28th, The New England Center held a Family Weekend retreat at the Sea Crest Resort in Falmouth, Massachusetts. Not only did folks enjoy the beautiful ocean setting and gala costume party, the training conducted by Dr. Jerry Petroff, New Jersey Deafblind Project, and Harry Anderson, the National Association of Deafblind Adults inspired families.

The training focused on the topic of self-determination and provided an opportunity for families to step back and think about where they want to go and " . . . how do you get there". On Sunday morning, families completed a two part plan. Part 1 answered the question how their child could be more independent and Part 2 parents listed ways they would address this issue when they returned home (a phone call to a specific agency, a request for specific services, reviewing their child's communication program to identify self-advocacy skills, etc.).

Of particular note, Brother/Sister Talk, a peer group comprised of teenagers shared thoughts and feelings with facilitator Ellen Lang, Social Worker for Perkins Deafblind Program, what it means to have a sibling with vision and hearing challenges. Che children enjoyed a range of coordinated activities: music, art & crafts, Mask making, sports, swim, and stuff it, under the supervision and facilitation of an excellent team of quality Activity Leaders and Childcare staff.

Here's what some of the families had to say about our speakers, Harry Anderson and Dr. Jerry Petroff, and about Family Weekend 2002 in general:

- *Harry Anderson is very uplifting and is a wonderful role model.*

- *Harry was real and relatable and helped us to believe in ourselves and our families.*

- *Wonderfully inspiring, and entertaining as well!*

- *You all get an A++ for this event!*

- *Jerry Petroff touched on a number of issues we personally have dealt with; he has a wealth of experience.*

- *Very practical and helpful information with stimulating and interesting delivery!*

- *Inspirational. Goal-setting was great! Meeting other families was wonderful; great support system!*

The NEC staff would also like to give special thanks to all the Perkins Staff and other volunteers who gave their time and effort to provide child care to the many children in attendence.

Melissa van Ham and Tom Collins with
Felix and Jazlene La Santa

Tabitha, Taylor, and Kim
at the "Stuff It" activity.

Sharon Stelzer and the kids making music with Music
Therapist Shannon Sherman

Playing the parachute game

Keynote deafblind speaker Harry Anderson with
Mara Evans and Jacey Shumaker

The Morris Family on the beach

by Glenda Longe
Madison, ME

As parents of deafblind children, how many times have we second-guessed our decisions? The right school, the right doctor, the right surgery, the right toys, the right equipment, even the right language (sign or speech)...the list goes on into infinity!

As the school year is about to begin again and you are still reeling from the spring I.E.P.'s and maintaining your child's learning level over the summer...take a break!

Not often do we get the chance to look back and reflect on the good things that we are doing with our children. Nor do we get to enjoy the simple pleasures of just family living and watching a child growing up. I want to encourage you to accept your family unit just as it is and enjoy your deafblind child, especially for who they are as people.

My son Ben was deafblind. He had his share of hospital visits (good and bad), teachers and schools (good and bad), and behaviors (good and bad). We all have our "war stories." That is part of raising a handicaped child (come to think of it, I have have of Ben are things that relate to his wonderful personality. He was above all else a human being with a personality that needed to be nourished. Take the time to truly love your child. I am so thankful for the memories that I have of times when we just let Ben be a kid and express his own uniqueness. This is not to say let your child rule the roost and run wild. (Trust me, I have spent my days trying to get Ben to remember when daytime and nighttime were when he had aparently forgotten).

Amidst all the decisions that you have to make, when the weight of those decisions seems to hard to bear, just step back and do something just plain fun with your child! Rediscover who your child really is, and then the hard decisions you have to make will see to come from within you. You are doing the right thing for your child, because you are doing your best. No one really expects more from you than that. Don't overburden yourself with "what ifs." Those thoughts will only prevent you from enjoying your child.

Someday, you will look back and realize that your child positively influenced those around him or her. It will be enjoy them.

This story is written by Glenda Longe. Her son Ben Giannola attended Perkins School from the time he was 6 years old until he was 20. Ben died in April 2000 after a very short illness.

Special Announcements

Maine Workshops

There will be an introductory training for teachers and other service providers working with children with visual and multiple disabilities. This training will be held twice at the end of the school year: once in May in Portland, and once in June in Orono. Please call Charlotte Cushman at 207-596-6209 for more information.

Announcing NEC's New Website

For information relat NEC and affiliated agencies, check us ou online at:

www.necdbp.org

January 28, 2002	Region IV, Part II	Quincy, MA	UCP Center
February 1-2, 2002	INSITE, Part II	Watertown, MA	Perkins School, Hilton Building
February 11, 2002	MA INSTATE	Watertown, MA	Perkins School, Hilton Building
February 13, 2002	Sensory Impairments	Shirley, MA	FIACC
February 25, 2002	MA INSTATE	Watertown, MA	Perkins School, Hilton Building
March, 2002 *dates TBA*	Developing Functional Goals and Objectives (Dr. Jennifer Grisham Brown)	Windsor, CT	Bureau of Educational Services for the Blind
March 11-12, 2002	Vision Assessment (Multiahndicappped/ Deafblind--Dr. Christine Roman)	Watertown, MA	Perkins School, Hilton Building
March 13-14, 2002	Vision Assessment (Multiahndicappped/ Deafblind--Dr. Christine Roman)	Windsor, CT	Bureau of Educational Services for the Blind
March 18, 2002	MA INSTATE	Watertown, MA	Perkins School, Hilton Building
March 26, 2002	Multistate Planning Team Meeting	Watertown, MA	Perkins School, Hilton Building
March 27, 2002	NEC Advisory Board	Watertown, MA	Perkins School, Hilton Building
April 3, 2002	An Introduction to Adaptive Design	Bangor, ME	call Charlotte Cushman for more information at 207-596-6209
April 8-9, 2002	NASDE	Watertown, MA	Perkins School, Hilton Building
April 12-13, 2002	Asssessment of Children who are Deafblind (van Dijk)	Watertown, MA	Perkins School, Hilton Building
April 13, 2002	Technology Day for People with Visual Impairments	Portsmouth, NH	Foundation for Seacoast Health

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