Summer is here!!
Hello there Families — and all professionals who worked so hard during the school year. Summer vacation is finally here — with all those plans to travel (or not!), to clear out closets, take out the bicycle and “dock” the car, and catch up with all that we could not do during the school year.

We had a wonderful “family” day on June 6th — where a few families were able to meet and chat, eat pizza, and make-and-take an “active learning” device for their child who is deafblind. Our “Family Focus” page will tell you more about this.

We also had our first training sessions on Usher Syndrome. Dr. William Kimberling was able to return to Oregon to let us know yet more about the exciting trends in research. He also shared that there are now plans “in the works” — and a grant to back it — that will help to coordinate Usher Syndrome screening at the newborn level. He anticipates coordinating this effort with the Early Hearing Detection Intervention (EHDI) programs.

In the afternoon of the training day, professionals and a few parents were invited to a panel discussion on Usher Syndrome. Dorothy Walt from HKNC provided really valuable personal perspectives; Mark McKeirnan (Southern Regional Program) and Dennis Crepeaux (Oregon Commission for the Blind) provided professional viewpoints relating to program modifications for school and transition beyond school.

HAVE A WONDERFUL SUMMER!
Below is the definition of "Deafblindness" that we use to determine whether a child or youth is deaf-blind. Many of our children who are deafblind (estimated 90%) have additional challenging conditions, including orthopedic or cognitive impairments, autism, traumatic brain injury etc. So we are looking at a population of children with complex and multiple needs!

"Children and youth having auditory and visual impairments, the combination of which creates such severe communication and other developmental and learning needs that they cannot be appropriately educated without special education and related services, beyond those that would be provided solely for children with hearing impairments, visual impairments, or severe disabilities, to address their educational needs due to these concurrent disabilities”

Within this group are also children who may have cochlear implants. Having cochlear implants changes what educational teams need to do and how they need to approach these children. Having a cochlear implant creates a set of needs very different than wearing hearing aids.

The Oregon Department of Education continues to be a major partner, collaborating with the Oregon Deafblind Project on many aspects of the grant. You can find updated information about the project on ODE’s website at: http://www.ode.state.or.us/search/results/?id=185
All newsletters and project brochures will continue to be posted at ODE’s site.

For planning our Family services, our main project partners are the National Consortium on Deaf-Blindness (NCDB), and the Oregon Parent Training and Information Center (OrPTI), and the Oregon Department of Education is the main funding agency for this aspect of our work. We are also beginning to work with teams of service providers at Providence’s Child Care Center in Portland.

Charlotte Reed, and other researchers from MIT are working to develop new devices that will aid persons who are Deaf to translate sound waves via vibrations — to augment lip reading: http://web.mit.edu/newsoffice/2009/deaf-touch-0226.html
These tactile devices will help distinguish nuances of speech that cannot be easily distinguished — such as the consonants “p” and “b”. They will be an "important tool for deaf people who rely on lip reading and can’t use or can’t afford cochlear implants". The research scientists involved with this project say that these aids will eventually be compatible with smart phones, "allowing such devices to be transformed into unobtrusive tactile aids for the deaf”.

The whole idea was originally gleaned from the field of deafblindness — and the Tadoma technique — a communication method used by persons who are deafblind. "Practitioners of that method hold their hands to someone’s face while they are talking, allowing them to feel the vibrations of the face and neck." Reed, in a study done 20 years ago, found tactile understanding of speech could be successful. She says, "We were inspired by seeing what deaf-blind people could accomplish just using the sense of touch alone.”
(Thank you to Ella Taylor of TRI for sharing this article.)

Take a look at the site below — it has information on Usher Syndrome: http://www.nidcd.nih.gov/health/hearing/usher.htm
And this one — which contains information on the less-frequently occurring Usher Syndrome III: http://allday.msnbc.msn.com archive/2009/ 03/19/1844254.aspx
It includes a video of a young woman who is losing her vision and hearing simultaneously. In her words, "It's like I'm slowly being taken from the world around me — like the end of an old Warner Brothers cartoon on TV where the picture becomes an increasingly smaller hole until it finally fades to black.” (Thank you to Angie O. from DBCI-CHAT)
On June 6, 2009, four families met at the Easter Seals Therapy Center in West Salem. Thank you Kathy — and Easter Seals Therapy Center, thank you Vicki (OrPTI) for suggesting this as a possible meeting place, and thank you planning group!

Parents in the planning group selected a make-and-take toy (a hula hoop mobile) out of the book "Hold Everything!" by Kay L. Clarke. This book is published by the Ohio Center for Deafblind Education and can actually be downloaded AT NO COST (or purchased for $18) from  
http://www.sSCO.org/ocdbe/products.html
It is also available in Spanish.

When you try this out for yourself, think of what appeals to your child’s senses. You might find a lot of items at home. Here are some ideas and examples:

For vision: Something shiny, sparkly, moving,brightly colored

For touch: Objects that are hard/firm, rough/smooth, soft/silky, prickly, "squeezzy", feathery, "tangly"/"twisty" (enticing the fingers!), warm/cold

For smell (and taste): (Items could be placed in potpourri sachets, on a spoon, in a sock) — lemon, vanilla, peanut butter, chocolate, spice, coffee.

For hearing: rattling, clanging, ringing, buzzing, rustling, ripping (Velcro),

For the "kinesthetic" sense (Muscles and joints): items that are heavy/light, long/short.

Stacey tries out their hoop with Mathew with sister Rylie making sure it works

Kay Clark, the author of the book, suggests trying to use the hoop when the child is in various positions and in various types of seats. She says, "sitting upright will give the child a spatially different experience than when laying down".

Positioning of the hoop should also take into consideration if the child prefers to, or is able to use one side of his/her body over the other.

She also cautions us that if a child likes to put toys in his/her mouth, to be cautious about what is selected.

Daci can’t believe his eyes!!!

The instructions for the Hula Hoop Hangar are on pages 19 & 20 of the book. It was fun shopping for what we needed! We did a round of the Dollar Tree, Home Depot, Wal-mart and Hancock Fabrics.
Caleb going to town with all that “stuff”!

The group was also lucky to be able to play in the Therapy Center’s “gym” with the therapy balls, and other equipment.

http://search.barnesandnoble.com/Poems-From-My-Life/Nella-Black/e/9781438939148

The News and Star, Sunday, 14 June, 2009 has an article about Nella Black by Steph Johnson. Nella is deafblind — and this is her first book. The really “cool” part is that she is 96 years old!

The news article states that the book is a “celebration” of Nella’s life, “a story of determination and a fight for independence”. Nella became deaf at 3 years old and had limited vision until 12 years before this article was written.

For much of her adult life, Nella cared for her mother who had suffered from strokes. She was 34 when her mother died. Nella was sent from England and lived in South Africa for a while — first with her brother and then in a home. She had a failed romance with a man who was also deafblind — mainly because her brother thought it was “indecent” for them to marry! With the help of a friend and a charity, Nella returned to England when she was 48.

"Nella has been writing poems since she was 21, keeping them safe in a box and hoping that one day they would be published.

"Her ambition has finally been achieved and Poems from my Life is on sale at W H Smith and Waterstones. The realisation of Nella’s dream has been a team effort from her friends, Oriel Temple provided the illustrations and Brian Rudd designed the layout. Nella is able to communicate thanks to a friend who signs questions onto her hand.

"And if the public agrees Nella will be able to fulfil another desire and help others with disabilities because the proceeds from Poems from my life will go to Deafblind UK. She told the News & Star: “I’m pleased with the book, it’s turned out very well.” (News and Star)

Thank you Angela O. of DBCI-CHAT for this info!
THE EVER-IMPORTANT “PAUSE”

Have you ever thought that our lives are made up of a series of pauses? We need to pause when we cross the street, or do a crossword puzzle, eat or drink, sing or dance — or just THINK. A PAUSE is also a major “tool” to ensure that children with deafblindness and/or multiple severe disabilities have the opportunity to understand, to respond, and to be motivated to listen.

“Rests” are pauses in a piece of music — and these can vary in length, some being simply take-a-breath-type of pauses. Without these, the music will sound different and will be really difficult to play or sing — like stringing together a whole lot of words in one long sentence or several. Difficult to read or understand! So the “silences” — or pauses — provide meaning and sense. Dance is comprised of movement — and PAUSES between movements. And then we have this button on our equipment — and we know how to use it.

With a child who is deafblind and/or multi-disabled some of the reasons we need to pause:

- To give a child time ADDITIONAL TIME to take in what was “said” in the first place — AND to allow this to happen uninterrupted;
- So that there is time for a response (from the child), no matter how subtle it is;
- To encourage the child to be a part of this “conversation”;
- To find interests in common — and therefore, motivators.

So, train yourself. PAUSE!

More next time....

THE TOOLBOX

A pause in speech is used to achieve some “effect”. We pause because we are trying to gather our thoughts and match these to what we are saying, or to emphasize a point, or to give listeners a chance to absorb what we are saying. Having a conversation with someone who talks non-stop is not just annoying, but we will probably not understand the communication. We need to think, breathe, leave a gap where another person can “jump in”. We also need to be aware of how to pause in the right place, and how long to pause — since these vary between languages, cultures, or even areas of a country such as the USA.

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More next time....
Attending a college, university, technical school or even a training program can be a challenge for individuals with a dual sensory loss. This is especially true for those who are transitioning from high school to one of these establishments.

Finding out what is available on campus; careful planning and self advocacy can assist with making sure that needed accommodations are available.

To assist the student, a resource guide was developed by Helen Keller National Center (HKNC) staff — Jo Ann Enos and Beth Jordan: “A Guide for Students Who are Deaf-Blind Considering College”. This is a useful tool for high school students who are deaf-blind, including those with Usher Syndrome, and deaf-blind adults needing further education to enhance career opportunities.

The publication is no longer in print. HOWEVER, you can download it from the HKNC web site, www.hknc.org:
http://www.hknc.org/Publications.htm — scroll down to number 6 where this publication is available in both text and pdf formats.

At this site, you can also find out about the National Registry and register yourself:
http://www.hknc.org/NationalRegistryMAIN.htm

It is important to do this because decisions at a national level are made based on your needs!!

Dorothy Walt is the northwest regional representative for the Helen Keller National Center (HKNC) and you can contact her for information, consultation and resources:

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PERSON-CENTERED PLANNING
“Person-centered planning involves the development of a ‘toolbox’ of methods and resources that enable people with disability labels to choose their own pathways to success; the planners simply help them to figure out where they want to go and how best to get there.”

If you want to learn more about this process, the Cornell University site below has seven courses.
http://www.ilr.cornell.edu/edi/pcp/

Each course provides an introduction, an activity, readings and resources, and a quiz:
1. Introduction to Person-Centered Planning
2. Community Membership: Opportunities for Meaningful Interaction
3. Self-Determination
4. Common threads between different person centered tools
5. Series: Popular Person-Centered Tools (This includes PPCT, MAPS, Person Futures Planning, PATH, and Circles of Support)
6. Organizational Change
7. Transition Planning

There are many useful links from each of these courses to sites on the worldwide web. Here are a few:

http://www.mncdd.org/extra/marc-gold1.html
Marc Gold’s “Try Another Way” is a values-based systematic training approach. He says, “The behaviors our children show are a reflection of our incompetence, not theirs.” This site has video and text to go with each segment being taught.

(links continued on next page)
http://www.qualitymall.org/main/
The Quality Mall is "a place where you can find lots of free information about person-centered supports......"

http://www.qualitymall.org/services/pcp1.asp

**PRINCIPLES**
(in outline)
- Each person shall have the authority to define and pursue his or her own vision.
- Self-determination is a must.
- Personal relationships and community membership are valued. (Inclusion!)
- All networks and systems of support must collaborate in support of the person's vision.
- People and families must participate as valued and empowered partners in all decision-making.
- Individuals must have supports to contribute to their communities and engage in meaningful work.
- Families are supported and valued.
- All people and families must have access to supports when and as they need them.
- The personal security and well being of people must be ensured.
- There must be a resolute, continuous commitment to achieve excellence in all dimensions of supporting individuals and families.

MAPS and PATH — two PCP processes — are used by many of us who work in the field of Deafblindness. The following two links contain a lot of excellent resources:

  Another MAPS site is at [www.circleofinclusion.org](http://www.circleofinclusion.org)

- [http://www.inclusion.com/path.html](http://www.inclusion.com/path.html)

The following page at the PACER center contains information on Person Centered Planning. It outlines the purpose, who should be involved, where to hold sessions, the tools needed and the steps for creating a successful plan. It is important to note their answer to the question "When should person centered planning take place?" is "At ANYTIME in a person's life. It is best done BEFORE transition services are determined".

http://www.pacer.org/tatra/resources/personal.asp

The site states that the PURPOSE of PCP is:
- To look at an individual in a different way
- To assist the focus person in gaining control over their own life
- To increase opportunities for participation in the community
- To recognize individual desires, interests and dreams, and
- Through team effort, develop a plan to turn dreams into reality.
THE DEAFBLIND WORKING GROUP

Marria Knight— Region one, Eastern Oregon
Colleen McLaughlin—Region two, Central Oregon
Mark McKeirnan— Region three, Southern Oregon
Terry Cadigan — Region four, Cascade Regional
Anne Olson-Murphy — Region five, Willamette Regional
Kim Puckett —Region six, Columbia
Kit Staples—Region seven, Lane Regional
Brenda Satter—Region eight, Northwest Regional
Jennifer Orton—Oregon School for the Blind
Donna Schuyler & Anne Harrington - Oregon School for the Deaf
Dennis Crepeaux— Oregon Commission for the Blind
Paddi Davies— NCDB representative, WOU
Tom Udell — NCDB representative, WOU
Sue Mathisen — Regional Services, Management Team
Sam Ko — Oregon Department of Education
Lyn Ayer — Oregon Deafblind Project

We have our newsletters on our web-page with the Oregon Department of Education:

http://www.ode.state.or.us/search/results/?id=185

Contact the Oregon Deafblind Project!

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