



# Oregon Deafblind Project



## Building Effective Programs

Lyn Ayer, Project Director • Fall 2009

### October 2009

Hello everyone!

Hope the new school year is going well! October 1st was our project's birthday — and we are now starting out on year 2 of activities. We are busy organizing team trainings in Portland, Salem, and Lincoln City. During summer, we trained one transition team in Mt. Angel; and volunteers, parents, CNAs and others participated in trainings at Providence Child Center in Portland.



We are still looking for a few more parents for our Leadership training. However, in the interim, we have had two Family get-togethers — one in West Salem (featured in our summer 2009 issue), and the other in Portland at the end of September.

The main focus of this fall newsletter is Respite Care (pages 5-7). Whenever parents fill out a needs assessment or a wish-list, this is usually at the top, or somewhere near there! And this ought not to come as any surprise to any of us. We all need a "breather"; we all need "space" or that "mental health" day that we talk about!

A few parents have their children at home and are home-schooling them. So I have added a short article on page 7, and web information too.

And last, but not least, we have some changes in our Deafblind Working Group. We had to say "good bye" to Mark McKeirnan from southern Oregon — and "Hello" to John Pierce. We also had to bid "Adieu" to Jennifer Orton (as the Oregon School for the Blind closed on August 31st); and "Hello" to Stephanie Karpouzis who is joining Kim Puckett to represent Columbia Regional.

Enjoy the newsletter!  
Lyn



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Project information:

- 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!
- Most children who are considered "deafblind" have some vision and/or hearing — and very few are totally blind and profoundly deaf.
- Within this group, there are children who may have cochlear implants. Having cochlear implants changes what educational teams 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 in our grant efforts, and will continue to assist us with family events and family-related project plans. Updated information, including all our newsletters, is at <http://www.ode.state.or.us/search/results?id=185>
- Other partners who continue to be involved with our Family services are the National Consortium on Deafblindness (NCDB), the Oregon Parent Training and Information Center (OrPTI), Oregon First, and the Swindell Center (Providence).



• Our project website is SLOWLY looking more like what we want. If you want to take a look at our "construction zone", go to: [www.oregondb.org/CommunicationHome.html](http://www.oregondb.org/CommunicationHome.html) and take a look at the first of our revised modules. We are really fortunate to have Roxanna Marvin from the Teaching Research Institute help us with this ambitious project. As you will see, she is not just someone who knows computer programs, but she is also creative, understands the content, edits out all the jargon that others and myself have put into the text, and is making the material more interesting and interactive. Thanks, Roxanna!



## NEWS ALERT!

There's a conference on **October 26th and 27th, 2009.**

**Theme: BUILDING FUTURES:**

Secondary Transition to College and Employment

### Session Topics:

- Age Appropriate Transition Assessment
- Intro to Brokerage Services
- Transition to Adult Mental Health Care
- Self Advocacy 101
- Become the Director of Your Own Life: An exploration of the Leadership Skills You Need
- Assistive Technology
- Tools for Success
- Voices of Youth with Mental Health Conditions
- Cultural Sensitivity
- It's More than Just color
- Transition to Employment
- Guess What Mom? A Panel Discussion on Youth Transition
- Diploma Options 2009;
- Work Incentive Topics,



**Target Audience:** Students and Young Adults with Disabilities, Parents and Professionals

Scholarships available for students and parents

**Where?** Salem Conference Center, 200 Commercial Street SE, Salem, OR 97301

### Keynote Speakers:

- Eleanor Bailey  
<http://www.mouthmag.com/issies/58/eleanorstory.htm>
- Logan Olson  
<http://loganmagazine.com/stories/logan.html>

**For more information** visit: [www.orpti.org/buildingfutures09.htm](http://www.orpti.org/buildingfutures09.htm) or call 1-888-505-2673

**To register** go to: <https://www.123signup.com/event?id=jgxxc>

### Sponsors:

**ODE (Office of Student Learning and Partnerships), Oregon VR, The Swindell Center, Providence Child Center, Oregon Competitive Employment Project, and the Oregon Parent Training and Information Center**

## THE TOOLBOX



### THE EVER-IMPORTANT PAUSE (2):

#### It's a matter of TIME

Have you ever "lost your voice"? It's a frustrating experience. Here are some of the things that happened to me:

- I could not respond when someone addressed me - not in a conventional way.
- I tried to "mouth" words - but most people around me couldn't lip read - and either misunderstood me, or did not "get" what I was saying.
- I gestured and waved my arms more than usual - and also attempted to put body language and facial expression to better use.
- I looked for a pen and paper - but found that people around me wouldn't wait for me to write things down.
- I lost control of many things around me - like checking the kids, sharing with my husband what happened during my day, ordering pizza over the phone, telling my friend that her new clothes looked really nice, etc.
- Most of all - I found that I wore down the patience of those around me!

Each one of us is so accustomed to running around and doing things quickly, that it becomes difficult to slow down, and to WAIT for someone who cannot keep up. It would have helped if people around me had:

- A. Given me more TIME to express what I was trying to express.
- B. Allowed me to use alternative communication and taken the TIME to understand these.
- B. Given me TIME to chat - via the written word (inevitably slower..... whether hand-written, or on a computer).
- C. Understood the "time = patience" formula!
- D. Tried to put themselves in my shoes — and FEEL the frustration of lack of TIME.
- E. Given me credit for being intelligent!

Transfer what happened to me to a child who is deafblind or has multiple severe disabilities - and you will find that issues are not that different:

- A child may not have conventional speech/language - but the urge to communicate is embedded in our very being. So - take time to learn how a child communicates -- or teach a child how to do this.
- STOP and watch - and see if you can detect subtle, and not-so-subtle communications - the blink of the eyes, stilling of the body, lift of a single finger, a smile or frown, a bounce or a stomp.
- A child may have an unconventional system that is being used - objects, pictures, touch cues - and we need to tap into these and make sure we use them - even when it takes more time.
- Provide the child with more "control" just by waiting for a response to each thing you say - or do. Being able to participate in the give-and-take of a conversation provides satisfaction.

STOP.

Take TIME.

PAUSE.

Learn PATIENCE!

#### Thoughts to ponder

- A child may need to move head, hands, arms — before pausing to attend (e.g., a child with Fragile-X syndrome who flaps his hands, walks around his chair, while he ponders "4 + 2 = ?" and then stops, picks up his pencil, and writes "6").
- Pausing sometimes may be a way for a child to create "sensory integration" for himself, or to "regroup" (e.g., when a child with CHARGE lies down flat on his back).
- A child creating a "quiet time" for himself — turning away, closing his eyes momentarily, holding a book over his face — may be the child's way to say, "I'm overwhelmed and need to stop for a moment."



More on next page.....

## THE TOOLBOX



### THE EVER-IMPORTANT PAUSE (2): It's a matter of TIME (contd.)

When we work with children who are deafblind, the pause becomes critical. Here are some techniques that persons working with children who are deafblind commonly use, but often without being conscious of the pauses and stops involved.

- When we approach a child, we must do so gently, allowing for time to pause — and for the child to figure out who it is. For example, if I hold out my wrist to a child, he needs time to feel the bead-bracelet I wear to confirm who it is. You don't just shake hands and walk away as you might do if the person could both see and hear. You would WAIT until you know you have been identified.
- Turn-taking would look quite crazy if it was done without a pause. "Your turn-my turn-your turn-my turn-your turn- my turn". It should be paced: "Your turn. PAUSE. My turn. PAUSE. Your turn. PAUSE" etc. Each person participating needs to pause before and after a turn — to reflect, to think, to transition.
- When trying to teach a child to indicate they want "more" of an activity, we create an artificial pause in an activity. For example, if you are bouncing a child on your lap or a trampoline, you would PAUSE and wait until the child indicates that he wants "more" bouncing, either through body-language, vocalizing, or sign language. In this case, the pause takes the place of a question — or is accompanied by it.

### Thoughts to ponder

- Music is the natural articulation — sometimes just within ourselves — of a series of tones and pauses. Sometimes we prefer one type of music to another — depending on our mood.:
  - Rapid, short pause music which is exciting and energizing;
  - Slow, enchanting music, with long pauses which is calming, "breathe-easy";
  - Staccato beats and rhythms which speed up the heart-beat and is exciting and challenging.

- When a child has completed an activity or a series of tasks within an activity, we teach him to indicate that it is "finished". This is a good way to create a pause that will help the child to transition to the next activity or series of tasks. Sometimes this "pause" may include a reward ("well done!", pat on the back, rub of the head, etc) or even a period of "down time" — a pause in his routines.
- As educators, we learn that repetition is very important. But that too would become confusing if there were no pauses between repetitions. We have to stop and think BEFORE we repeat something or have the child repeat it. It could be repetition of a series of movements (such as riding a bicycle), repetition of a word or a sign, or even just repetition of a response to a toy.
- We pause to create or ensure anticipation. How often have you been a part of a story-telling session where you pause for "effect"?

• The wolf huffed and puffed, and huffed and puffed and [PAUSE] — the house fell down!  
[PAUSE] and the three pigs had to scamper away really fast. [LONG PAUSE]

- Those ghost stories would be so much less effective without the pauses that create the drama — and the anticipation! We essentially do the same thing when we play "peek-a-boo" games.
- Tickling games, games such as "incy-wincy spider" would have little effect if we did not pause. In fact, they would be no fun at all! Imagine playing "This little piggy...." without pausing at the end before the last little piggy cried "Wee wee wee — all the way home!"



More next time!



## DID YOU KNOW?

**Thursday, October 29, 2009**

Ambridge Event Center  
1333 NE Martin Luther King Blvd.  
Portland, OR 97232

Parents, attorneys and professionals in special education — The Autism Society of Oregon is sponsoring a training by Pete Wright, Esq. [ of [www.wrightslaw.com](http://www.wrightslaw.com) ]. Learn more about the recent U.S. Supreme Court pro-child decision in *Forest Grove School District c. T.A*

The one-day special education law and advocacy sessions will focus on four areas:

- Special Education law, rights and responsibilities
- Tests and measurements to measure progress and regression
- SMART IEPs
- Introduction to tactics and strategies for effective advocacy.

For a detailed agenda and to register, go to:

[http://www.wrightslaw.comspeak/09\\_10\\_or.htm](http://www.wrightslaw.comspeak/09_10_or.htm)

Rates are reasonable!

Parent	\$35.00
Couple	\$50.00
Professionals/Teachers	\$65.00

- October 21-22, 2009, Seattle, WA: CAREER PLANNING FOR INDIVIDUALS WITH AUTISM SPECTRUM DISORDERS  
[www.SpectrumTrainingSystemsInc.com/Conferences.html](http://www.SpectrumTrainingSystemsInc.com/Conferences.html) (920) 749-0332

### FREE Workshops:

- November 7, 2009, Swindells Center, Toledo, OR: Navigating special education, and preparing your child for the future  
Contact: Danielle Bethell 1-888-505-2673, Ext. 105 or [dbethell@orpti.org](mailto:dbethell@orpti.org)
- October 20, 2009, Salem OR: EI/ECSE: Understanding, Supporting and Participating in your child's IFSP  
Contact Leah Skipworth 1-888-505-2673, ext. 214 [lskipworth@orpti.org](mailto:lskipworth@orpti.org)

## Thoughts Of A Deaf-blind Woman

By Tonilyn W.

Silence is for the hearing,  
Not the deaf;  
A deaf world is full  
Of many, many sounds.

Darkness is for the sighted,  
Not the blind;  
For the blind see  
Many wonderful things.

The world of the deaf-blind  
Is a wondrous place.  
We are not limited  
By our eyes and ears.

Everything we touch  
We see.  
Everything that moves within our touch  
We hear.

To smell a flower  
Is to see it,  
To hear it,  
To know the mystery of it.

We feel the breeze  
And see the leaves  
As they sway  
To Nature's music.

The sun on our faces  
Shows us the sunshine  
And the brightness  
Of the day.

Our lives are fulfilled,  
And filled with a multitude  
Of sights, sounds,  
Feelings, and living.

Don't mourn the deaf-blind  
For we have some of the  
Most fulfilled lives  
Of anyone that ever lived.

Share in our joys,  
Experience life to the fullest.

(Thank you, Toni!)



## RESPITE CARE SERVICES

is usually THE topic at the very top of an "interest list" from parents. This summer, one of our parents asked about this. In the process of finding out what was "out there", we talked to Mary Ann Hard who wrote this informational article below. Thank you, Mary Ann, for this information!

The Lifespan Respite Care Programs in Oregon are a result of HB 1013 which was passed by the Oregon Legislature in 1997. Oregon was the first state to recognize that "families are Oregon's most important and constant providers for individuals with special needs – of all ages." Caregivers face enormous stress, emotionally, physically, financially and socially. The majority of caregivers report experiencing depression, feelings of isolation, medical problems of their own due to the stress of caregiving, and frustration. "An occasional break, or respite, from the extraordinary demands of providing ongoing care strengthens the stability of families and caregivers." This break can also help family caregivers avoid abusing or neglecting their loved ones with special needs or placing them prematurely in out-of-home alternatives.

Lifespan Respite Care programs are designed to provide:

- Increased access to respite services
- Increased respite resources
- Improved quality of services
- Increased public awareness
- Increased community involvement
- A central point of contact for families and caregivers seeking respite and related supports

To receive services the family caregiver must be a non-paid family caregiver and the family must not be receiving respite care assistance from any other entity. Depending on funding for each of the 36 counties the Lifespan Respite Care Networks may vary in what is offered to family caregivers. Clackamas County provides all of the above components. The Clackamas County Lifespan Respite Care Network is also fortunate enough to provide a \$250.00 grant to families with special needs individuals. This funding is not based on income or medical diagnosis.

The funding begins each fiscal year (July 1-June 30). The Clackamas County Lifespan Respite Care Network tries to be as flexible as possible in understanding that respite care for each family looks different. Therefore, respite care can encompass the following:

- Traditional respite care in which a care provider comes into the home or the individual with special needs visits a site or center so that the family caregiver can take a break
- Housekeeping or yard work
- Equipment that may help the loved one with special needs and provide some relief for the family caregiver (computer equipment, walker, swings, specific play equipment, help with paying for a therapeutic animal)
- Horseback riding or other therapies
- Gym memberships for the family caregiver or family
- Massages
- Mental Health or Legal Counseling
- Lodging to get away
- Travel expenses – such as airline fare

The program does not pay for clothing, gas or food.

These are a few of the examples of the flexibility of the program and our desire to empower the family caregiver to decide what respite looks like and means to them. Our goal is to help caregivers "thrive, not just survive".

The application process is easy. Family members age 18 and above can be used as respite care providers. For more information about the Clackamas County program please call Mary Ann Hard at 503-650-5724.

Quotes are from "Building Oregon's Lifespan Respite Care System".

Mary Ann Hard, Program Coordinator  
Clackamas County Social Services  
Lifespan Respite Care and Family Caregiver Support  
P.O. Box 2950  
Oregon City, OR 97045

Other sources of information are:

- United Cerebral Palsy (503) 777-4166
- Other Lifespan Respite Care contacts around the state (see information on page 7)
- ARC of Oregon (503) 581-2726
- Oregon Council on Developmental Disabilities:  
<http://ocdd.org/index.php/ocdd/> ; Ask about funding, including Consumer Involvement Funds:  
[http://ocdd.org/index.php/ocdd/getinvolved/apply\\_for\\_consumer\\_involvement\\_funds/](http://ocdd.org/index.php/ocdd/getinvolved/apply_for_consumer_involvement_funds/)

## RESPITE CARE Web information

There is a "respite locator" on the ARCH website that contains a lot of valuable information: <http://chtop.org/ARCH/National-Respite-Locator.html>

You can

- search for Oregon's list of Respite Care services,
- Contact Oregon's Respite Coalition: <http://www.oregon.gov/DHS/respite/>

This site states: "Respite care is relief for families who are caring for someone with special needs: disabilities, chronic or terminal illness, aging or problems such as abuse or neglect. Respite care is short-term and temporary, lasting from a few hours to a month. Respite can take place once in a while, or be regularly scheduled care such as an after-school program.

"Everyone needs time: time to complete tasks; time to do things that are fun and rewarding; time to simply relax; time to think about day-to-day plans or to plan for dealing with major challenges. Without time for those things, anyone can become overwhelmed and exhausted. Families caring for someone with special needs need refreshing and energizing breaks. Respite is also very important to persons receiving care, regardless of their age or special need."

- You can find a local contact for Lifespan Respite Care on this site, learn how to find and select a provider, and how to pay for respite care. The Lifespan Respite coordinator map and directory is at:

[http://www.oregon.gov/DHS/respite/coordinators/local\\_coordinators.shtml](http://www.oregon.gov/DHS/respite/coordinators/local_coordinators.shtml)

It is really important that families know that "respite care" can be provided for many reasons. The examples this site provides:

- You may need to go shopping, keep an appointment, go for a movie, or just take a much-needed nap;
- You need to take a vacation;

- You would like to work or participate in volunteer activities outside your home;
- Parent
- Helping other family members who may need your assistance;
- Spending time with siblings of a child with disabilities.

As a family, you decide how you would like to use your respite care time. It will depend on what you need, and what services you may already have from your local community.

- Find a provider.

Look in the provider directories on the OHCC (Oregon Home Care Commission) website, find out how to hire, train and communicate better with persons you may hire.

<https://www.or-hcc.org/SelectUserGroup.aspx?PageID=118>

See the Spanish PDF version of the registry and referral system information at:

[http://www.oregon.gov/DHS/spd/adv/hcc/tools\\_emp.shtml](http://www.oregon.gov/DHS/spd/adv/hcc/tools_emp.shtml)

- Enrol for STEPS — a training to teach you how to do this without becoming frustrated! The brochure for the training is also on the page listed immediately above.
- Subscribe to OHCC's free e-mail service and receive alerts when there are updates.
- Attend OHCC meetings
- Read National Respite Coalition News, as well as our State Respite Coalition News — and stay updated!

<http://chtop.org/ARCH/ARCH-National-Respite-Coalition.html>

<http://chtop.org/ARCH/State-Respite-NEWS.html#Oregon>

- Read fact-sheets concerning respite care. You can print any of these. See "highlights" from one of these on page 8.
- Read the new FRIENDS factsheet #14 on Respite and Crisis Care:

<http://www.archrespite.org/docs/>

## RESPITE CARE Web information

Highlights from ARCH Factsheet Number 4: *Respite Care for Children with Developmental and/or Physical Disabilities: A Parent's Perspective*. (Author: Scott Miller, Family Support Services Coordinator for West Virginia, and parent of Josh, who has Down Syndrome)

- "Personal care through the Title XIX Medicaid program and grants through the "Temporary Child Care for Children with Disabilities and Crisis Nurseries Act of 1986 (as amended), have enabled families to receive respite care for free, or at a reduced, reasonable cost."
- Parents are reluctant to allow others to care for their child with a disability because they are concerned that caregivers do not have the training needed, and also because they believe no one can take care of their child as they can.
- The KEYS to a successful respite program are:
  - Building an infrastructure of "trust" between the agency and the family is absolutely crucial.
  - Providing flexibility and a variety of options
  - Empowering the family to make the decisions needed
  - Providing support, answering questions and linking the families to other agencies/ services
  - And — last but not least — Allowing families to train the providers.
- Aside from the training families will provide, the author states that respite providers should be trained in first-aid, CPR, disability awareness issues (they should "speak DD" — i.e., developmental disability terminology). They should know about specific medical conditions, and behavior management.
- There must be a "hands on" segment to the process where the care provider gets to know the family and the child, learns what is needed AND practices this until the parents are comfortable about leaving their child with this person.

## ANNOUNCEMENT

A statue of 7-year old Helen Keller was unveiled on Wednesday October 7th, 2009 — in Alabama.

"It is the first in the National Statuary Hall Collection depicting a person with a disability and the only one of a child." (AP)

Learn more, and watch a video by going to:

<http://www.wkrg.com/420503>

Or take a look at more photographs at:

<http://Photos.al.com/birmingham-news>

(Thank you to Mary Jean Sanspree of the Alabama Deafblind Project, and Toni Hollingsworth of the Mississippi DeafBlind Project for forwarding this information!)



## Homeschooling

I was browsing through my e-mail and remembered that a friend had sent me this information about her family's homeschooling website. If you or a friend's family are homeschooling your children, you might be interested in this:

<http://www.homeschool-rewards.com/>

The site discusses the pros and cons of homeschooling, curricula, fundraising ideas; it also has a blog site. You can register on their secure site to receive the "Homeschool Rewards newsletter". The great thing about this site is how it came together — not because of one person in the family, but because the family participates in this together, sharing the work that goes into creating the site.

These other websites give information about homeschooling children with disabilities :

<http://maaja.tripod.com/>

<http://www.familyvillage.wisc.edu/education/homeschooling.html>

<http://www.bellaonline.com/articles/art45894.asp>

<http://www.kidscanlearn.net/>



## THE DEAFBLIND WORKING GROUP

**Marria Knight**— Region one, Eastern Oregon  
**Colleen McLaughlin**—Region two, Central Oregon  
**John Pierce**— Region three, Southern Oregon  
**Terry Cadigan** — Region four, Cascade Regional  
**Anne Olson-Murphy** — Region five, Willamette Regional  
**Kim Puckett & Stephanie Karpouzis**—Region six, Columbia Regional  
**Kit Staples**—Region seven, Lane Regional  
**Brenda Satter**—Region eight, Northwest Regional  
**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  
**Wendy White**—Parent  
**Sam Ko** — Oregon Department of Education  
**Lyn Ayer** — Oregon Deafblind Project



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

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

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## Contact the Oregon Deafblind Project!



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