



Building Effective Programs

D. Jay Gense, Project Director • Lyn Ayer, Project Coordinator • Fall 2007

A Message from the Project Director

I can't believe that November is already upon us. If a sign of aging is that time seems to pass quickly, I truly must be getting old!

The Oregon Deafblind Project is excited about beginning what will undoubtedly be an activity-filled year. I'd like to take a moment and offer a "big-picture" perspective about the Project, about our work, and specifically about the current year. As most know, the Oregon Deafblind Project is a federally funded project, with funding provided by the U.S. Department of Education's Office of Special Education and Rehabilitation Programs. The current grant cycle began on October 1, 2003, with funding provided for 5 years. This means that the current cycle ends September 30, 2008. Although we have received no formal announcement from the U.S. Department of Education about future funding, we are hopeful that another cycle of funding will be available, and that we will have the opportunity to submit an application to continue with Project activities.

To that end, we will be contacting parents, teachers, partner agencies, and others to help identify present and future needs for students, families, and service providers. This information will be gathered both formally and informally, with this "needs assessment" information used to identify the Project's goals and activities for the future. Please know that we very much want to hear from all people interested in better supporting students who are deafblind and their families and teachers. We are presently working to gather information from parents, and have already begun working with school districts, Regional Program staff, and other service providers to identify needs. I ask that you help the Project identify the future direction by taking the time to offer your perspective through surveys and/or discussions we will be making available in the coming months.

The Oregon Deafblind Project is fortunate to have built a solid base for operating successfully, able to offer services and supports through collaboration with partner agencies and organizations. We plan to continue to enhance our services in any way possible, and promise that as information about future funding becomes available we will pass it along to all our partners. So ~ stay tuned!



The Oregon Deafblind Project is funded in part through grant # H326C030040, U.S. Department of Education, Office of Special Education.

BACK AT SCHOOL!

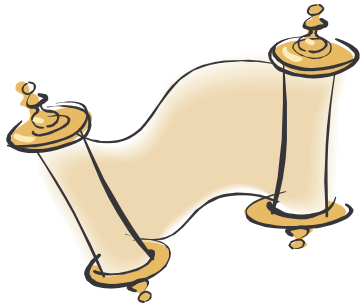
Here we all are — in the midst of another school year! In fact, we'll soon be waving goodbye to 2007.



Here's a thought. We know there are brothers and sisters out there who have someone in their family who is deafblind. We wish you would write to us and tell us about your family, especially about the person who is deafblind. Maybe tell us something interesting that you did over summer; or perhaps you have a story about something that happened as the new school year started. Maybe you are good at writing poetry. We would LOVE to hear from you! Send your written material to us: ayerl@wou.edu You will find a mailing address too at the end of this newsletter.

Parents — please share your stories too — about school, about family events, things you have learned. Maybe there is a special way you communicate with your child who is deafblind. Perhaps you have some "tips" about clothes (especially all those cold-weather layers!), or food preparation. Maybe you use a strategy at home that you think might help other families. Perhaps you are a "whiz" with online media — and have tips for that. SO — do share! This newsletter goes out to folks in Oregon, but it is on our website too — and can be accessed by people not just in the U.S., but also in other countries! Who knows who you may help.





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Overview of Services:

The Oregon Deafblind Project, funded by the U.S. Department of Education, is coordinated through the Oregon Department of Education. We provide technical assistance in support of mandated early intervention and special education services to children and youth who are deafblind, birth through age 21. Technical assistance and support is provided to IEP teams serving students who are deafblind. Students eligible to receive services through the Project must meet the federal definition of deafblindness:

“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 education needs due to these concurrent disabilities”

Services are provided via each of the eight Regional programs, the Oregon School for the Blind, the Oregon School for the Deaf, and partner organizations such as the Commission for the Blind. Each Regional program, and each of the special schools have a Regional Consulting Teacher working with the teams for children who are deafblind. They assist them to identify these children, and then provide individualized training to the teams. They also provide support, consultation and assistance to families of students who are deafblind. Technical assistance includes on-site consultation, inservice training, workshops, and assistance with program development.

The Project's DEAFBLIND WORKING GROUP

In each issue of this newsletter, we will introduce you to one or more members of our Deafblind Working Group:

- Jay Gense: Director, Oregon Deafblind Project
Lyn Ayer: Coordinator, Oregon Deafblind Project
Susan McDonald— 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 & Missi Hanson—Region six, Columbia
Kit Staples—Region seven, Lane Regional
Brenda Satter—Region eight, Northwest Regional
Jennifer Orton —Oregon School for the Blind
Vacant—Oregon School for the Deaf
Dennis Crepeaux— Oregon Commission for the Blind
Paddi Davies— NCDB representative, WOU
Tom Udell — NCDB representative, WOU
Wendy White — Parent
Adriana Alcazar — Parent



Colleen McLaughlin—Region two, Central Oregon

Colleen is a native Californian. She got her bachelor's degree in Speech Pathology at Chico State and her master's in Deaf/Hard of Hearing at San Francisco State. Colleen worked in public school in a total communication classroom and was an administrator at a private auditory/oral school in California. She has been in Bend for 15 years as an itinerant D/HH Teacher. She has been a Deafblind Consulting Teacher for 3 years. Colleen is enjoying learning from fellow members of the Working Group who have extensive experience working with students with deafblindness.

cmclaugh@hdesd.k12.or.us

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

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

Susan McDonald — Region one, Eastern Oregon

In 1984, Susan graduated from the University of Portland with a degree in Elementary Education and certification in Early Childhood Education. After teaching in a private preschool for a year, Sue earned her masters in Deaf Education from Lewis and Clark College. Sue taught Hearing Impaired preschool students in a classroom setting in Hawaii for two years. She has worked as an itinerant teacher for the Hearing Impaired in Coos County for one year and in Eastern Oregon for 13 years. Sue recently went through the Portland State University Visually Impaired Learner Program and has been working with both vision and hearing students for two years.

smcdonald@umesd.k12.or.us

Mark McKeirnan— Region three, Southern Oregon

Mark is from Oakland California. He attended the University of California in Berkeley. He went to graduate school at San Francisco State University and graduated with a credential in Deafblind Education and a Masters in Special Education. Mark reports that he has enjoyed the wonderful people that he has met as a result of working with the Project and that he has had the opportunity to shape the Project from the early years. He feels fortunate to have contributed to the education of deafblind and severely handicapped by introducing the concept of "touch cues" as a technique in 1982 at the AER International Conference.

mark_mckeirnan@soesd.k12.or.us

Causes of Deafblindness

USHER SYNDROME

- The syndrome was first described by Albrecht Von Graef in 1858.
- However, it was named after Charles Usher, a British eye doctor who determined it was an inherited condition.
- Approximately 3-6 % of all deaf children and perhaps 3-6% of all hard-of-hearing children have Usher syndrome.
- In developed countries such as the United States, about 4 babies in every 100,000 have Usher syndrome.

<http://www.nidcd.nih.gov/health/hearing/usher.htm>

♦ Describing Usher Syndrome

Usher Syndrome is one of many causes of deafblindness. Children who have Usher Syndrome are born Deaf or Hard of hearing. Later on — usually when in their teens (or later) — they begin to lose their vision to an eye condition called "Retinitis Pigmentosa" — or "RP". In the early stages of RP, all a person may notice is that they have problems with their night-vision, seeing when lighting is dim, e.g., at dusk. As the RP advances, they develop what is called "tunnel vision". The visual effect is like looking through a tube. The "tube" or tunnel through which the person sees gradually gets narrower. The vision usually decreases until they have significantly reduced or no useful vision. RP progresses slowly, and it is difficult to predict how rapidly it may affect vision, or how many years it will take to reduce a person's ability to see.

♦ What Causes Usher Syndrome?

This condition occurs when two persons, who EACH carry an Usher Syndrome gene, marry. BOTH parents have to carry the gene for a child to be affected. It is important to know that not

all children born to these parents will have Usher Syndrome. Some children may become carriers of the gene, even though they do not show signs of having Usher Syndrome. In fact, parents may not be aware that they have the gene. That is why genetic testing and/or counseling may be advised.

♦ Does Usher Syndrome look the same in all persons who have it?

There are several types of Usher Syndrome, the three most common ones being:

Usher Syndrome I: Persons with USI are profoundly deaf from birth, and have balance issues as well. Infants/Toddlers may take a longer time to sit or walk because balance is affected. However, they do not become dizzy easily — as on equipment that spins them around and around! As they cannot hear, they usually learn to sign rather than use voice. Their RP starts early — around 10 years or so — and, as the disease progresses, these persons usually lose all their vision.

Usher Syndrome II: These persons are born with moderate to severe hearing impairment, but with normal balance. The majority of them benefit from hearing aids, and most of them learn to speak. Their RP usually begins to affect their vision when in their early teens, and the progress of the condition is slower than that for persons with USI

Usher Syndrome III: These persons are born with normal hearing, and near-normal balance — and, typically, during the teenage years, begin to lose both vision and hearing.

Something important to note is that persons who have Usher Syndrome typically do not have additional disabilities.



GOOD NEWS FOR PERSONS WITH USHER SYNDROME

Are researchers closing in on a cure?

Research has been looking at a variety of treatments for retinitis pigmentosa — to slow down or change the course of the disease. Among the therapies are treatment via vitamins and anti-oxidants, gene replacement — and now researchers are even looking at gene repair rather than replacement, Dr. William Kimberling, the Director of the National Center for the Study and Treatment of Usher Syndrome has very encouraging words:

“It's no longer a matter of "if" it can happen, but a matter of funding to assemble the best scientists and acquire the necessary laboratory equipment.”

It is exciting to know there are cures for retinitis Pigmentosa in the not-so-distant future. Stay current by keeping track of research!

<http://www.boystownhospital.org/Usher/insights.asp>

<http://www.boystownhospital.org/Usher/index.asp>

Stem Cells for the Treatment of Inherited Retinal Diseases

<http://www.blindness.org/research.asp?id=295&type=2,%203,%204,%205,%206>

Human Neural Stem Cells Show Potential for Vision Rescue

<http://www.blindness.org/research.asp?id=306&type=2,%203,%204,%205,%206>

Umbilical Cord Tissue Shows Promise as Retinal Disease Treatment

<http://www.blindness.org/research.asp?id=309&type=2,%203,%204,%205,%206>

Nanoparticles Show Promise for Delivering Vision-Restoring Genes to the Retina

<http://www.blindness.org/research.asp?id=311&type=3>

What about cochlear implants?

We should also try and keep pace with information on Cochlear Implants. An increasing number of persons now have these devices — which are helping persons who are deaf, even profoundly deaf, to be able to hear.

<http://www.boystownhospital.org/Cochlear/index.asp>

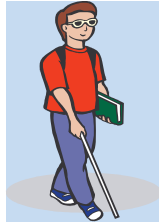
Information from the US Food and Drug Administration website:

<http://www.fda.gov/cdrh/cochlear/index.html>

Be aware of the “debate” around cochlear implants:

<http://www.pbs.org/wnet/soundandfury/cochlear/debate.html>





Dr. William Kimberling, in coordination with Dr. Richard Weleber (Oregon Health Sciences University), are in the process of determining whether children can be accurately screened for Usher Syndrome by collecting saliva samples, rather than having to go through a process of drawing blood and having that analyzed. The pilot phase, which involved around 100 children who are deaf/hard of hearing from Oregon, is close to being completed and has been successful. Dr. Kimberling is now preparing to collect more saliva samples from another 200 children this year, with perhaps a doubling of that number in the following year.

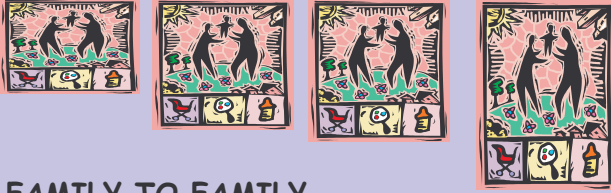
WHY IS EARLY DETECTION IMPORTANT?

- ◆ A child may be eligible to receive a cochlear implant. Generally, the earlier a child receives this, the more likely he/she will acquire language.
- ◆ As Dr. Kimberling and his associates, and others elsewhere are telling us — we are much closer to a cure for retinitis pigmentosa. As amazing as this may still seem, it is possible that children will either have delayed visual loss, or none at all! We are not quite there yet — but research has shown that the medical field is well on its way to getting there.
- ◆ There are educational implications if a child receives a cochlear implant — and a new set of strategies for educational teams to learn.
- ◆ If a child is losing vision, techniques using the sense of touch may be needed — and can be learned. This would include braille,

tactile sign, and strategies to learn about one's world and access it via touch.

- ◆ There is also the issue of SAFETY. Vision loss as a result of RP is gradual — so gradual, in fact, that a child may not even notice it unless someone observes this child, or asks some questions such as, "Do you see okay at night, at dusk, in dull/dark places?" or "Do you trip over things to the right/left of you?" or "Do you miss steps when going up or down stairs?"
- ◆ Sometimes a person developing RP also develops a problem with "glare". This may be solved with something as simple as a pair of darkened spectacles, using a visor when walking in bright sunlight, or working with an overhead light/table lamp that can be dimmed or brightened as needed. When one is "photosensitive", this affects how clearly we see and also how much detail. It is also very annoying at night — and potentially dangerous — when one is faced with oncoming headlights on vehicles.
- ◆ A child who was born profoundly deaf will more than likely have ASL (American Sign Language) as their main means of communication. If the onset of RP progresses to the point that the child can no longer see the hands of a person signing to him/her, then he/she probably needs to make the switch to tactile sign — where the language is basically the same, but the mode, being tactile, is different. There are also some new "rules" to follow as a person gradually makes this switch. In fact, depending on the narrowness of the "tunnel" of vision, these "rules" will help a person continue to use remaining vision.
- ◆ Orientation and Mobility skills may also need to be learned — so that a child can continue to be as independent as possible. People who are deafblind use a cane, guide dogs, even GPS technology.





FAMILY TO FAMILY

A family who has made contact with another family of a child who is deafblind will tell you that it is not just a lot of fun, but that it is reassuring, comforting, just plain "feel good".

We urge parents from Oregon to start the process for themselves by joining what NCDB (the National Consortium on Deaf-Blindness) Area 1 states call the **"Family-to-Family Support Network"**.

They have a Directory of families and you can also ask to be on their listserv. There is a simple, one page of information to fill out to get into the directory.

For the listserv — just drop us a line via e-mail and tell us you want to be included. There is no cost for joining! There are already 6 families from OR that are a part of this, and several others from the Western states.

You could also make contact with families by going through the NFADB (National Family Association of Deaf-Blind). Take a look at their website and information on how to join:

<http://www.nfadb.org/membership.htm>

As a project, we are interested in training some parents — possibly regionally — to act as mentors to other parents in their regions, and to coordinate with our Regional Consulting Teachers (see page 2 of the newsletter) who work with children who are deafblind. We would like to know if you are interested in becoming a part of this "Regional Parent Consultant" team. If yes, please get in touch with Lyn at ayerl@wou.edu so that we can include you on our list.

RESPIRE CARE — WHAT WE NEED!

- ◆ Did you know that there is a National Family Caregivers Association (NFCA) and that parents can be a part of this? And that November is "National Caregivers Month"? <http://www.thefamilycaregiver.org/national%5Ffamily%5Fcaregiver%5Fmonth/>
- ◆ Below is a website to a Colorado respite care "home". It shows us what is "possible" and is inspiring. Watch the video and explore the site — and share your thoughts with us by e-mailing Lyn Ayer (see page 9 for contact information): http://www.respitecareinc.org/care_care.html
- ◆ It may be possible to "organize" the community around a family by using a "free" system such as the one given below: <http://archrespite.lotsahelpinghands.com/>
- ◆ Use a respite care services locator system to find out where you may be able to go: <http://www.respitelocator.org/index.htm>

"The mission of the ARCH National Respite Network is to assist and promote the development of quality respite and crisis care programs; to help families locate respite and crisis care services in their communities; and to serve as a strong voice for respite in all forums. "

<http://www.archrespite.or>



About TOUCH Part II

"A human being can spend his life blind and deaf and completely lacking the sense of smell and taste, but he cannot survive at all without the functions performed by the skin." Montagu gives the example of Helen Keller, deaf-blind from infancy, "whose mind was literally created through the stimulation of her skin". (See Montagu, 1986)

Montagu (1986) as well as Eliot (1999) express concern that the Western world has produced a new "race of untouchables". Montagu says that we rely more on our distance senses (vision and hearing) to communicate, and this appears to have placed a taboo on taste, smell and touch. Eliot states that perhaps it is time for us to rethink the "general mandate against social touch by teachers and child-care providers". To professionals working with many children who NEED to use their sense of touch — and to be touched in order to communicate and be taught — this is significant.

Barbara Miles and many others in the field of deafblindness point out that we not only need to teach and communicate via touch, but that we should change the way we manipulate children's hands:

<http://www.dblink.org/pdf/hands.pdf>

- Just as we would not poke or try to manipulate a child's eyes, we should not do this with a child's hands either.
- The reason — Children who are deafblind not only use their hands (a) as tools (as we do), (b) as sense organs (to fill in information they cannot get through vision and hearing), BUT (c) their hands are also their VOICES — their primary means for expression.

- How children use their hands and their sense of touch affects the development of their brains. Miles (quoting Lane, 1997), points out that Braille readers and string players "give evidence of increased cortical representation of the fingers".
- Miles and many professionals in the field of deafblindness recommend the use of a technique called "Hand-UNDER-hand" — especially when helping a child explore, initiate topics or express feelings.

Hand-UNDER-hand

This technique:

- *Initially provides "joint" attention — essential for good communication to occur*
- *Is not as intrusive as the more commonly used hand-OVER-hand*
- *Allows the child's brain to "read" only what is under the child's hand; with hand-over-hand, both surfaces of a child hand receive and send different messages to the brain*
- *Allows the child a greater level of control*
- *Is respectful and gentle*
- *Gives a child the TIME to think*
- *Encourages a child to touch — and not draw back — having a shared experience helps!*
- *Helps to better teach a child how something is to be manipulated or managed*
- *Encourages a child to want to "see" more*

Eliot, L. (1999) *What's going on in there? How the brain and mind develop in the first five years of life*. Bantam Books

<http://www.amazon.com/Whats-Going-There-Brain-Develop/dp/0553378252>

Miles, B. (Rev.ed. 2003). *Talking the language of the hands to the hands*. DB-LINK fact-sheet.

<http://www.dblink.org/pdf/hands.pdf>

Montagu, A. (1986; 3rd ed.). *Touching: The human significance of the skin*. Harper and Rowe.

<http://www.amazon.com/Touching-Human-Significance-Ashley-Montagu/dp/0060960280>



Read the "how-to's" about Hand-UNDER-hand in next issue



Please let us know how we can be of service!

FEEDBACK/RESPONSE CARD

This edition of **Building Effective Programs** was:

very useful

somewhat useful

not useful

SEND US YOUR SUGGESTIONS FOR TOPICS YOU WOULD LIKE TO SEE IN THE NEWSLETTER:

You can write to Lyn Ayer, e-mail, or call her at:

Western Oregon University
Teaching Research Institute
345 N. Monmouth Avenue
Monmouth, OR. 97361

(503) 838-8328 ayerl@wou.edu

YOUR E-MAIL ADDRESS: _____

We would like to send you the e-mail version of our newsletter. It is colored and easy to read. If you would like us to send this to you instead of a paper copy, let us know by supplying your e-mail address to Lyn Ayer at ayerl@wou.edu

Phone Numbers for the Oregon Deafblind Project!


D. Jay Gense, Director
Oregon Deafblind Project
503-947-5760

David Jones
Deafblind Project Program Support
503-947-5731



Lyn Ayer, Coordinator
Oregon Deafblind Project
(503) 838-8328

Oregon Deafblind Project

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Lyn Ayer, Project Coordinator
Oregon Deafblind Project
Western Oregon University, TRI
345 N Monmouth Ave
Monmouth, OR 97361
TRD 588

