



# Building Effective Programs

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

## Project Changes

In Summer 2006, this project said goodbye to Project Coordinator, Sylvia Carnes, who left to return to Texas and her family. Here is a message from her to you:



To My Friends in Oregon

Oregon is a state of incredible beauty and good people. Traveling around the state was such a pleasure. After seven years as Coordinator of the Oregon Deafblind Project, my husband and I had the opportunity to move back to Texas and be close to our children, grandchildren and extended family. I am happy to be home, but I have fond memories of the time I spent in Oregon and the wonderful people that became my friends.

I have been fortunate in my professional career.

After my short time in public schools in Texas, I worked for the Texas School for the Blind and Visually Impaired for 10 years. Moving to Oregon and becoming the Coordinator of the Oregon Deafblind Project was a great opportunity for professional growth. I had many wonderful teachers there. Jay Gense was a terrific mentor and friend to me. I admire his passion for providing the best education for students who are deafblind. I learned valuable lessons and strategies for working with students with deafblindness from all the Regional Deafblind Consulting Teachers and Dennis Crepeaux of Oregon Commission for the Blind. What a pleasure to work with this group of professionals. Our two Parent Liaisons with the project were a constant inspiration to me. They and their children were great teachers in my life. I cannot fail to mention the folks from ORPTI and NTAC who provided great collaborative opportunities.

Now that I am back in Texas, I have a job as an itinerant vision teacher in a very large district in San Antonio. I have used all of my professional experience in this job, plus I have learned new skills as well. Learning new things and getting yourself out of your comfort zone is a good thing.

Thanks to all of you!

Sincerely,  
Sylvia Carnes

### Introducing Lyn Ayer, the new Project Coordinator

Lyn moved from Wisconsin to Oregon at the beginning of January 2007 to take this position which is housed at the Teaching Research Institute, Western Oregon University, Monmouth.

She has worked in the field of disability since 1974, and with children/youth who are Deafblind since 1995. She is originally from India, where she earned her teaching degree (High School). Her specialist degrees are from the University of Birmingham, England (Visual Impairment] and Ohio State University, Columbus, OH (Ph.D). Lyn has had a varied career — as a teacher in a regular education classroom, teacher and principal at a residential special school for the blind, rehabilitation specialist at the rehabilitation unit of the Lions Eye Hospital., and rural community program organizer. She worked for 3 years with the Ohio Department of Education, as their Consultant for Traumatic Brain Injury. For the past 12 years she was Outreach Specialist and Project Director for Wisconsin's Deafblind program.

Lyn is enjoying Oregon's climate, flowers and birds while she learns to drive around in the rain instead of snow. Watch those curves — she is not yet used to driving in hilly terrain! She is enjoying working with the members of this group — and counts it a privilege to do so.

#### Contact information:

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## DEAFBLIND WORKING GROUP

In each issue of this newsletter, we will introduce you to a member of our Deafblind Working Group:  
Jay Gense — Project Director, 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

Terri Nichols—Oregon School for the Blind

Stephanie Alves de Lima- Oregon School for the Deaf

Dennis Crepeaux— Oregon Commission for the Blind

Paddi Davies— NCDB representative, WOU

Tom Udell — NCDB representative, WOU

Have you ever visited the project's web page? If not, take a look at it. It is located at the Oregon Department of Education's website:

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

We have added some national resources to our listing. One site is NCDB (National Consortium on Deaf-Blindness) which also houses our National clearinghouse for information on deafblindness — which we knew as "DB-LINK".

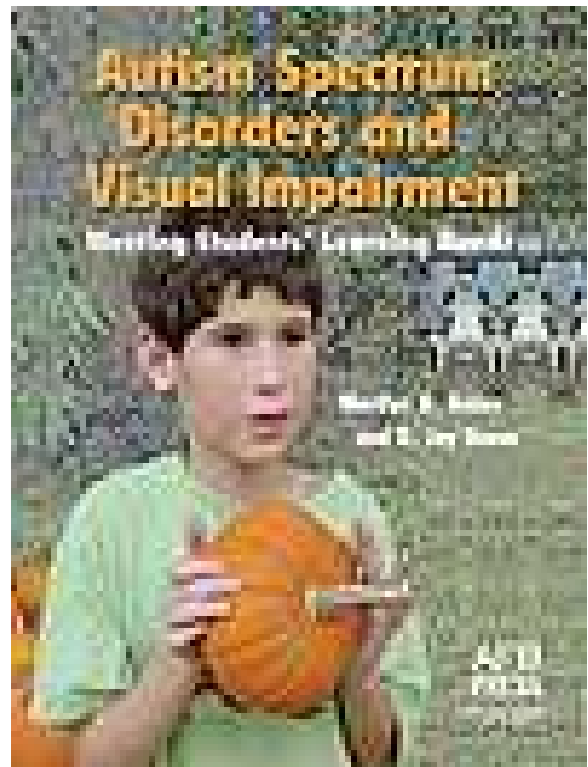
We plan on adding other materials to the website during the coming months.

### Oregon Deafblind Project Director

**D. Jay Gense** [jay.gense@state.or.us](mailto:jay.gense@state.or.us)

Jay has worked in the field of deafblindness since 1979. Currently, he is a Director with the Oregon Department of Education, and has oversight of statewide services for students with low incidence disabilities. In addition, he administers statewide services for Psychiatric Residential Education Programs, Youth Corrections Education Programs, and Hospital Education Programs. He serves as Director of the Oregon Deafblind Project, and is also adjunct faculty with the Pennsylvania College of Optometry.

Jay holds a BS degree in Elementary Education/ Special Education, an Ed.S. degree from University of Northern Colorado (emphasis in the areas of deafblindness, and orientation and mobility), and an Educational Administration degree from George Fox University. Jay has written and presented widely on orientation & mobility, deafblindness, and autism spectrum disorders and visual impairments. Jay and Marilyn Gense's book "Autism Spectrum Disorders and Visual Impairments: Meeting Students Learning Needs" was published by AFB Press in July, 2005.



# Causes of Deafblindness

## CHARGE Syndrome/Association

An excellent source of information — for parents and others — can be found at the website of the CHARGE Foundation:

<http://www.chargesyndrome.org/resources-manual.asp>

COLOBOMA of the eye (or part of eye)  
HEART defects  
ATRESIA of the choanae ( nasal passages)  
RETARDED growth and development  
GENITAL anomalies  
EAR anomalies

When we collect census data each year, the causes of deafblindness are listed under 5 categories, including general categories such as Complications of Prematurity and Hereditary/Chromosomal disorders. However, the largest number of students with a single identifiable cause are those with CHARGE. Listed nationally as the "fastest growing" group, there are now 572 children/youth who are deafblind who are diagnosed with CHARGE (Killoran, 2007). Over 3/4 of all children with CHARGE are deafblind (Davenport, 1999). The CHARGE Foundation estimates that one in every 9-10,000 births worldwide is a child with CHARGE.

CHARGE syndrome was first identified in 1979. By 1981 six diagnostic criteria (seen in the box above) were established as a cluster of features used to recognize the syndrome — and these made up the acronym "CHARGE". Since then, over 40 associated anomalies have been identified, making CHARGE one of the most complex conditions that we know. Children with CHARGE have difficulties not just with vision and hearing, but also with balance, and the senses that perceive touch, temperature, pain, pressure, smell and possibly also taste.

This complexity impacts the education of a child with CHARGE. We need to:

- ◆ Figure out what anomalies, or combination, are most affecting a child at a given moment
- ◆ Think about the variables that may impact the whole situation. For example, this could include time of day, energy levels and sleep, health and well-being, physical position and support, activity and materials involved, level of physical comfort, familiarity, and emotional security.
- ◆ Always note the "context" in which something occurs — including a child's physical position.

- ◆ Expect fluctuations in how a child functions.
- ◆ Recognize behaviors exhibited as communication.
- ◆ Recognize that dysfunctional or missing balance can affect a child's rate of development. For more details see Brown (2003):  
<http://www.sfsu.edu/~cadbs/Spring03.pdf>  
(Educational and Behavioral Implications in the Missing Balance Sense in CHARGE Syndrome)
- ◆ Recognize the critical need to motivate a child with CHARGE as this child is "input-impaired" (Davenport, 1999):  
<http://www.chargesyndrome.org/manual/sensoryloss.pdf>
- ◆ Acknowledge that there will be delays in walking — but do not give up! If a child has very low muscle tone, it is partly an outcome of the balance issues. It is also connected to low vision, difficulties with breathing, and greatly diminished sensory input which reduces awareness of the world around. Basically, there is no motivation for this child to walk! (Brown, 2003).
- ◆ Emphasize communication, communication, communication. Use a variety of modes that may "fit" a specific child. This could include very basic object and touch cues, picture cards, or may extend to more complex sign language or sign systems.
- ◆ Be aware that the sense of touch is very important and a child with CHARGE should be encouraged to use it — including using lips and tongue. This becomes "socially unacceptable" as a child grows, but is a developmentally legitimate way to gather information (Davenport, 1999).
- ◆ Keep in mind that a child with CHARGE might have a high threshold for pain — and may display behaviors that result in self-injury or injury to others.
- ◆ Realize that a diminished sense of smell will not just result in a disinterest in food, but may also make a child wonder why people are annoyed when they pass gas or take off their sweaty shoes!
- ◆ Be aware that a coloboma may create glare issues — facing a window, looking at text on glossy paper, sitting facing into light, having too much overhead light may all affect how a child learns.
- ◆ Know that each eye may have different vision — and that a child will probably use one eye over the other.

(CHARGE contd.)

Brown (2003) <http://www.sfsu.edu/~cadbs/Spring03.pdf> points out that Sensory Integration Dysfunction is inherent in CHARGE. An indicator of this is that the child may display "contradictory" behaviors. Examples that he gives:

- ☛ Rejection of textures in the mouth apart from pureed food, BUT mouthing all kinds of non-food items (e.g., stones, wood, cloth, soil)
- ☛ Inability to chew and bite on solid foods, BUT excessive biting and chewing on non-food items/persistent teeth-grinding
- ☛ Rejection of certain tactile inputs as if they are painful, BUT apparent non-awareness of certain other tactile inputs that we would consider painful
- ☛ Extreme postural insecurity when sat or stood by another person, BUT pleasurable responses to strong rhythmic movement (e.g., rocking, bouncing, swinging)
- ☛ Periods of frantic over-activity, BUT also sudden periods of apparent "burn-out"

Other possible indicators of sensory dysfunction are:

- ☛ Abnormally high pain-thresholds
- ☛ Very delayed awareness of bowel and bladder movements
- ☛ Disturbed and inconsistent sleep patterns
- ☛ Behaviors that seek and provide very strong sensory inputs, e.g., self-biting or scratching, skin picking, spinning, hand flapping, self-slapping.

Many of the behaviors may be just a way for a child to "reorganize" the body.

Children with CHARGE also persevere, and Brown (2003) suggests they may use this strategy to "establish a firm physical, emotional, perceptual, and cognitive base each time before they move on into comparatively uncharted territory." It is for the same reason they may lie down flat on their backs from time to time. Educators need to allow time for a child to do this; but also to keep the child alert to the fact that you are still present, ensuring the child knows who you are, what activity you will be doing together, and how this will be done. As we said earlier — communication is critical.

CHARGE Foundation:  
2004 Parkade Blvd.  
Columbia MO 65202-3121 ·  
800-442-7604 ·  
[info@chargesyndrome.org](mailto:info@chargesyndrome.org)

#### REFERENCES:

Hefner, M., Davenport, S.L.H. (Eds.)(1999) CHARGE syndrome: A management manual for parents. Columbia, MO: CHARGE Syndrome Foundation  
<http://www.chargesyndrome.org/resources-manual.asp>

Killoran, J (2007). The National Deaf-Blind Child Count: 1998-2005 in Review. NTAC (National Technical Assistance Consortium), WOU, Monmouth. <http://www.nationaldb.org/documents/Childcountreview0607Final.pdf>

<http://www.semse/prg/uk/publications/allpubs/magazine/tsarticles/1997/charge.htm>

<http://www.ucdmc.ucdavis.edu/children/services/cleft/health/anomalies/charge.html>

<http://www.sfsu.edu/~cadbs/Spring03.pdf>  
(Educational and Behavioral Implications in the Missing Balance Sense in CHARGE Syndrome)



#### Communication Modes—Some Examples

Gesture, facial expression, body language

Touch Cues: touch wrist to say "Hello", tap shoulder to say "good bye"; tug gently at sock for "remove sock"

Object cues: cup representing "drink", diaper to say "Let's get the wet one off", toothbrush for.....

Tangible Symbol: cup handle on a card to represent drink, diaper Velcro tag to represent "let's change"...

American Sign Language  
(Also sign "systems" such as Signing Exact English)

Speech

Braille, Print





## Web Resources

A Deafblindness Web Resource

[www.deafblind.co.uk](http://www.deafblind.co.uk)

American Association of the Deaf-Blind (AADB)

[www.aadb.org](http://www.aadb.org)

A-Z to Deafblindness

[www.deafblind.com](http://www.deafblind.com)

Deaf-Blind Perspectives

[www.tr.wou.edu/tr/dbp](http://www.tr.wou.edu/tr/dbp)

Helen Keller National Center

[www.hknc.org](http://www.hknc.org)

AND

Helen Keller Services for the Blind

[www.helenkeller.org/national](http://www.helenkeller.org/national)

National Organization for Rare Disorders  
(NORD)

[www.rarediseases.org](http://www.rarediseases.org)

NCDB: The National Consortium on Deaf-  
Blindness

<http://www.nationaldb.org/>

AND

DB-Link: The National Information Clearing-  
house on Children Who Are Deaf-Blind

[www.tr.wou.edu/dblink](http://www.tr.wou.edu/dblink)

The Coalition on Deafblindness

<http://dbcoalition.org/>

Katlyn's Hope Inc.

<http://www.idir.net/%7Ekhope/>

National Family Association for Deaf-Blind

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

Office of Special Education Programs

<http://www.ed.gov/about/offices/list/osep/osep/index.html>

## Did you Know....?

The Oregon Deafblind Project offers training to teams who work with children who are deafblind. The format for the training is a series of face-to-face workshops on various topics. It takes a year for most teams to complete the training series. Teams assist the trainers in selecting the modules they need, the sequencing of these modules, and in determining a schedule. Each training is individualized to suit the needs of a specific child who is deafblind. The modules are:

- An overview of deafblindness (with a sub-module on family involvement, and a MAPS process for getting to know the child)
- Every Child is a Communicator
- Developing Routines and Documenting Student Progress
- Calendars
- Orientation and Mobility
- Sensory Motor Learning
- IEP Development and Program Planning
- Observation and Interpretation
- Transition
- Involving the child's parents/family

Teams that apply for the training can take advantage of a grant to help offset the costs (e.g., hiring of substitutes, paying honoraria, etc). The time trainers can devote to doing team trainings, and the money set aside to do this is limited. Between 3 and 6 trainings are held per school year. So, the sooner a team gets in a request for training and come up with a draft plan for this, the more likely they are to be put on a trainer's calendar and to get a grant. School year 2006-2007 is already tentatively full. However, if you are interested, you could be put on a waiting list — so that if another team decides not to do the training, you could get the slot instead. Need more information? Call Lyn Ayer at (503) 838-8328 or write to her at [ayerl@wou.edu](mailto:ayerl@wou.edu). PDUs are available.

# About TOUCH

## Part I

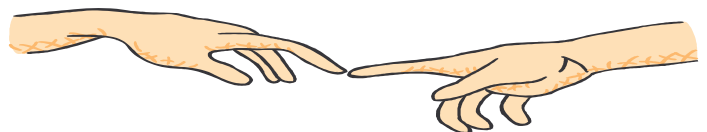
Derived from: Eliot, L. (1999) *What's going on in there? How the brain and mind develop in the first five years of life.* Bantam Books

As you read each of the following facts about the sense of touch, consider a child who is deafblind. Why is this fact important to know? How might we make use of this fact when we are planning activities? What significance might this fact have when teaching a child to communicate? What difference might it make to how we teach a child to access his/her environment, explore space, or find something?

Facts about touch that should be considered as we teach children who are deafblind:

- ✓ In the embryo, touch is the very first sense to emerge.
- ✓ Although not fully developed at birth, the sense of touch is one of a baby's most advanced abilities — more so than sight, hearing or taste.
- ✓ Early touch experiences will mold later tactile sensitivity, motor skills, understanding of the physical world around, and will impact health and emotional well-being.
- ✓ Touch includes not one, but four different sensory abilities, each having their own neural pathways: (a) cutaneous sensation — skin touching something, (b) temperature sensitivity, (c) pain, (d) and proprioception — the ability that allows us to determine where we are in space (via muscles, tendons, joints, and the skin).
- ✓ Sometimes, these may combine. An example is a child holding an ice-cold teething ring feels the "hardness" sensation as well as the "coldness" of the ring.
- ✓ Proprioception allows us to relate to the space around us. For instance, it allows us to know whether our arms or legs are crossed, whether we are walking up or down a slope — even with our eyes closed.

- ✓ The REAL ability to feel is not in the skin etc., but in the two strips of "somatosensory" cortex — one on each side of the brain.
- ✓ The two "strips" combined have a "map" of the person's body surface — the strip on the right side of the brain has a left-body surface map and vice versa.
- ✓ The amount of space allocated for various body surfaces depends on the sensitivity of the area — lips and fingertips taking up a disproportionate amount of space.
- ✓ Touch develops in a head-to-toe sequence — and is why, early on, the mouth is used to explore and tactilely discriminate, not just to taste! A baby can actually transfer tactile to visual information and visually pick the object he/she has been exploring with the tongue. Conversely, the hands do not work this way early on — and a baby will be unable to visually distinguish something he/she has touched only with the hands.
- ✓ Hand preference changes and develops over the first two years. Object discrimination is usually best done with the left hand (regardless of whether young or old). This means that even if we are right-handed, we generally use our right brain (or left hand) to understand shapes and their properties.
  - ✓ As hand-preference is emerging, a toddler's left brain becomes increasingly involved with language development.
- ✓ Generally, newborn girls are more sensitive to touch — and this gender-related characteristic continues into adult life.
- ✓ Touch sensitivity in boys is more "lateralized" — that is their non-dominant side (usually the left) is more touch sensitive than their dominant side; girls are more symmetrical in their touch sensitivity.
- ✓ The early "critical" period is not the final chance for plasticity in this system; experience continues to fine-tune perceptual maps throughout life.



# IS ASL A LANGUAGE?



Information derived from Schein, J. D. & Stewart, D.A. (1995). *Language in motion: Exploring the Nature of Sign*. Gallaudet University Press.

While determining where language learning is located in the brain, Pierre Broca hypothesized that in most right-handed people, the left side of the brain is usually the primary area for this purpose. That is, the left side of the brain responds to auditory signals, just as the right side responds more to the pictorial.

What happens when a person uses sign language? Logically, since sign is visuo-spatial, it would seem that if there is damage to the right cortex, a person's signing ability would be impaired. Not so. In fact, like their hearing counterparts with damage to the right cortex, they have problems with perspective and spatial organization. Both groups had NO impairment to their language abilities. That is, Deaf signers with right cortex damage showed no linguistic or signing deficits; however, Deaf signers with left cortex damage had severely impaired language functions. So ASL is processed mainly in the left cortex as any other language. Schein and Stewart quote: "[T]he left hemisphere...is dominant for sign language, even though processing sign language involves processing spatial relations at all linguistic levels" (Bellugi, et al 1994)\*.

\*Bellugi, U., O'Grady, L., et al (1994). Enhancement of spatial cognition in deaf children. In *From Gesture to language in hearing and deaf children*, ed. V. Volterra & C. J. Erting, 278-98. New York: Springer-Verlag, 1990. Reprint, Washington, D.C.: Gallaudet University Press.



*Learn  
American  
Sign  
Language*

<http://www.lifeprint.com/asl101/>

*Take a look at the above website and learn sign on your computer. This is a useful website as the vocabulary is practical and the photographs and line drawings are clear. You can also use the site to teach others. Above all, the instruction is **FREE!***

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## New 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



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:**

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**You can write to Lyn Ayer or call her at:**

Western Oregon University  
Teaching Research Institute  
345 N. Monmouth Avenue  
Monmouth, OR. 97361  
(503) 838-8328


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](mailto:ayerl@wou.edu)

**YOUR E-MAIL ADDRESS:** \_\_\_\_\_

**Additional Comments:**



# Oregon Deafblind Project

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

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