



# Oregon Deafblind Project



## Building Effective Programs

Lyn Ayer, Project Director • Spring 2013



### March 2013

Hello everyone!

I guess spring is here — since I see the daffodils in full bloom! Some of the winter birds still linger — maybe can't make up their minds to leave or stay? It is definitely time for another newsletter.

I hope everyone had a good winter/rainy season — and that some of you took advantage of the snow.

The rain can be fun too. Hold a metal bowl or box upside down — and listen to the pitter-patter, as well as feel it tap on your hands as you hold it. You can also hold it on your head and feel the sounds resound. And then there are rain sticks .... Percussion instruments. Did you know that you can learn to actually "play" a rain stick? I loved the sounds — but never knew much else. Listen to someone playing a rainstick to a musical piece....

<http://tiny.cc/dnfutw>.

There are other things you and the kids can do in the rain too. Take a look at the ideas on the following page — and be sure to look at the sidebar of "You May Like" topics too: [http://www.ehow.com/how\\_2300471\\_play-rain.html](http://www.ehow.com/how_2300471_play-rain.html) ; Among other things, learn about "puddle races", make a "rain painting", create rain art - or decorate for a Dancing in the Rain Party. You can even add rain sound effects to your party, or create a pitter-patter with the help of a spraying hose.

Did you know — if you were born in March, you share your birth month with Michelangelo, Harry Houdini, and Sandra Day O'Conner — among others?

**PARENTS — be sure to check on info on the upcoming Parent Learning Weekend in August!**

Lyn



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**"Sometimes the questions are complicated and the answers are simple." Dr. Seuss**

## BOOK NOOK



I count myself fortunate to have been a "listener" to the conversation while this book was being produced. The conversation still rings in my head, even as I read the book — and every person comes alive for me. How did this come about? I needed to learn more about cochlear implants and asked permission from the DB Cochlear Implant listserve owner and group to listen to their chatter. I was soon to learn that this was to be one of the most active listserves I have ever been on — and I learned far more than just information on cochlear implants! So thank you Ilana and the DBCI listserve group for all your insights and conversations and for allowing me to participate!

About the book: It took three years of hard work to draw all the pieces together. Scott Stoffel, also an author in his own right, offered to edit and pull everything together. The group did not want the book to be just another book of success stories, but one that was based in reality. And that is what the tone of the book conveys. Not criticism, not complaints — but how each of this group lives and sees their lives. It does touch on success stories too — and, believe me, they could write another whole book just based on that!! The contributors are not only from several states of the USA, but also from South Africa (Ilana runs the listserve via NCDB), England, and New Zealand. So there is some international flavor as well. They are all Deafblind, and — as we

**The editor talks about “a prevalent misconception in modern society that if a person who is disabled accomplishes some goal, such as attaining a college degree or winning a sporting competition, the disability essentially vanishes, and life becomes ‘normal’.....”**

**“Unfortunately, the reality of life for people who are deaf-blind is not so simple.”**

experience in our population of persons who are deafblind —many of them have additional challenging conditions as well. Be sure to read the entire introduction because Scott Stoffel introduces each contributor to the readers. Here is a peek into the book:

**The contributors seek “genuine understanding” and hope that those who are willing to read this book and take the time to think about what is said might find “ a shard of that precious thing, just being understood and accepted...”**

Chapter 1—Family Reaction and Support — is not meant to be a “report card for parents”. It is rather is a recounting of memories that will hopefully provide insights to families who may need to meet the challenge of having a deafblind child. Here are some of the things I learned:

- Listen attentively to what your child tells you — and observe your child for indicators of what he/she may need.
- Get medical and “expert” professional help — but also don't be afraid to ask questions or voice an opinion, especially if you don't think the medical advice or the suggestions of the experts is working for your child.
- If vision loss occurs, be sure to check your child's hearing as well. Remember that hearing loss is a less “obvious” loss—often called the “hidden” disability. If your child has issues with hearing, make sure you check his/her vision too.
- Accept your child's limitations, encourage his/her strengths — and realize you have strengths and limitations too.
- Giving your child a pet as a companion can be helpful.

Chapter 2— Education Part 1: Primary and Secondary School Experiences

The discussions in this section look at challenges - academic and social—and point to a real need for self-determination. Here are a few key points that I gleaned:

- Schools and educational teams are often thrown for a “loop” if they find out a child in middle school or older is acquiring a vision or hearing loss. KG and elementary schools have less of a problem establishing a program.
- A child who is losing vision or hearing does not always understand the situation — and may not even really know what is happening.
- Self-determination is very important. There is power in self-advocacy! So — encourage it in children and youth who are deafblind.
- Isolation is a huge factor for a young person who is deafblind. Families and educational teams must ensure this does not happen.
- Technology—one size doesn't fit all. Each child needs to have his/her specific needs met. The persons who meet those needs may not just be a specialist in deafblindness, vision or hearing.

**“Unfortunately, the accommodations advertised my disabilities and made me ‘weird’ to the other kids.....Soon, the kids started calling me ‘the freak’.”..... “Ultimately I began to hate myself.”**

- Braille and sign language are very important — and should be taught and practiced consistently. Since both of these are difficult to learn — especially initially — it is really important that the person or persons teaching and practicing should have a close bond with the child. He/she should trust this person.

**“Necessity made me learn to lip read on my own....I didn’t learn much sign language and never took an interest in learning until I was eighteen and took ASL classes. Then I fell in love with ASL.”**

- Children's preferences for oral language only, ASL, or a combination — should be respected and encouraged. After all, ASL is the natural first language for many children who are deaf-blind.

### Chapter 3 — Transition to Adulthood

This chapter is brief — but very significant. The key difference between childhood and adulthood is “the level of responsibility and independence expected of us”.

**“...note how many of the supports these people had known as children changed or vanished when they became legal adults....”**

The Social aspects, isolation and the diminishing of prior friendships are particularly important to note, especially when one of the distance senses was deteriorating.

**“I felt like I’d been buried alive. With no effective communication mode or any real direction in life. I retreated to my parents’ house and lived on books. They were all I had for years.”**

### Chapter 4 — Degeneration

This section expresses a smorgasbord of emotions — embarrassment, denial, physical and emotional pain, feelings of rejection, loss of friendships, loss of family, hopelessness, loss of trust, lack of

**“In an instant, I lost all will to live.... I had a son who was now a year old.....I thought my husband should marry someone else and give Daniel a ‘real’ mother..... My love for my son gave me the strength to go on, find peace in the world, and accept my disabilities.”**

self-confidence — and how each person coped with the devastating changes in their lives. There are also many acknowledgments of parents, therapists, a chiropractor, and many others without whose help things would have been much worse. It is significant that many of the writers had issues with balance and with neurological issues that added to the sensory challenges.

**“My vision and hearing losses are not a big deal. What really frustrates me is my balance issues....I can look like a foolish drunk when it gets bad.”**

In past articles, we have discussed music — and the important part it may play in the life of a person, even a person who is deafblind. One contributor describes how she taught herself to play a musical instrument, while for another the losses were so grave that music was counted as a loss.

**“The loss of music was a blow to my spirit.”**

Other health issues only add to the challenges of having sensory losses that are degenerative. I have already mentioned balance, but there were many other challenges as well — including processes relating to aging.

**“I also have spinal arthritis and can’t stand up for long. I use a walker to get around the house. Heart disease is another health issue, and it means that I get tired easily. But the isolation of being deaf-blind is the most acute of all these problems.”**

**“The nerves controlling my fingers also declined ...leaving me limited use of my hands.....I just assumed my vision and hands were my only significant problems. When my hearing went through rapid decline at eighteen, it took me totally by surprise and left me shell-shocked.”**

Chapter 5 — Bad Medicine underlines the importance of honest medical opinions and diagnoses. The editor states that it is not an attack on the medical profession, but rather “to show how poor judgment, lack of concern, and inadequate communication” can negatively affect a person who is deafblind, especially if the person’s disabilities are “non text book”!

Chapter 6: Rehabilitation emphasizes how to view clients with multiple disabilities. This chapter also talks about the role of the Helen Keller National Center (HKNC) in rehabilitation efforts. While all the persons who wrote for this book are eminently capable of many things, sadly, they often had to struggle through on their own.

**“In the ten years that I have been deaf, two years completely without sound, I have never received any rehab. In the two years that I’ve been blind, I have not received any rehab. I have applied for it but was turned down until recently. I was promised tactile ASL lessons and mobility training, but there has been no follow-up.....It’s very frustrating..... I also requested help with finding work and getting any necessary job training. The rehab counselor declared I am too disabled to work and refused to help me.”**

Chapter 7—Education Part II: Adult Education and Chapter 8— Careers

These are uplifting chapters where each person recounts many positive experiences — amidst continued misunderstanding of their disabilities — and trial and error. What a variety of outcomes! Each person is, deservedly so, proud of their achievements and their capacity to be gainfully and satisfyingly employed. One person became a teacher; another works in a factory. A third person now owns her own business — The Relax Center — where she uses her knowledge of reflexology, meridian therapy and Swedish massage, and employs others to assist in services she is unable to provide. Another person — with a dual major in electrical and computer engineering — worked for the Federal Aviation Administration as a Systems Engineer.

Chapter 9 — Daily Life

We take so much for granted. This is a chapter for us to read to realize just how much we do so. Time is a factor. So also is the assumption that adaptations that suit persons who are visually impaired will also work for persons who are deafblind. We also cannot assume that equipment that is modified or adapted is even affordable. Some persons like shopping and cooking; others dislike it. Sound familiar?? Some of the writers discuss how things changed as vision and hearing became worse.

Chapter 10 — Adult Relationships

Chapter 11 — Communication

Chapter 12 — Cochlear Implants

These three chapters are inextricably linked because the group essentially discusses the impact of deafblindness on their social lives — on friendships, love, family affections. They talk about how families interfered with relationships, how relationships developed or were destroyed by lack of understanding. Most often the struggle is with communicating with others, the lack of someone who can interpret and be a “bridge” to foster interaction. It also describes some of their children and how everything affected them too.

**“The deeply ingrained wish not to be a nuisance makes me non-assertive with new people. ...  
..in any social situation, we are marginal, and don’t quite belong.”**

Chapter 13 — Coping

This is a very revealing word. Coping. Not “overcoming”, “accepting” — but COPING.

**“In truth, it is rare for a deaf-blind person to be completely accepting of the disabilities. ...There is frequently a constant inner struggle to cope and be content.”**

AFTERTHOUGHTS

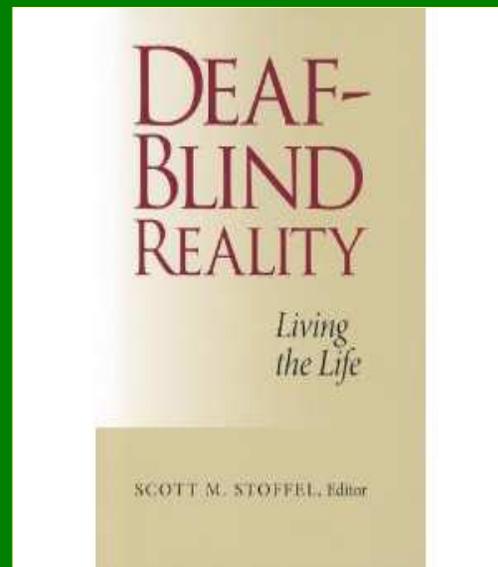
In my mind, these are not really “after” thoughts, but powerful expressions of what the writers think about themselves, about life, about others — and expressions of hope too. Be sure to read every one of these expressions in poetry — a fitting end to this book that was the result of enduring labor.

Thank you, all!

From Scott Stoffel’s “DB in the Race”:

It’s time to go;  
Let’s start the drive;  
Soon we will know  
Who can survive.....

Wheels with no  
screams  
Roar through the  
night;  
Hope barely gleams.  
Faint hearts won’t go,  
Perilous strive;  
Soon we will know  
Who can survive.



**Control+Click ON THE BOOK above to get to Amazon.com**

The Book is:

**“Deaf-Blind Reality: Living the Life” (2012)**

edited by Scott M. Stoffel  
Pub.: Gallaudet University Press,  
Washington D.C.

<http://gupress.galludet.edu>

This overview is just that — a quick look at the writings of a diverse group of persons who are deafblind — and my impressions. I hope that this article has at least made you curious — and that you will read the whole book to see the many things you will learn from it. Thank you Scott—and all those who contributed to make this book a reality! SO — read on, take notes, learn from each of these impassioned writers about the reality of being deafblind.





## The **what, why and how** of Early Identification of Children who are Deafblind

### WHY IDENTIFY AN INFANT OR TODDLER AS "DEAFBLIND"?

- Most babies who are born deafblind, are also probably children with additional challenges - including those involving their other senses as well. The earlier sensory integration strategies are used, the better.
- Major neural connections in the brain develop at a rapid rate during the first three years. In order to do this, the brain is "fed" with information from the sensory systems - and mostly from the distance senses of vision and hearing - both of which are affected in a child who is deafblind. The brain is most "plastic" during the first three years - and specific learning strategies can help the brain to continue to develop - if needed, via alternate routes.
- At birth, the sense of touch is probably the most highly developed sense - even though it will develop further - and emphasis of the tactile is critical for the development of a child who is deafblind. This sense is especially important for a child who is deafblind -- for bonding and emotional stability.
- Most children who are considered "deafblind" have residual vision and hearing - and should be taught to make the best use of both residual senses - and as early in life as possible.

- Communication is a major concern for children born with or acquiring deaf-blindness soon after birth. All human beings need to communicate - and should have the right, and the opportunity, to learn how to do so. These infants/toddlers will often need to learn how to communicate in alternate and sometimes unusual ways and need to do so from the time they are born - just as any other infant/toddler learns to respond to and use voice/sign etc.
- Movement occurs when there is motivation. If a child does not see or hear very well, and if the other senses are also possibly affected, motivating a child to move is that much harder. The use of special strategies used with infants and toddlers who are deafblind will help create this motivation.
- Socialization occurs from the time a child is born. When a baby is born deafblind, learning socialization skills - much of it incidental - does not occur or occurs minimally if there is no intervention.
- Incidental learning - through ALL the senses - occurs from the day a baby is born. A baby who is deafblind cannot access this type of learning unless specifically directed. Obviously - this must happen early! An environment where incidental learning is missing is one where concept-development is compromised.



## THE TOOLBOX



The National Consortium on Deaf-Blindness (NCDB) has had an Early Identification Initiative for several years. During the process, they completed a self-assessment guide "designed to analyze deaf-blind count data", and to try and determine why a state might have under-identification or under-referral. The site to look for this information is:

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

- To download the Self-Assessment Guide, use the pull-down menu to identify your state. This will ensure that state-specific data is included in what you will be looking at. The contents now reflect the most current (2011) data as well.
- Look through the OVERVIEW of the Self-Assessment Guide or download the attractive PDF version.
- READ the "TIPS FOR USING THE GUIDE". They are tips from the groups of persons who actually field-tested the Guide — and so relate very closely to what they experienced.
- If you would like to know more about the states that piloted the Guide, read "Early Identification and Referral: Partnerships in Action" in the Fall 2012 issue of Deaf-blind Perspectives:  
<http://www.nationaldb.org/dbp/current.htm#heather>
- The Self-Assessment Guide is a tool that takes a state through a "discovery" process, learning what exists, looking at possible reasons, and determining what interventions might help. See the following box to get more quick information about the Guide and its Process.



## THE SELF-ASSESSMENT GUIDE



The tool outlines a three step process:

1. Analysis of existing data
2. Scrutinizing the current situation, identifying systems and issues with potential for change; and creating an action plan.
3. Implementing the action plan.

You will notice that in Step One Deaf-Blind Child Count data are analyzed — with tables being pre-populated for Oregon (unless you requested a Guide for another state). Using the pre-populated data we can

- Compare proportionality of OR birth-2 Deafblind Child count to Part C count, or
- Compare OR birth -2 deafblind count to the national birth-2 count
- Look at the birth-2 count in relation to overall age distribution; or
- See a detailed breakdown of birth through 3 — Oregon and National count
- Section E (starts on p.7) suggests a study of additional factors such as rural/isolated geographic areas, and race/ethnicity.

Part 2 of the guide is a determination of the NEED for improvement in early identification. It contains a reflective question, and a series of indicators.

Part 3 reviews Oregon's Systems (including Part C, the medical community, The Early Hearing Detection and Intervention Program or EHDI, other Community Programs), and the DB project connections.

Parts 4 and 5 guide us through Under-Identification and Under-Referral Analysis—again looking at the DB Project as well as the Systems. This section also suggests how to determine issues to target in addressing under-identification and under-referral.

Part 6 covers the development of an action plan, and includes a decision-making matrix.



## THE TOOLBOX



The process of identifying children who are deafblind is often not straightforward and sometimes more time-consuming than we would like. However, there are many tools available to us in the field.

Take for instance this information from **TSBVI**: <http://tiny.cc/gng7tw> which looks at screening, both formal and informal assessment. Their note states: "Many of these documents are forms. They are presented as MS Word.doc files for downloading. Some of the documents are mostly text and are presented as html files with a link to a Word version."

And then there's this page — also from Texas on why it is important to identify these children EARLY: <http://tiny.cc/ceg7tw>. Under "red flags" this page also contains lists of etiologies with which deafblindness may be associated. There are also "at risk" factors noted — for both vision and hearing.

**Nevada** has a quick page of information "Does this child see? Does this child hear?" — and looks at "behaviors" that may occur as a result of vision or hearing issues: <http://www.unr.edu/ndsip/secpagesEnglish/seehear.html>

From **Kentucky** Outreach to the Medical Community, there are several useful items that could be used by any project. For example, there is a sample "letter to physicians" — and a power point by Dr. Sara Cawthon on early identification of children with deafblindness: <http://www.nationaldb.org/ISKyMedOutreach.php>

**Georgia** has a "Screening Protocol for Visual Impairments in Children who are Deaf/Hard of Hearing; and **New York's** Deaf-Blind Collaborative has "A tool for identifying vision and hearing loss in children with multiple disabilities": <http://www.nationaldb.org/ISSelectedTopics.php?topicCatID=71>

**Washington** has a two-part training "Identifying and supporting young children with Multiple disabilities that may include hearing loss and/or vision impairment".

## READINGS FOR PARENTS AND OTHERS ON BABIES AND INFANTS



NCDB's paper by Deborah Gleason, "Early Interactions with Children who are Deaf-Blind" is an excellent starting point.

<http://www.nationaldb.org/NCDBProducts.php?prodID=34>

It can be downloaded as a PDF file and is also available in Spanish. This paper is a really wonderful overview of what parents (and others) should know about interacting with babies and children who are deafblind. The author emphasizes communication, anticipation, and illustrates what she is saying through brief scenarios. Her tips for developing "good" communication are based on four ideas:

- Developing a close and trusting relationship with your child
- Using consistent daily routines in which your child is fully involved
- Providing your child with cues so he or she can learn to anticipate what is going to happen
- Giving your child opportunities to have some control over his or her environment.

She reminds us that it is important to always greet the child, establish beginnings and ends to routines, provide choices, offer pauses, watch for cues the child may give, and explore the world together, hand under hand.

**PEGGY FREEMAN's** book "The Deaf-blind Disabled Baby" is long since out of print, but still well worth reading. You can download the whole book, or sections of the book from NCDB's page: <http://www.nationaldb.org/ISSelectedTopics.php?topicID=475&topicCatID=66>



## PARENT CORNER



Continuing the theme of infants and toddlers, here are some articles to look at, think about and ideas to try out:

- <http://www.tsbvi.edu/resources/1986-almost-100-motor-activities-for-infants-and-toddlers> - Motor activities for infants and toddlers
- Millie Smith's article: "Here's Looking at You Mom: The Role of Gaze in Early Attachment": <http://www.tsbvi.edu/seehear/summer99/gaze.htm>
- Some practical ideas from Queensland (Australia): <http://www.deafblind.com/sjoint.html>
- Need to learn more about hearing screening for your baby? Take a look at this page on the NIDCD site: <http://www.nidcd.nih.gov/health/hearing/pages/screened.aspx>
- Take a look at the Sound Beginnings videos (English and Spanish): <http://www.infanthearing.org/videos/ncham.html#sb>
- Is it Important for you to teach your blind baby sign language? Read on: <http://www.tsbvi.edu/resources/2278-teaching-your-blind-baby-sign-language>



**SAVE THE DATE!**

### Annual Parent Weekend

When: August 9 (5:00 p.m.) - August 11 (1:00 p.m.)

Where: Oregon Garden Resort,  
Silverton

*Invitations (with RSVPs) will be sent out later.*

Questions?: Contact Lyn Ayer,  
[ayerl@wou.edu](mailto:ayerl@wou.edu) or (503) 837-0093.

## Attention all Parents!

Hurray! The Parent Pages on our website are up — although some pages are still under construction. If ANY of you have contributions to make to the pages, please e-mail me with the information at [ayerl@wou.edu](mailto:ayerl@wou.edu)

Many thanks to Trisha and Dave McCready — two of our Parent Leaders — and to Roxanna Marvin from The Teaching Research Institute, for all their work on these pages. Get to the site: <http://www.oregondb.org/Family/index.html>

The Parent pages include:

- Coming to Terms
- Getting the Support you Need
- Teaching Your Child
- Intervenors
- Typical Development
- Resources and Links

NOTE: A couple of the pages are still under construction. We will also be adding as parents contribute ....



## THE OREGON DEAFBLIND WORKING GROUP

TBD – Region one, Eastern Oregon

**Colleen McLaughlin**—Region two, Central Oregon

**Lynette Kleespies**—Region three, Southern Oregon

**Terry Cadigan** – Region four, Cascade Regional

**Anne Olson-Murphy** – Region five, Willamette Regional

**Darlene Daniels** – Region six, Columbia Regional

**Trish Orr** –Region seven, Lane Regional

**Brenda Satter**—Region eight, Northwest Regional

TBD - Oregon School for the Deaf

**Dennis Crepeaux**— Oregon Commission for the Blind

**Kathy Eckert-Mason** – Department of Vocational Rehabilitation

**Amy Parker** – NCDB representative, The Teaching Research Institute, WOU

**Sue Mathisen** – Regional Services, Management Team

**Julie York** – Oregon Department of Education

**Laura Petschauer** – Oregon Department of Education

**Lyn Ayer** – Oregon Deafblind Project, The Teaching Research Institute, WOU



### WEB INFORMATION:

The Oregon Deafblind Project Website: [www.oregondb.org](http://www.oregondb.org)

The home page has our newsletters, both current and archived.

Also get information almost daily from our Facebook page:

<http://www.facebook.com/pages/Oregon-Deafblind-Project/132672043449117>

and our Pinterest page: [www.pinterest.com/lynbayer](http://www.pinterest.com/lynbayer)

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

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



### Contact the Oregon Deafblind Project!

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