



Oregon Deafblind Project



Building Effective Programs

Lyn Ayer, Project Director • November 2015

Hello and **Happy Thanksgiving** everyone!

I hope you are all enjoying the “Welcome to Oregon” weather—the final fall leaves, the first frost, and the squirrels burying their last nuts.



I have attended several IEP and program-related meetings recently—and so chose the book to review that is included in this newsletter. It is worth reading and thinking about. I love that it has blank spaces to jot down thoughts and ideas, and also that it sometimes has questions directed at the readers. Definitely — makes you think.

I was also fortunate to attend an excellent webinar — really directed at medical professionals — but I learned a lot, and also learned where to go to look for more such information. This is shared on the pages of “Webinars and such”.

NCDB has just posted exciting new OHOA modules that can be used as part of trainings, or topically. Take a look at them at www.nationaldb.org and pp 5-6 here.

I continue to post on the project’s Facebook page, but would also like to highlight some of the postings—especially for those persons who do not go on Facebook. So I have a new section in this issue called “Facebook share”. Hope this helps those who don’t want to deal with facebook — and also act as a reminder to those who may have seen something fleetingly and then forgotten about it. I myself sometimes forget what I post....

We still have an “open cohort” system for the OHOA modules—and any team that would like to participate, please get in touch with me. Small teams seem to work better — usually a parent, a teacher, an IA/EA who works one on one with a child. Within the moodle system, there are ways to talk to each other, comment on what each person thinks, and ask for or receive additional information. You can also pair a series training with modules. Get in touch with me: ayerl@wou.edu

Thanks!

Lyn



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*"Life is like riding a bicycle: you don't fall off unless you stop pedaling."
Claude Pepper*

BOOK NOOK



WILL YOU DANCE?

As we all weave in and out of IEP meetings each year, I thought it would be good to share a book that gives us a really great perspective on this PROCESS. For the most part, we tend to treat an IEP as a meeting – and forget that it is truly a PROCESS – or should be. We need to see IEPs as not just a “legal” requirement, but as a life-building tool for every child who has a disability. I really enjoyed the concept that the authors present – that it is a Dance – and that we need to be in step to have a successful performance. The introductory chapter ends, very aptly, in a Hopi saying: “To watch us dance is to hear our hearts speak”. The authors represent parents and professionals and their joint authorship gives us a balanced viewpoint that is neither “parent” nor “professional”, but a blend of both.

Ann Turnbull who wrote the Foreword is well-known for her advocacy in special education – beginning her path with her own child. She directs us to Micah Fialka-Feldman’s website that is very aptly called “Through the Same Door”, an enduring image for Inclusion: www.throughthesamedoor.com

Parents – listen to Janice Fialka’s thoughts in an extended visual poem – and I believe you can relate to her experiences:

http://www.broadreachtraining.com/videos/puddles_pride.htm

Professionals – listen to her beautiful words of wisdom and appeal: [http://](http://www.broadreachtraining.com/videos/advice.htm)

www.broadreachtraining.com/videos/advice.htm

On her website (www.danceofpartnership.com) also take a look at Emma’s writings. Among them are her “The Sibling Slam Book” – and get a feel for what siblings without disabilities ponder. There is contact information for both Janice Fialka and Arlene Feldman at the beginning of the book where the authors are introduced.

Every chapter has spaces for reflections and notes – where you can scribble away! You can make notes about what you might do at the very next IEP meeting – or what you might avoid. But each chapter provides food for thought – and action.



Chapter one dives right into the concept of the process being a dance. It starts out by being awkward with the partners not being in sync, each participant listening to “their own music”. The authors point out that there is no lack of music – just the absence of shared music (and dance steps). The concept involves creating a NEW song from the many voices. *“It’s no longer just “your” swing dance, or “my” salsa. It’s an original musical score with new choreography based on the unique needs and gifts of each child”*.

The authors remind us of the TV show, *Dancing With the Stars* – and how awkward partners are at the beginning. But they build trust in each other, while they learn to relate their steps and unique rhythms – all leading to dances that are awe-inspiring. I believe they draw on this example to emphasize that there must be a beginning and that it takes time to truly build the partnership. And it is good to be reminded that sometimes being out of sync may be an integral part of the dance – or the process of ensuring a better outcome.

The authors remind us that parents, this relationship that needs to be developed, is initially not one that they chose. Less experienced professionals may feel like they were just trying to be helpful – but ended up stepping on toes. More experienced professionals might be able to advise – not to take things personally. So – both partners may begin by not even know if they WANT to dance with each other.

The authors list these other common Qs that may arise (pp10-11):

- *What if I am ready to dance hard and fast when you want a slow, gentle dance?*
- *If I follow your lead, where will you take me? Will you follow my lead?*
- *What if we collide, trip, or fall? Will we be able to pick ourselves up and continue dancing?*
- *Can I set aside my experiences with previous partnerships and truly begin this new one with a clean sheet of music?*
- *And for those who have already been dancing strenuously on behalf of their children or students, a quiet question, born of exhaustion: How much energy do I have to begin another partnership?*

BOOK NOOK

The authors then take you through three phases, providing examples for each phase, along with the “dance steps” to practice: STOP, LOOK, LISTEN, SHARE, TAKE CARE.

1. Colliding and campaigning
2. Cooperating and compromising – the position now being of “polite cooperation”
3. Creative partnering and collaborating – which changes to the language of “possibility”

The chapter ends with some practical thoughts and suggestions. While the “dance” usually occurs in these phases, these are not always predictable as some partners may return to an earlier phase or skip a phase. The development of relationships takes time, and effort – collaboration. Listening is an extremely important skill, especially as both parents and professionals have much to offer.

Chapter two is an extended, very touching and meaningful chapter titled “Listening to the Hidden Lyrics”. There are two “stories” within it – The Story of Sam, and The Story of Rachel. For each story, the authors describe the hidden “lyrics” for the parents, and the professionals in several “scenes” – like in a drama being played out. Each scene is followed by clarifying ideas from both perspectives – and a whole blank page for your own notes. I believe this chapter will truly resonate with parents and professionals who read it. I am sure your heads will nod, “YES. That is how I feel. That is what I think” – and you will begin to see how the clarifying ideas could help. Personally, I felt this was such a unique way to present this information – and to make it meaningful and practical for each reader. I hope that you will read these for yourselves and not just stop with reading this book review!

Chapter three is “The Dance Manual”. The authors provide essential steps – first for parents, and then for professionals. They urge parents to “Share your dreams, high expectations, and hopes for your child and engage others to share”. I will share an abbreviated version of the “essential dance steps”, but reading the full text is far more meaningful – and I urge you to read it all!

Janice Fialka ends this section remembering a conversation with Marsha Forest – who was very involved in the movement for inclusion. Marsha reminded the author that “the Rev. Martin Luther King Jr. shouted to the world, ‘I have a dream’. She paused, winked and continued, “He did not say, ‘I have goals and objectives.’”. This is followed by a box titled, “Is it Denial, or is it Hope?” – and I think this is well worth thinking through – and talking through – with spouses and families, and professionals in partnership in the “dance”.



Essential Steps: For Parents (pp 95-97):

- ◆ *Go slow. Give yourself time to feel, think, question, absorb and learn. Ask for support.*
- ◆ *Ask for input from professionals.*
- ◆ *Trust yourself.*
- ◆ *Trust that your partners really mean to support your child.*
- ◆ *Communicate.*
- ◆ *Be prepared. Ask ahead what to expect, what to bring, what you should be prepared to talk about.*
- ◆ *Read carefully. Seek a mentor. Take time to review written reports.*
- ◆ *Ask.*
- ◆ *Speak out. Express your opinions, thoughts, agreements, disagreements – with respect.*
- ◆ *Take five.*
- ◆ *Aim high.*
- ◆ *Learn.*
- ◆ *Share your family’s cultural values, traditions, routines.*
- ◆ *Give feedback – especially positive.*
- ◆ *Involve your child.*
- ◆ *Remember that your child is the same unique, wonderful child she or he was before the assessments.*
- ◆ *Be kind to yourself.*



BOOK NOOK



Essential Steps: For Professionals (pp. 100-108)
There are several lists in this section of the chapter, under 5 areas. I took the liberty of selecting/highlighting two from each of these really valuable lists:

1. For all Partnerships

⇒ Strive to learn about the parent as a PERSON.

⇒ Avoid jargon, poor body language

2. Preparing Parents

⇒ Create a sense of welcome – e.g., attach a sticky note with a personal message to a formal letter.

⇒ Ask parents how they want to be addressed – and avoid “Mom” or “Dad”

3. Beginning Meetings

⇒ Avoid having professionals talking only to one another – and excluding the parents

⇒ Provide table tents or name tags – with names and roles in bold letters; don't forget to provide these for parents and any other guests who may attend

4. During Meetings

⇒ Check for understanding frequently. Clarify.

⇒ Check with parents if it is all making sense – and if not, what does not “fit”.

5. Ending Meetings

⇒ Encourage parents to follow up with questions or concerns after the meeting

⇒ Encourage each person to share one final thought, question, or observation

In a highlighted box on page 100, the authors state: “Without these essential steps, the dance comes to a screeching halt. With them the partnership succeeds and the child can dance the dream.”

Chapter four is titled, “When the Dance is Complicated”. It addresses two scenarios – (1) when parents appear angry, and (2) when parents are absent, not involved or appear to be uninterested. The authors’ sage advice is not to be “derailed” by anger – but to find out more. In a scenario from the Movie “*Terms of Endearment*” they show that outwardly what may appear as “causes” (rage, powerlessness, desperation, frustration, anxiety etc.) may really, deep down, be LOVE.

And for possible reasons that a parent may seem uninterested or uninvolved, the authors suggest a long list of “possibles” from a brainstorming session. For example, parents may be living in a homeless shelter and are embarrassed, they find it impossible to take off from work and still try to make ends meet, language difficulties, and so on. Some parents may not believe that they are valued members of the team, and that the team genuinely believe they have something to contribute. The authors state that genuine concern for parents will be beneficial to all. Their concluding thoughts are “We are all People First”.

Chapter five addresses “Enhancing the Dance” – and address the importance of keeping those lines of communication open – with suggestions that might work. I know of at least one building in a school in Oregon that sends home newsletters and announcements that are charming and upbeat – and very readable; They also invite parents into their classroom and the staff prepare pot-luck meals for everyone. How inviting! This chapter contains many practical suggestions, and examples of “Partnership Notes” that are doable – and will certainly get results.

The authors conclude this book with a quote from Margaret Wheatley (2009):

I believe we can change the world if we start listening to one another again. Simple, honest, human conversation. Not mediation, negotiation, problem solving, debate, or public meetings. Simple, truthful conversation where we each have a chance to speak, we each feel heard, and we listen well.

And the book is:

**Title: A Dance That Matters
Parents and Professionals PARTNERING for
CHILDREN WITH DISABILITIES
(Revised Edition)**

**Authors: Janice M. Fialka, Arlene K. Feldman,
Karen C. Mikus.**

Foreword by Ann P. Turnbull

Date and publisher: 2012. Corwin



UPDATE on Online Training through the OPEN HANDS OPEN ACCESS Modules

NEW modules are now available to look at. Terrific topics, terrific modules. Here is information directly from the NCDB website:

<https://nationaldb.org/ohoa/modules>

Module 9: Routines for participation and learning

Learning outcomes:

- Describe routines as a foundation for early learning, concept development, and interactions.
- Describe how routines support and organize learning for students who are deaf-blind by compensating for sensory gaps.
- Explain the importance of collaboration with family members and the use of routines in both home and school environments.
- Identify how routines support the student, the intervener, the teacher, and the family.
- Identify how routines are a framework for assessment and intervention.
- Describe the intervener's role in the development of routines.
- List the prerequisites and considerations for designing and using routines.
- Identify the steps of reviewing routine materials with a student and the process for developing a dialogue for communication.
- Create and evaluate an effective routine for a case-study student.
- Describe ways to expand on routines to help a student make progress.
- Summarize the importance of routines for learning all types of skills.

Module 10: Concept development and Active Learning

Learning outcomes:

- Recognize the impact of deaf-blindness on an individual's development of concepts and incidental learning.
- Compare and contrast skill development and concept development.
- Recognize that trusting relationships are essential for the development of concepts about the self (and concepts about the self are essential for learning).
- Recognize the role of touch and exploration in the development of concepts and active learning.
- Identify the role of language and communication in the development of concepts.

- Describe methods for incorporating experiential learning and functional tasks.
- Apply deaf-blind strategies in the development of routines which support active learning and concept development.

Module 11: Intervener strategies

Learning outcomes:

- Demonstrate observation skills that promote understanding of the intervener strategies covered in this module.
- Describe the principle of "do with not for" and identify ways to "do with" students who are deaf-blind.
- Describe the challenges of being a bridge, rather than a barrier. Identify possible solutions to these challenges.
- Explain the importance and rationale of hand-under-hand technique and demonstrate the technique.
- Understand the importance of "pace, process and wait."

Module 12: Maximizing vision and hearing

Learning outcomes:

- Demonstrate understanding of instructional modifications and strategies that maximize vision and hearing.
- Demonstrate understanding of medical and assistive devices used to maximize vision and hearing.
- Understand when you need to adapt a vision or hearing device or strategy to accommodate both sensory needs.
- Understand the role of the intervener during the assessment process.
- Know how to use and maintain amplification, cochlear implants, and assistive listening devices as directed.
- Know how to make adaptations for auditory needs as directed.
- Know how to make adaptations for visual needs as directed.

Module 13: Calendars

Learning outcomes:

- Explain why a student with deaf-blindness might have difficulty learning time concepts, time vocabulary, and understanding traditional timepieces.
- List the continuum of time frames in calendar systems and identify several student characteristics that are prerequisites for each.
- Identify ways that calendar systems are individualized for students with deaf-blindness.



UPDATE on Online Training through the OPEN HANDS OPEN ACCESS Modules (contd.)

- Describe strategies to depict and discuss the past events for each time frame.
- Describe how calendars move from concrete to abstract across the time frames to teach vocabulary about the future.
- List example of how calendars support communication for students with deaf-blindness.

Module 14: Introduction to Orientation and Mobility for Interveners

- Describe the role of the intervener in supporting a student's orientation and mobility.
- Describe the role of the orientation and mobility specialist.
- Describe the 5 levels of the Spatiotemporal Development Framework as it relates to students who are deaf-blind.
- Identify ways to support students who are deaf-blind within the 5 levels of development.
- Identify basic O&M tools and techniques.

Module 15: Orientation and Mobility in Everyday Routines

Learning outcomes:

- Understand how an effective travel routine can support a student's practice of O&M skills.
- Understand the "10 Principles of Effective Travel Routines" and how to apply intervener strategies to support student learning related to each principle.
- Understand how environmental features help a student learn about the concepts of space and distance.
- Understand how environmental features can be sequenced to help a student know where he or she is in space (orientation).
- Understand that the skills a student acquires in the context of travel routines have a direct, positive impact on his or her inclusion in family, school, and community life.
- Understand that the skills acquired in the context of travel routines lead to higher levels of safe, efficient, and independent travel.

Module 16: Self Determination

Learning Outcomes:

- Learners will be able to describe four components of self-determination as they relate to the specific needs of students who are deaf-blind.
- Learners will be able to define basic vocabulary, as it relates to self-determination.
- Learners will identify opportunities for self-determination within video-based case studies.
- Learners will conduct environmental analyses to determine what opportunities there are for students with deaf-blindness to develop self-determination skills with partners in actual school settings.

Module 17: Social Skills

Learning Outcomes:

- Understand the important role that social skills play in school and post-school success.
- Understand how deaf-blindness and decreased opportunities for incidental learning can impact the development of social skills.
- Describe how to support natural social interactions based on shared activities and interests within the framework of family culture and local norms.
- Describe how the intervener can facilitate friendships and interactions between the student and others in the school and community.
- Understand how the Circle of Friends process can be used to identify challenges and strategies to support social connections.

Module 18: Collaborative Teaming and Family Partnerships

Learning Outcomes:

- Understand the importance of clear communication for the team dynamic.
- Describe strategies to support good team communication.
- Recognize the role and responsibilities of each member of the team, including the family.
- Understand the importance of role release.
- Describe strategies for conflict resolution.

WEBINARS AND SUCH

Last month I was fortunate, through the Early Hearing Detection and Intervention program (EHDI), to attend a webinar presentation titled *Early Hearing Detection and Intervention: Doing the Right Thing in Primary Care Practice*. I learned a great deal and was able to locate some really great sources of information. There is SO much information! As I listened, I tried to grasp what was relevant to us in the field of deafblindness. Here is the link for those of you who might like to listen in to the whole webinar. I think you will find it interesting too:

<https://www.youtube.com/watch?v=9iSXvX3nj8Q&feature=youtu.be>

One piece of information was on risk factors for developing hearing changes later on — i.e., not detected at birth.

Following is the link to an informative algorithm on EHDI guidelines for Pediatric Medical Home Providers. It outlines the screening that occurs at birth and the 1, 3 and 6 month routine that is used for follow up. At the 6-month period (purple side box), there is a recommendation (but **not** a requirement) to refer the child to an ophthalmologist as well as a geneticist. Also — look at the green box at the bottom of the page where it states “Ongoing Care for all Infants; by the Medical Home Provider”. It includes several items, including referral for vision screening or other checks if needed:

https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/PEHDIC/Documents/Algorithm1_2010.pdf

Also in the green box is a list of late-onset hearing loss factors. We in the field of deafblindness will recognize many of these factors and can match them to the etiology page on our annual child-count forms:

- Family history of permanent childhood hearing loss
- Neonatal intensive care unit stay of more than 5 days duration, or any of the following (regardless of length of stay):
- ECMO, mechanically-assisted ventilation, ototoxic medications or loop diuretics, exchange transfusion for hyperbilirubinemia

- In utero infections such as cytomegalovirus, herpes, rubella, syphilis, and toxoplasmosis
- Postnatal infections associated with hearing loss, including bacterial and viral meningitis
- Craniofacial anomalies, particularly those that involve the pinna, ear canal, ear tags, ear pits, and temporal bone anomalies
- Findings suggestive of a syndrome associated with hearing loss (Waardenburg, Alport, Jervell and Lange-Nielsen, Pendred)
- Syndromes associated with progressive or delayed-onset hearing loss‡ (neurofibromatosis, osteopetrosis, Usher Syndrome)
- Neurodegenerative disorders‡ (such as Hunter Syndrome) or sensory motor neuropathies (such as Friedreich’s ataxia and Charcot Marie Tooth disease)
- Head trauma, especially basal skull/temporal bone fracture that requires hospitalization
- Chemotherapy

Thank you to Dr. Bob Ciocco for emphasizing that PARENTAL CONCERN is a very important risk factor—to trigger an evaluation. He emphasized that we should be sensitive to parental concerns and not say to them, “It’s probably nothing”.

Other Topics of Interest via AAP

Want to know a bit more about EHDI and pediatric services? Take a look at this page: <https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/PEHDIC/Pages/Early-Hearing-Detection-and-Intervention.aspx>

On the AAP site, if you search for EHDI related articles — this is the page you may get to:

http://www.aappublications.org/search/Early%252Bhearing%252Bdetection%20numresults%3A10%20sort%3Arelevance-rank%20format_result%3Astandard

<http://pediatrics.aappublications.org/content/136/4/e1120> — Providing Psychosocial support to children and families in the aftermath of disasters and Crises. Also this webinar: <https://www.youtube.com/watch?v=w8prNqH2W4I>

<http://pediatrics.aappublications.org/content/136/3/596> — Those of us who are interested in Kangaroo Care and Infant and Child Massage, will find this article interesting: Skin to skin care for term and preterm infants in the neonatal ICU

<http://pediatrics.aappublications.org/content/134/2/404> — Literacy promotion: an essential component of primary care pediatric practice

FACEBOOK SHARE



Cortical Visual Impairment

Ever wondered about how to teach children with Cortical Visual Impairment to understand 2-D pictures? Paths to Literacy has a new blog on this:

<http://www.pathstoliteracy.org/blog/teaching-students-cvi-identify-2-d-pictures>

Previous blogs include:

- Developing learning strategies for children with CVI:

<http://www.pathstoliteracy.org/resources/developing-learning-strategies-cvi>

And the webinar on the same topic:

<http://www.perkinselearning.org/videos/webinar/building-strategies-around-cvi-phases>

- Modifying books for children with CVI:

<http://www.pathstoliteracy.org/strategies/modifying-books-cvi>

And one on beginning books for children with CVI:

<http://www.pathstoliteracy.org/strategies/beginning-books-children-cvi>

- And what about the idea of having a “CVI fish tank”?

<http://www.pathstoliteracy.org/strategies/cvi-fish-tank>

- What about using iPads with these children?

<http://www.pathstoliteracy.org/blog/using-ipads-students-who-have-cvi-multiple-impairments>

- There are several pages of blog titles to look at on the Paths to Literacy site. Take a look!

<http://www.pathstoliteracy.org/search/node/CVI>



FACT has their Regional Conference coming up — APRIL 2016 at West Salem — and have the announcement on their site. You can register there too:

http://factoregon.org/event/fact-special-education-regional-conference-salem/?instance_id=10404

Toys to buy, things to make.....

Do you need stocking stuffers

<https://www.therapysoppe.com/category/8-fidget-toys>

And WonderBaby is having a “giveaway” of some really cool items. For example — take a look at this tactile sketch pad: <http://www.wonderbaby.org/articles/intact-tactile-sketchpad-giveaway>

Or what about these really lovely braille ornaments:

<http://www.wonderbaby.org/articles/braille-christmas-ornament-giveaway>

In fact, take a look at their entire giveaway site:

<http://www.wonderbaby.org/holiday-giveaways>

Wipe-clean weighted blankets: <https://www.therapysoppe.com/category/P2752-wipe-clean-weighted-blankets-blanket-autism-therapy>

Story boxes you can make: <http://www.pathstoliteracy.org/blog/easy-create-story-boxes>

And there are all those wonderful Pinterest Boards

with a ton of ideas through WonderBaby: <https://www.pinterest.com/wonderbabyorg/>

Horseriding

Horses Adaptive Riding & Therapy (HART) — “Harnessing the Magic of Horses to Change Lives” - OUR MISSION: To improve the lives of people with special needs by providing barrier-free, safe and affordable, horse-centered activities Horses. HART is a local, grass-roots organization assisting special needs individuals in our community.

<http://horsesadaptiveriding.com/>

ScreenReaders

<http://www.pathstoliteracy.org/blog/accessing-internet-windows-screen-reading-software>

Find Accessible Places

<http://www.axsmap.com/>

Medical Technology

Wonder where technology like this will take us?

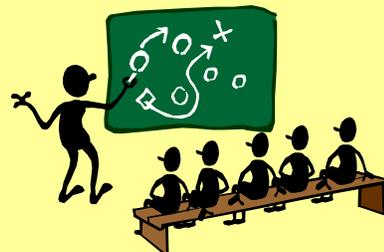
http://www.npr.org/sections/health-shots/2015/09/15/440361621/engineers-create-a-titanium-rib-cage-worthy-of-wolverine?utm_campaign=storyshare&utm_source=facebook.com&utm_medium=social

To all our non-Facebook friends — hope you enjoy these!



THE OREGON DEAFBLIND WORK GROUP

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Noelle Sisk:	FACT/PTI parent representative
Lyn Ayer:	Oregon Deafblind Project, The Research Institute at WOU



WEB INFORMATION:

The Oregon Deafblind Project Website: www.oregondb.org

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

Also get frequent information from our Facebook page:

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

and our Pinterest page: 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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