



Oregon Deafblind Project



Building Effective Programs

Lyn Ayer, Project Director • Fall 2014

November 2014



Hello everyone!

Almost all the leaves are down....just those last few, clinging desperately to the branches — before that cold weather! I hope everyone had a wonderful summer vacation, found time to do some exciting and different things—and that the back-to-school process was good too. And now — on to the holiday season!

Our parent group will tell you that we had a really good learning weekend this year — productive, relaxing and fun. It was wonderful to have new families join us — and enjoy the atmosphere of acceptance and understanding. Thank you to our lead parents in the planning group—the McCready and Smith families. We were fortunate to have Anne Olson-Murphy weave her magic with the group— organizing and facilitating sessions. Thank you, Anne for being the warm and wonderful person you are! Robbie Blaha— from the Texas Deafblind Project was our main presenter — and she was marvelous. Thank you, Robbie! And on our final morning, we had Tamara Bakewell— from the Family to Family Health Services at OHSU. She was a mine of useful information for all of us. Thank you, Tami! Our meeting place was at Newport this year. Even though it was too cold and blustery for most of us to venture down to the beaches, it was still beautiful and serene — and very suited to our purpose of respite for parents. We are looking for another location for next year — possibly in the Bend area. If you have any ideas, send them our way.

PARENTS — explore NCDB’s new website: www.familieslead.org See more info on page 5.



Lyn



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“Autumn is a second spring when every leaf is a flower.” Albert Camus



Victoria School's MSI Curriculum

At our Annual Parent Learning Weekend in August this year, Robbie Blaha presented and challenged all of us with some wonderful ideas. Among a host of other things, she shared a Curriculum for multi-sensory children from the MSI unit at the Victoria School, Birmingham, UK. So — thank you, Robbie.

The children being considered in this document are children who have “combined vision and hearing impairments, often with additional physical, sensory, medical and/or learning difficulties.”

The purpose of the curriculum is to help develop “awareness, experience, understanding and learning skills” so that these children can better access UK’s National Curriculum—each in their individual way. The document is based on best practice, observation, the work of renowned specialists in the field, and discussion. For us — keep in mind the Common Core Standards as you look through it.

The Curriculum is designed for use by persons on the child’s team, including teaching assistants.

The curriculum considers how MSI’s compounding effects on “children’s ability to gain information from and about their environment,..slows the pace of learning....” In particular, it affects:

- Communication—relationships
- Processing and INTEGRATION of information from all senses
- Understanding time and space
- Generalization of skills, concepts
- Abstract reasoning



What does the curriculum cover?

The following are considered “features” of learning and can be seen in phases 1-4

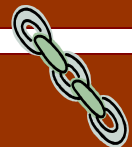
- Social relationship and emotional development
- Communication
- Conceptual development
- Sensory responses
- Understanding time and place
- Orientation, movement and mobility
- Ownership of learning
- Responses to routines and changes

The first part talks about the fact that children with MSI develop and learn very differently than do children regarded as “typical”. I love the example they give on page 11 of building a tower of blocks. A typical child uses eye-hand coordination. A child with MSI may rely on touch and spatial memory — and his/her concept of what is being constructed may not generalize to other similar “structures” and concepts — such as piles of laundry and stacks of plates. The child with MSI may need to be shown directly. How true!

Because their world and their approach to it is so different, the MSI child will also have different interests and preferences.

“Children with MSI share the universal drives to understand, anticipate and control the events affecting them and to observe, interact with and learn from their environment, BUT THEY ARE HUGELY DISADVANTAGED in doing so” (upper case are mine!) They do not share the advantage of having the following that typical children have by the time they get to school:

- A huge range of skills, concepts
- Learning skills to integrate “new” experiences
- Familiarity with everyday concepts
- Pre-skills for learning
- Structures needed to benefit from school experiences



THE TOOLBOX



The curriculum is based on the following:

- Assume that the child's knowledge base is very limited at the start
- It is necessary to TEACH how to interact with the environment (social, physical)
- Repeat, repeat, repeat — even if it seems redundant
- Providing access is critical—no matter the combination of sensory impairments
- Emphasize a sense of SELF and self-advocacy
- Have broad implications, be balanced, and be RELEVANT
- Support generalization by providing opportunities
- Apply existing learning, PLUS encourage progression, new learning
- Providing FLEXIBLE programming is important.

Each child featured in the curriculum—to provide an example-in-practice—has his/her individual timetable, and activities selected specifically to meet his/her combination of sensory and other impairments. It takes into account individual ability, age, strengths, preferences. All activities are cross-curricular—to encourage generalization.

IMPORTANT to note:

There is a diagram on page 14 that shows the connections between UK's **National Curriculum subjects** to the **MSI curriculum domains** and the interconnectedness between all of the areas. For example, the diagram connects:

- **Understanding time and place** with **Geography, History**
- **Sensory responses** with **Art and Design, Design and Technology, Music, PE**
- **Orientation, Movement & Mobility** with **Geography, PE**
- **Communication** with **English, Modern Foreign Language**
- **Conceptual development** with **Math, Science, Design and Technology, Information and Communication Technology**

The MSI Curriculum is divided into four phases:

- Phase 1: Pre-intentional
- Phase 2: Intentional non symbolic
- Phase 3: Early symbolic
- Phase 4: Formal

These reflect a progression that become increasingly differentiated for each child as he/she learns. Children are assessed using a Phase "Profile".

Important to note (p.16):

The curriculum provides

- Appropriately planned and delivered activities which enable pupils to succeed and progress
- A highly responsive environment which treats all behavior as communicative and helps pupils to develop appropriate and effective means of communication
- An emphasis on practical, relevant activities which enable pupils to access concepts of health and safety
- Specific support to develop self-confidence and positive relationships with others and to deal with life changes and challenges
- An increasing emphasis on autonomy and interdependence with age, including learning how to access and direct support appropriately when needed.

What do the teachers DO?

They provide:

1. ROUTINES to emphasize consistency, following cues, and that support anticipation, communication and student-control. At a later stage— they provide a "routine mismatch" to encourage spontaneous responses.
2. A sense of SAFETY/SECURITY by having only one or two persons working with a child initially. They begin with an environment that is restricted, but gradually include more spaces.
3. MOVEMENT-BASED LEARNING (the van Dijk approach) - using resonance, co-active movement, modeling and imitation.
4. SHARED TOPICS of communication via intensive interaction—the adult "following the child's lead".



THE TOOLBOX



5. An ARRAY of Communication MODES, encouraging children to use a wide range, and vary the modes for receptive and expressive communication.
6. An understanding of BEHAVIORS AS COMMUNICATION
7. The correct PACE to interact with a child, based on his/her sensory and other needs
8. A physical and social environment (visual, auditory) that is optimally beneficial to a specific child and reduces what is extraneous. As a child grows and learns, they also teach the children how to deal with changes and to perhaps modify these for themselves.
9. CUES and PROMPTS — fading these appropriately over time. Stages: Working Coactively (one with the adult), Cooperatively (each contributing to the same activity), and Reactively (separately, but alongside each other).
10. A process for GENERALIZATION—e.g., teaching the same concepts many times, and in different contexts—thus reducing prompt-dependency, and context-dependency.
11. A process for INCLUDING children who are MSI in other environments

The Curriculum itself begins on page 24. Each Phase uses the “Features of Learning” (See buff box on page 2 of the newsletter). Each phase contains:

- A content and instructions section of what the person is doing with a child and why
- A case-study to demonstrate a child’s progression through it
- An explanation of the context in which this is occurring—with examples from the child featured in the case-study. This includes a personal Time table (Schedule). You will notice that the Timetable becomes increasingly more complex in each phase. You will also see how the child is moving from interacting with mainly one or two persons, to several persons—in a consistent manner. It also indicates that there has been an expansion in environments.

The Assessment PROFILE (p.105) is criterion-referenced, linked to the phases, and are not generic developmental measures.

The same domains/features of learning that are used in the profile as are used in the curriculum. It is used for recording a child’s progress, providing a basis for staff reflection, and in assisting to determine further targets (goals).

There are three check boxes: aware, achieved in specific contexts, and generalized. There is also a “Comments” section. The summary sheet provides an overall at-a-glance picture of a child’s progress within a phase.

There is one profile that corresponds to each phase.

The Curriculum concludes with a glossary of terms that are used in the curriculum.



Want a copy of the Curriculum? It is published by SENSE. Go to the following site and fill out the form to download:

<http://www.sense.org.uk/content/msi-curriculum>

ANNOUNCEMENT

Do you want to learn more about the Open Hands Open Access Intervener Training Modules? Would you like to join a cohort? More details are on the next page. Cohort 1 is on their way—3 teams, including teachers/supervisors, several individuals, including parents.

Cohort 2 will begin in January 2015. If you are not part of Cohort 1 and would like to register for Cohort 2, please send Lyn the following information before the end of December 2014 (see Page 8 for contact information for Lyn):

- First and last name
- E-mail address (all lower case)
- City/town you are from
- Your job/title

If you are a graduate - Are you interested in receiving information on graduate credits?

Thanks!



PARENTS—EXCITING NEW WEBSITE:

On December 18, 12:00 noon Pacific time, NCDB will be conducting a “tour” of a new website for families:

www.familieslead.org

Prior to the meeting: Adobe has recently updated Adobe Connect. Prior to the meeting, please run this meeting test and follow any instructions as needed.

http://hknc.adobeconnect.com/common/help/en/support/meeting_test.htm

On the day of the meeting:

Connect your browser to: <http://hknc.adobeconnect.com/family/>

- Type your name, enter as a guest
- Phone connection information will be posted in the room

For VRS users, call-in numbers are: [888-450-5996](tel:888-450-5996) Participant Code: 499500

The OPEN HANDS OPEN ACCESS MODULES

Note: Just so you know — you will see the word spelled “**intervener**” in documents about the United States, and “**intervenor**” in documents and information from Canada and elsewhere.

Here is how the modules came about. NCDB went through a “discovery” process with regard to intervener services and then wrote their recommendations for OSEP (Federal government: Office of Special Education Programs) and for the field. Take a look at the recommendations: <http://interveners.nationaldb.org/>. The Modules were one of the outcomes. An update on the status of NCDB’s work relating to the recommendations can be found on their wiki: <https://nationaldb.org/wiki/page/9/324>

It is the hope – and anticipation – of all of us that “Interveners” will become an official related-service.

If you want to learn more about WHO an intervener is, go to one or all the following:

- Read the latest publication (2014) on the subject: **Interveners in the Home and Community: An Under-recognized Imperative**. Read the definition on page 4.
- Download the definition from this library page on the NCDB website: <https://nationaldb.org/library/page/2266>
- www.intervener.org

At the present time, you can obtain an intervener credential through the National Paraprofessional organization by taking the coursework offered through Utah State University (info is at www.intervener.org). At the request of OSEP, NCDB is now in the process of exploring the awarding of a National Intervener Certificate. This will provide an additional avenue for persons who are interested, to become interveners.

If you are interested in knowing more and actually taking a look at the modules:

Go to: <https://nationaldb.org/library/page/2269> and fill out the form. You will be given access to the “Library” copies of the modules. (Be aware that if you use an e-mail address here, you may need to use a different one if you join a cohort). What you see here are the first 8. There are several more going through field testing and in draft form. The whole set of modules cover a very wide range of topics that include, among others, information on communication, movement, the sensory system, teaching and support techniques and so on. The modules are aligned to the CEC (Council for Exceptional Children) competencies for interveners. The list of topics for modules is at: <https://nationaldb.org/wiki/page/9/325>. The modules are gradually being translated into Spanish.

Remember that the primary audience for the modules are persons interested in becoming INTERVENERS (usually paraprofessionals, who will be trained in deafblindness). However, anyone interested in learning about deafblindness can take these – including parents, educational professionals, therapists, administrators, medical personnel and so on.

Cohort 1 for Oregon has already begun looking at the modules. In order to become part of a cohort, we need to provide the National Center with information (see announcement on previous page). NCDB staff will register you and provide you with log-in information and a password to the Oregon modules. Registration will begin for Cohort 2 in December—and module access will be provided in January 2015.

PARENTS: Perhaps you are interested in forming a **parent-cohort**, and want to get specific information from the modules. If so, contact me and we will talk about doing this.

VIDEO-WATCH



The other day I was viewing a TED video and script on “Working Memory” by Peter Doolittle. It started some interesting thoughts running through my mind – and I thought I would share them. First – here is a link to the video itself. It’s not very long, but the speaker captures a lot of information within it:

<https://search.yahoo.com/search?p=tet+talks+peter+doolittle&ei=UTF-8&fr=moz35>

I think the presenter captures many thoughts that should impact us.

For example, he says that working memory is “not something we can turn off” – and if it is turned off, it’s a coma. So when someone makes the assumption or says that a child is not doing anything, doesn’t react to anything, or has no preferences or motivators – this is inherently false. They are not in a coma – and therefore, something MUST be happening in their working memories. Just because we have not discovered what this is, or don’t understand, doesn’t mean it is not happening. Working memory must attach to something we directly experience. Example:

I am being taken in my wheelchair from the bus to my classroom. I mainly feel the rumble of my wheelchair’s wheels – different-feeling when I get off the bus, go over some bumpy areas, and then some areas where there are no bumpy spots. I feel the wheelchair turn a couple of times. I have begun to realize that after the second turn, we are nearing my classroom. I learn later (because someone made me feel these) that the bus ramp is made from this cold, hard stuff; that the pavement is different to the touch; the stones are a bit rough, and that the floor of the hallways is smooth. On a another trip, I learn that the bus ramp has rails that I can grasp, that there is grass beside the stone footpath, and that there is actually a door – which I can help to open by pressing a button. The door also has another way to open – by these things called handles – but since I am in a wheelchair, I wouldn’t really be able to use these very well – unless, of course, I stood up to do this. At first, I don’t know the names for all these things – the metal ramp, the glass-and-metal door, the hallway, grass, the two right turns I have to take before I get to the classroom. I also don’t know what these metal things are that are attached to the walls in the hallway. I later learn that these are lockers – and that I have one too. I didn’t know that when my coat disappeared, it went into my locker! The classroom has a door too – and I can actually reach my arms out and touch the entryway. It is made of this thing called wood.

He states that working memory does four basic things:

(1) Stores immediate experiences and the knowledge that goes with this.

For children we serve, these immediate experiences/knowledge are tempered with what they can actually access at a moment in time. Two things are inter-linked here. First, there are the experiences that are “out there” and available – but a child who has sensory issues may not be able to see, hear, touch or reach out through the senses to truly get to the whole experience.

Second, the information and experience he/she may get from a situation may be distorted or incomplete. And what might be some of the implications of this? A child who is deafblind needs someone to guide their understanding of the information/experience, perhaps to piece it together in some way so the child can at least begin to put some meaning to it. We get incidental information all the time – in a continuous stream. A child who is deafblind does not have the advantage of this non-stop flow of information. For him/her “incidental” may not happen – unless someone is there to provide a way to learn about it. To stir working memory into action, this would definitely be step one. A simple example:

I am in our bedroom. My little sister and I share a room. I think I hear Mom’s voice, but it is fuzzy. To begin with, and since I can’t see very well, all I see is her hand moving up – and then coming down. Up and down. Up. Down. What is she doing to my sister? (Brushing her hair)

(2) Reaches into long-term memory as needed – to create links.

For children who are deafblind, concepts are developed and stored via direct access to them. But generalization is tough, unless someone helps to create **the links** to what they may have experienced/learned in the past. We may use cues, memory cards or books or any other such devices to make these connections. If you think about it, most of what we use are visual, some auditory, and a few tactile memories – and therefore, visual, auditory, and tactile links. The sense of smell and taste also help us create links, but are usually additionally connected to sight, sound, touch. Proprioception (where our muscles/tendons/whole body “remember” what certain experiences feel like –



e.g., going up or down a ramp, or in an elevator) is also connected to other senses. SO – with children who are deafblind – these links may not be obvious, or they could be incorrect or incomplete.

VIDEO-WATCH (contd.)



Links that connect to an emotional experience are the strongest of all. Not surprisingly, the less positive ones may be stronger than those that are positive.

Another important factor to remember in linking to the past — we may not consciously remember something that is stored in our long-term memories. Our behaviors may be seen as strange, because the link is not obvious. For example, many children who are deafblind may have been born prematurely. They may have feet that are overly sensitive — and they don't like foot massage. This is because they had "heel sticks" done as premies. And there is a connection, even if there is no conscious memory of it. An example:

I learned how to open the door to my room. I could then go in and out when I wanted. But I couldn't do the same for the door leading out to the back garden. It was different. I struggled to find this thing called a "knob" — but there was nothing like it on the garden door. I kept running my hands all over that door, until Tami noticed me doing that. At first she thought I was feeling the door. She didn't realize I was searching. When she did figure out I was searching for something, it took her a while to realize what it was. Then she showed me that this one had a handle, not a knob — and that it went up and down and did not need to be twisted. When I made it out into the garden, I sniffed the air — and caught the scent of something familiar — something that grandma had at her house. Roses. I headed towards the scent of roses, but ended up falling down. I did not know there was a step down off the patio. Grandma's patio has no step.....

(3) Combines this information

This is a natural result of putting things together to make more sense of the world. You combine them—as you would combine the ingredients in a recipe. You create something just a little different each time you do this each time you add or subtract from the original. Think of a child who is deafblind as a "Master chef"! He/she produces an end product from working memory (current happenings) that combines in a unique way to produce a formula or product that is different from one that you or I may have. This is because our worlds are very different. We have a different set of experiences. We select and store different things. And we provide ourselves with a very different set of ingredients from which we can choose. Sometimes when we are teaching children, we seem to expect them to have the same recollections.

As teachers, we know we have to repeat something so a child learns. We say that repetition is important. Actually, it is repetition WITH a connection to the child's context that is more important.

So we need to not only repeat, but observe what a child's response might be. If it is different and unexpected, it is not because the child is wrong — but that there is a difference in how the connection is happening and what the child is making of everything that he/she is putting together. Example:

Ah! I can smell that wonderful smell. Yum — cookies. I follow my nose — and get to the cookies. They are on a table and I have to reach up to grab one. I remember cookies because Mom bakes them all the time. And every time she bakes a batch, she allows me to get one for myself. SO — I reach up to get a cookie — and I hear all this yelling. Someone smacks my hand away. And I cry. I'm confused. Then someone reminds me I am not at home. I'm at school. And it is a group of students who made these for the school fair..... So I can't have one.

(4) Helps us figure out what we are doing or need to do in the immediate situation

With children who are deafblind, given all the processing that has to be done, it may be difficult indeed to cope with an "immediate situation". If concepts of things, place, time, people are unclear or unlearned—how can they be expected to make the right choices of what to do when a situation presents itself. Concept development must be constant, deal with the "flow" of information, have "connections" made as we go along — and so much of it has to be hands-on and concrete! Sound complex? It is.

Peter Doolittle points out what the use of working memory does for us. Try putting the following into the context of children who are deafblind. Ask yourself, after each bulleted item—How can a child who is deafblind do this — or how can we help make this happen?

- We take information from working memory and "leverage it in ways that allow us to satisfy our current goal".
- We retain some items from working/immediate memory even when there are interruptions. He actually gives his audience a "test" —memorizing 5 words, and then interrupting their process of remembering the words by asking questions to "disrupt" the process of remembering. Some people do better than others—probably because they already have a strategy that they use.

VIDEO-WATCH (contd.)



Three TAKEAWAYS from Peter Doolittle's talk:

- We pick and choose from an “amorphous flow of experience” and extract meaning from it via our working memories.
- Working memory allows us to deal with what is current — and allows us to move forward at the same time.

- *And here is one that is truly significant for our field of deafblindness:*

Conversation employs working memory. It is what allows us to contribute. During the time we are employing working memory to do this, we are also able to problem-solve and be involved in critical thinking.

Of course, working memory has limitations:

- In capacity (it's volume)
- In duration (time)
- In focus (attention span)

Therefore, in order to sustain working memory — and “prolong” what we gain from it, we need to DO something with it. We could:

- Process it
- Apply it
- Discuss it with someone

Here are some of the strategies we use:

- *We could process the information quickly, going over it with questions to ourselves — What did I learn? Did I agree? Can I apply this to my own life? How? What more would I like to know?*
- *We could repeat. Practice. Maybe we would talk to someone about it. We could document it — like, write it down in a journal — so you can check you notes later.*
- *We often “PIN” in into our long-term memory by using images. Images are pictures — and you know what they say — a picture is worth a thousand words!*
- *Organization always helps. Structure helps to create sense out of something.*
- *We know something will change — or should expect this to happen. We then allow ourselves to support this change.*

We want to take all of our existence and wrap it around the new knowledge and make all of these connections.

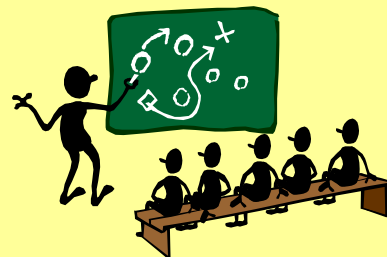
We are meaning-making machines.

If we're not processing life, we're not living it.
Live life.



THE OREGON DEAFBLIND WORK GROUP

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WEB INFORMATION:

The Oregon Deafblind Project Website: 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

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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The Oregon Deafblind Project is funded through grant award # H326T130008 OSEP CFDA 84.326T U.S. Department of Education Office of Special Education OSEP Project Officer: Susan Weigert



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