

 **OREGON DEAFBLIND PROJECT: BUILDING EFFECTIVE PROGRAMS**

 Lyn Ayer, Ph.D., Grant Project Director; FEBRUARY, 2017

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**"The flowers of late winter and early spring occupy places in our hearts well out of proportion to their size."
Gertrude S. Wister**

Hello everyone!

Hopefully spring is a tad closer! I saw a robin this past weekend — and hopefully the early spring flowers will follow soon. And — hurray — my lawn and garden are no longer white, but green! Apologies to those who love the snow….

Did you know that February this year has 4 of each of the days of the week? Take a look at your calendar — four Sundays, four Mondays, etc. Someone sent me this information and I thought I would share this with you.

Enjoy this February issue of the newsletter—and hope you find it useful. Remember — please feel free to re-circulate and use any information you care to share.

Now that you are all back in school — after those snow and ice days — have a fun spring!

**Lyn**

P.S. Sharing something I love — other than the children, families and teams I work with:

[**https://www.youtube.com/watch?v=ByzSRhvEEbc**](https://www.youtube.com/watch?v=ByzSRhvEEbc)

HOW IMPORTANT IS IT FOR US TO KNOW ABOUT FEEDING?

*This article contains notes I took while at a feeding seminar, as well as my own experiences and reflections. There was a great deal of information shared at the seminar — and so I had to pick and choose what I wanted to share. I wish I could share more!!*

Feeding has always been of interest to me since it affects so many of our children. In November 2016 I was fortunate to attend a seminar with Dr. Suzanne Evans Morris as the presenter: “Moving from gastrointestinal discomfort to **Inner-Directed** Eating”. It was the word “Inner-Directed” that caught and held my attention. Any action that is “inner directed” needs no external motivation, and leads to the most satisfying outcomes. To me this indicated that feeding was — or should be —a very child-centered activity—and Suzanne’s focus was definitely on the child and family.

 **Suzanne Evans Morris, Ph.D.,** is a speech-language pathologist with New Visions near Charlottesville, VA ( <http://www.new-vis.com/> ) She is known both nationally and internationally for working to identify and intervene with children who have feeding and pre-speech disorders. Her work is strongly family-focused. You can learn more — including looking at resources such as blogs, and videos from the Feeding Matters site: <https://www.feedingmatters.org/video-library>

Some “quick facts” relating to the gastrointestinal system:

 Positioning while feeding matters a great deal. The gastrointestinal tract depends on the influence of gravity – and downward movement. What if a child is lying down and being fed? Does this make a difference? Yes. Can this be helped? If a child must lie down, a solution to this depends on what you are trying to do.

 If you are trying to prevent reflux, then lying on the **left** side keeps more of the food in the stomach and prevents it from going back into the esophagus.

 If you are trying to make sure the food passes into the intestines – lying on the **right** will help get the food flowing from stomach to intestine.

 Talking about reflux – what does this actually feel like? Many of us think occasional mild burning is all it is. For many of our children it is much more. Imagine having a really bad sore throat and how annoying and painful that can be. That is what happens when gastric juices from the stomach constantly come up and burn the throat. Think of how painful it is to eat when we have a really bad sore throat. Even liquids affect us.

 The intestinal system is also known as the “enteric nervous system”. Consider it the “other brain” of the body. It has a large network of nerves, including the large vagus nerve. It is also responsible for the release of several hormones such as adrenaline, noradrenaline, dopamine; and 90% of the chemical/hormone serotonin is found here. <http://medical-dictionary.thefreedictionary.com/serotonin> . Some of these hormones are related to stress – and it is why we really FEEL the stress —or the relief from stress — in our “guts”. Seratonin may control the intensity of pain, affect how a child sleeps or feels, and how efficiently the guts function. Once on a CHARGE syndrome foundation webinar on pain I heard that many children have what has come to be known as an “abdominal migraine”. I don’t know enough about this – but it is worth asking questions of the medical community to see if these migraines connect to the facts in this segment. Link to CHARGE webinar: <https://hknc.adobeconnect.com/_a772371855/p6p2t2fxsiq/?launcher=false&fcsContent=true&pbMode=normal>

 There is a key role played by “good” bacteria in our GI system. Our cells and genes are actually outnumbered by bacteria 100:1. Microbes we acquire at birth assist our bodies to resemble our parents, affect our immune systems, and have their own antibiotics. We even acquire these at birth. Babies born by C-section, or who do not breast feed miss out on essential microorganisms from the birth canal and their mother’s milk. Inevitably—although we don’t know details — medications and vaccinations will compromise some of these good bacteria. This is important to realize because many of our children who are deafblind may need the medicines for survival. We should always consider what we do – relating to this information. We may not have the answers, but sometimes our bodies “tell” us:

 For example – Can we find out what side-effects there may be of medications – on our hormones and good bacteria in the gut?

 Another example –Is there any correlation of poorer immune systems and various immunization shots given to children (and adults)?

 Is there a way that we can counteract some of the less desirable results/side effects — e.g., by using probiotics?

 New research on Melatonin suggests that not only does it help with sleep, but with reducing acid reflux, migraines, SAD (Seasonal Affective Disorder). <https://www.youtube.com/watch?v=XNqKvwqDs60> We all know that sleep affects how we eat, how we feel — and how we behave. Think about children who are deafblind and have complex health issues who have no real way to tell us that their eating is being affected by lack of sleep. Also think about mothers who are afraid their child is going to choke in their sleep — and suffer from insomnia themselves!

 As research is carried out, it is worth learning more about CRF (corticotrophin-releasing hormone) that is secreted by the hypothalamus, and controls the secretion of the stress hormone (cortisol). In turn, this will suppress appetite and increase anxiety. Smaller quantities of CRF are made by certain white blood cells — which stimulates swelling or tenderness/inflammation, especially in the gut. CRF follows a 24 hour “rhythm” in non-stressful circumstances—highest in the morning around 8:00 a.m. and lowest overnight. A stressful experience, an infection, even exercise can trigger an increase in the hormone, to counteract the situation. If there is too much CRF in the system, appetite is suppressed. If this high level continues, it can lead to disorders such as anorexia, severe sleep disturbances, and clinical depression; and making certain inflammatory conditions worse—e.g., rheumatoid arthritis. In fact, it may actually cause inflammation. Too little CRF may affect sleep, memory and concentration. (1) <http://www.yourhormones.info/hormones/corticotrophinreleasing_hormone.aspx>; (2) <https://www.ncbi.nlm.nih.gov/pubmed/2234606> Research still continues on how to control the levels of CRF.

Medications may be life-saving (such as if too much acid is going into the lungs). But be aware that most medical procedures tackle the symptoms and may sometimes disguise them, but may not get to the underlying problem. The symptoms will usually come back when the medication is stopped. One must also consider the side-effects of medical interventions, including surgery. For example, after a surgery called fundoplication, a child is unable to vomit so will retch and gag instead. Medication (e.g., Prilosec) usually does not stop reflux — but makes it less acidic and feels more “comfortable”. We need to keep in mind that acid is the first defense against food-borne bacteria/viruses! Essential minerals such as calcium, iron and zinc cannot be assimilated without the acid in the stomach and may be destroyed or compromised by drugs. Since zinc is connected to how well we can smell, as well as to “feeling hungry”, this will affect eating.

Common gastrointestinal disorders:

* Reflux and esophagitis : Food comes up
* Aspiration : Reflux causes irritation, acid going into airways, causing pneumonia. <https://medlineplus.gov/ency/article/000121.htm>— see **aspiration pneumonia**
* Inflammation (eosinophilic esophagitis): Usually no reflux, but eosinophils cause an allergic reaction
* Emptying of stomach: Influenced by stress and can lead to reflux. It is affected by the contents of the meal, the age of the child, the size of the meal, and how long the food stays in the stomach. Slow emptying—”not hungry”; Rapid emptying (“Dumping syndrome”) can lead to nausea, vomiting, discomfort, bloating, cramping, diarrhea, dizziness, fatigue, sweating.
* Constipation: Caused by less fiber, dehydration. Suggested – use real foods blended. Feels “full”. – appetite reduced.
* Encopresis: Entire large intestines filled with feces – resulting in pain and discomfort. If child strains, reflux can occur.

**What are the responsibilities of feeding therapists?**

They need to understand:

* That swallow mechanisms are a part of the gastrointestinal system
* What gastroenterologists and other physicians are saying or suggesting, and know what questions to ask
* Reports and suggestions from nutritionists—and ask questions
* How the recommendations affect the child’s interest in food and learning eating skills, and also their comfort level
* Nutrition and hydration—and work with a dietitian to know how to incorporate powdered foods into preferred foods (e.g., yogurt)
* The impact of stress on the gastrointestinal system, and learning how to calm a child (e.g., breathing, humming, imaging a favorite place, specific types of music)
* And become familiar with alternatives to pharmaceutical solutions (e.g., cranio-sacral therapy, cider videgar, CALM powder). They need to not believe everything they read, but read with “wise eyes” and look for evidence.

There are four main priorities to achieve “Inner directed” eating. Suzanne talks about the “4 Cs” of therapy: **Connection, Comfort, Confidence, Competence.** I’m sure that these will resonate with us:

* **Connection:** This is foundational to the other three. What is “connection”? This is about our relationships with the persons involved in feeding or at a meal. Does the person who is involved in the meal have a bond with the child? Does this person “listen” to the child’s voice or body language? Is there empathy? We know this — especially as we talk a lot about how an intervener (or others) need to first develop a bond with a child and have the child really trust him/her. We also know how to have “conversations” that do not use symbolic language, but rely on gesture, facial expression, body language and movement.
* **Comfort:** Suzanne talks about three areas where “comfort” measures should be explored: gastrointestinal, sensorimotor, and emotional. I see those as interconnected—and can be complex to deal with. Often medical intervention, or therapeutic intervention is needed to patiently get children into this “comfortable” place. Often, especially with children who are tube-fed, there are both internal and external pressures on the child—dealing with the type of food, possible allergies, pain and discomfort while eating, too much food etc. There are a whole lot of other contributing factors to discomfort such as medication side-effects, surgical side-effects etc. The person feeding the child is also somewhat anxious—trying to figure out how much is “enough” or too much; how fast or slow to administer the food; what to do about medication changes, or simply how to help their child not experience stress. They are often going by what someone has told them to do, or what the can or container says, but do not know if this is what it really should be. The child may be losing weight, and so the parent feels pressure to feed more food. Real food that is blended has helped several children and families that I know—by reducing the discomfort a child feels, and also reducing tension in the parents. Another way to help with comfort is to regulate breathing, and what the brain is doing. Suzanne has used Hemi-sync technology successfully. See another brief article on this in this issue.
* **Confidence**: Not only does a child have to develop trust and confidence in the person or persons involved in their feeding, but they must also trust what they are eating. If they are at all uncertain about the food, they will not be comfortable with it either. Think about yourself — if you find some new, strange food on your plate. You may react in one of several ways. You may outright reject the food because you don’t like changes or novel food. You may briefly taste it and reject it. You may throw a tantrum because it reminds you of something that repulses you. Also — ask yourself the question: How did I learn to eat some things that I originally did not like or have a taste for? You may have been influenced by another person. It is possible that you learned to like it slowly — and in small doses. And you may also have learned something more about the food — perhaps the nutritional value too. You also build confidence when you are not forced to eat something, but learn to do so willingly.
* **Competence**: Something that has been tried, enjoyed, and repeated will have a child feeling that he is in control. Once this control exists, the mind and body become more relaxed and emotions are in control. This is truly when eating becomes “inner-directed”.

The notes above are my very brief ramblings — but if you can read the details in Suzanne’s blogs and other writings, you can read a whole lot more about this foundation for inner-directed mealtimes.

Some resources for you!

¨ Homemade Blended Formula Handbook: [https://www.amazon.com/Homemade-Blended-Formula-Handbook-Marsha/dp/0615147127/ref=sr\_1\_5?ie=UTF8&qid=1484173650&sr=8-5&keywords=suzanne+evans+morris](https://www.amazon.com/Homemade-Blended-Formula-Handbook-Marsha/dp/0615147127/ref%3Dsr_1_5?ie=UTF8&qid=1484173650&sr=8-5&keywords=suzanne+evans+morris)

¨ Meal time Participation Guide: [https://www.amazon.com/Mealtime-Participation-Guide-Marsha-Klein/dp/076167408X/ref=sr\_1\_6?ie=UTF8&qid=1484173650&sr=8-6&keywords=suzanne+evans+morris](https://www.amazon.com/Mealtime-Participation-Guide-Marsha-Klein/dp/076167408X/ref%3Dsr_1_6?ie=UTF8&qid=1484173650&sr=8-6&keywords=suzanne+evans+morris)

¨ Marvellous Mouth Music: Songames for Speech Development: [https://www.amazon.com/Marvelous-Mouth-Music-Songames-Development/dp/1935567098/ref=sr\_1\_4?ie=UTF8&qid=1484173650&sr=8-4&keywords=suzanne+evans+morris](https://www.amazon.com/Marvelous-Mouth-Music-Songames-Development/dp/1935567098/ref%3Dsr_1_4?ie=UTF8&qid=1484173650&sr=8-4&keywords=suzanne+evans+morris) and the CD too: <https://www.autismcommunitystore.com/marvelous-mouth-music-cd-by-suzanne-evans-morris>

**Talking about Metamusic…..**

Metamusic is a trade name for a type of music that uses Hemi-Sync tones. Basically this music targets the brain, can affect the emotions positively — and through that process, calm both body and mind. In a feeding situation, it can relax a child so that feeding becomes an easier and more pleasant process. It is not the type of music that distracts, but it plays in the background. The music must be something a child likes. If he does not connect with the music, it will not affect his brain in the way you would like it to. You have to select music purposefully — for a reason you want it to work. This could be to calm, or to help to sleep; to make a child pay attention, or to support creativity. Suzanne aptly notes that “Stress thrives in a mental environment of unfocused attention where every random though diverts the mind into patterns that promote fear and anxiety”. If interested in reading more, you can inquire at New Visions about the availability of a manual titled “*Learning to say yes: Moving from gastrointestinal discomfort to inner-directed eating*” and authored by Dr. Suzanne Evans Morris. She has quite an extensive section on Hemi-Sync and how to use it for various children. It is well worth reading, but since the manual is in draft form, I cannot provide a link.

* Hemi-Sync recordings can be purchased from the New Vision Mealtimes catalog — 800-606-7112 or [www.new-vis.com](http://www.new-vis.com) or from Monroe Products — 800-541-2488 or [www.hemi-sync.com](http://www.hemi-sync.com)

* Also take a look at the other sources on the next page of this newsletter.

**METAMUSIC AND HEMI-SYNC BINAURAL BEAT TECHNOLOGY: WHAT IS THIS, AND HOW MIGHT IT BE USEFUL TO US?**

Watch this video to start with: <https://www.hemi-sync.com/hemi-sync-technology/hemi-sync-video-introduction/>. It explains what this technology is, and demonstrates through brain simulations.

Here are a couple of sites which describe what hemi-sync is: <https://www.hemi-sync.com/hemi-sync-technology/how-hemi-sync-works/> or the Wikipedia site: <https://en.wikipedia.org/wiki/Hemi-Sync>

They call it noninvasive “audio-guidance”. How does this work? The person wears stereo headphones. Different sounds (tones) are sent to each ear. The two hemispheres of the brain then “act in unison to ‘hear’ a third signal – the difference between the two tones.” (binaural beats). The sites explain that this is not an actual sound, but an electrical impulse within the brain, synchronizing the two hemispheres. Since the whole brain is being used, performance will be improved. The official site says, “As an analogy, lasers produce focused, coherent light. Hemi-Sync produces a focused, coherent mind, which is an optimal condition for improving human performance”.

This technology “syncs” the two hemispheres of the brain. It also helps to positively impact the corpus callosum. Be aware that this type of music may not be suitable for some persons, and may have a different effect than expected. So read the reviews and know more before you try it. For example, reading user-reviews I see both pro and con remarks. Perhaps try it out yourself. This music does not contain subliminal messages — just in case someone thinks about that! Nor will it put you into a trance or take away control. It is more scientific than that and is actually a patented technology related to biofeedback. In fact, it should be used for very specific purposes, at specific times — and not continuously.

I found the FAQ page interesting too: <https://www.hemi-sync.com/hemi-sync-technology/hemi-sync-faqs/> For instance, I learned that persons who are deaf can also benefit since sounds are effectively carried via the bones. They also address the question of whether there are subliminal messages, and whether or not it is recommended for children.

Find out more about this — and see what music might work to calm a child who may be experiencing stress, especially at meal times. Suzanne has successfully used Hemi-Sync for children with feeding issues. She suggested that various beats/levels were good for various purposes. For example, the “theta level” was good for learning; “delta” for sleep.

Here are some links for finding hemi-sync and metamusic CDs:

 <https://www.hemi-sync.com/>

 <http://www.unexplainablestore.com/store.php?utm_source=bing&utm_medium=cpc&utm_campaign=2016.11.7%20Search&utm_term=hemi-sync&utm_content=competitor> If you scroll down on this home page, you will find categories, but you will also find recordings classified by hertz, connected to specific body anatomy, or desired states of mind.

 [http://shop.hemi-sync.com/products/c302-Metamusic%c2%ae/](http://shop.hemi-sync.com/products/c302-Metamusic%C2%AE/) Metamusic combines “delightful musical selections (from a variety of genres) with Hemi-Sync binaural beats” that will both entertain and benefit the listener.

 Amazon has a selection of CDs

**FACEBOOK SHARE:**

GAMES AND APPS

 Adapt Candyland for your child who is deafblind: [http://www.pathstoliteracy.org/…/adapting-candy-land-player…](http://www.pathstoliteracy.org/strategies/adapting-candy-land-players-who-are-blind-or-deafblind)

 Another day, another app! [http://www.pathstoliteracy.org/technolo…/ballyland-rotor-app](http://www.pathstoliteracy.org/technology/ballyland-rotor-app)

LITERACY, BRAILLE, THE EXPANDED CORE CURRICULUM

 Does your child struggle with braille because of CP or sensitivity issues? Read this blog from Paths to Literacy: [http://www.pathstoliteracy.org/…/teaching-braille-mechanics…](http://www.pathstoliteracy.org/blog/teaching-braille-mechanics-students-cp-or-decreased-tactile-sensitivity)

 Tracking and pre-braille: [http://www.pathstoliteracy.org/…/tracking-activities-pre-br…](http://www.pathstoliteracy.org/strategies/tracking-activities-pre-braille-learners)

 Another Braille game! [http://www.pathstoliteracy.org/st…/french-fries-braille-game](http://www.pathstoliteracy.org/strategies/french-fries-braille-game)

 The Expanded Core....and literacy: [http://www.pathstoliteracy.org/…/integrating-ecc-activities…](http://www.pathstoliteracy.org/blog/integrating-ecc-activities-literacy-instruction)

 We have met Liam before! Take a look at his "story" in video: [http://www.pathstoliteracy.org/…/meet-liam-video-story-7-ye…](http://www.pathstoliteracy.org/resources/meet-liam-video-story-7-year-old-who-deafblind)

 Follow the design for "Hello Kitty": [http://www.pathstoliteracy.org/s…/braille-design-hello-kitty](http://www.pathstoliteracy.org/strategies/braille-design-hello-kitty)

 Encouragement to start young! Blog on Career Exploration and Self-Determination: [http://www.pathstoliteracy.org/…/student-practices-career-e…](http://www.pathstoliteracy.org/strategies/student-practices-career-exploration-and-self-determination-teaching-lesson)

LEGAL ISSUES

 Supreme Court decision coming up soon. Read this article: [https://www.washingtonpost.com/…/3e8e14ca-d690-11e6-9f9f-5c…](https://www.washingtonpost.com/local/education/supreme-court-to-decide-what-level-of-education-do-public-schools-legally-owe-to-students-with-disabilities/2017/01/10/3e8e14ca-d690-11e6-9f9f-5cdb4b7f8dd7_story.html?utm_term=.5c6f142fe647)

TO READ….

 Walk in My Shoes -- new book. [https://www.amazon.com/dp/B01MSXMO5X/ref=sr\_1\_1…](https://www.amazon.com/dp/B01MSXMO5X/ref%3Dsr_1_1?ie=UTF8&qid=1481393776&sr=8-1&keywords=walk+in+my+shoes%2C+charlotte+dewitt)

 This research article makes me think of some of our kids who are DB who become good at video games......They learn to follow what they need to follow - despite the speed! I know I couldn't keep up with them! Read info on the research: [http://www.pathstoliteracy.org/study-shows-brain-training-v…](http://www.pathstoliteracy.org/study-shows-brain-training-videos-can-improve-peripheral-vision)

EMOTIONS

 The new issue of Complex Child has the theme of EMOTIONS. Take a look: [http://complexchild.org/…/2…/january/parent-or-professional/](http://complexchild.org/articles/2017-articles/january/parent-or-professional/)

TACTILE GRAPHICS

 Excellent blog from Paths to Literacy on tactile graphics -- it is not how it LOOKS, but how it feels and how meaningful it is!! [http://www.pathstoliteracy.org/…/tactile-graphics-standards…](http://www.pathstoliteracy.org/blog/tactile-graphics-standards-types-and-practical-examples)

SPECIAL/ADAPTED EQUIPMENT

 From Parenting Special Needs: the GoTo Shop Cart: <http://community.fireflyfriends.com/campaigns/gotoshop>

 I'm thinking that not just children who are visually impaired/blind/ Deafblind would appreciate this -- too cool! [http://www.pathstoliteracy.org/st…/homework-manipulative-box](http://www.pathstoliteracy.org/strategies/homework-manipulative-box)

TECHNOLOGY

 Learn about Cortana for Windows 10 -- It's a personal assistant like Apple's Siri, Google's Google Now, and Amazon's Alexa: <http://www.pathstoliteracy.org/technology/cortana-windows-10>

USHER SYNDROME, CVI:

 Read Nancy's blog on finding students with Usher Syndrome: [https://nationaldb.org/…/starting-a-national-dialogue-on-fi…](https://nationaldb.org/blog/post/53/starting-a-national-dialogue-on-finding-children-with-usher-syndrome)

 Paths to literacy shared an interesting article “Research on CVI: Cerebral vs Ocular visual impairment” : [http://www.pathstoliteracy.org/…/cerebral-vs-ocular-visual-…](http://www.pathstoliteracy.org/research/cerebral-vs-ocular-visual-impairment-impact-developmental-neuroplasticity)

INTERVENERS

 Want to know more about interveners -- and the program that offers a credential at Utah State University? Here's the link to a recent webinar: [https://1530551.mediaspace.kaltura.com/…/0\_hrgoetj7/61248242](https://1530551.mediaspace.kaltura.com/media/Interveners/0_hrgoetj7/61248242)

SAFETY/EMERGENCY PREPAREDNESS

 "Unwanted intruders" in a classroom? Here’s an idea: <https://www.youtube.com/watch?v=sJ19_qYPuyM>

 What about at home? <https://www.youtube.com/watch?v=R0-3iIlDM1M>

**THE OREGON DEAFBLIND WORK GROUP**

**Malina Lindell:** Region one, Eastern Oregon

**Jan Hearing:** 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

**Claudia Martin:** Region eight, Northwest Regional

**Sharla Jones:** Oregon School for the Deaf/RMT representative

**Linda Brown**: Oregon Department of Education

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

**Sarah Mora**: Oregon Commission for the Blind

**Linda McDowell:** NCDB representative, The Research Institute at WOU

**Caitlin Shockley**: FACT/PTI parent representative

**Lyn Ayer:** Oregon Deafblind Project, The Research Institute at WOU

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The Oregon Deafblind Project Website: **www.oregondb.**[**org**](http://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**](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**](http://www.ode.state.or.us/search/results/?id=185)

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