



The Beacon

The Newsletter of the Wisconsin Deafblind Technical Assistance Project

Volume 6, Issue 4

December 2016

National Innovator on Deafblind Education Provides Valuable Insight at Annual Conference.

By Jodi Anderson

In early November, Wisconsin was honored to have Linda Alsop present at the WESP-DHH Annual Family Conference in Appleton. Linda Alsop is the Director of Deafblind Programs at the SKI-HI Institute/Center for Persons with Disabilities at Utah State University in Logan, Utah. She has extensive experience working directly with children with deafblindness and their families. She acts as a national consultant in deafblindness, and has developed and implemented the first nationally credentialed online higher education training program in the country that trains interveners to work with children and youth who are deafblind.



Her two-part presentation focused on communication with children who have combined vision and hearing loss.

Effective Strategies of Communication and Interaction:

- Repetition
- Consistency
- Use Preferred Activities for Motivation
- Develop Daily Routines and Use as Opportunities for Communication and Learning
- Allow Extra Time for Child To Respond
- Patience, Patience, Patience
- Prioritize Goals
- Work On Only 1 or 2 Goals At A Time
- Reinforcement By All Team Members

Because of the combined sensory loss, children with deafblindness do not have the same opportunity as typical learners to acquire symbols to represent what they want to communicate. They may express wants and needs through behaviors, but be unaware that their actions are being observed and interpreted by others. They may not be getting enough information to understand that they have caused something to happen.

They do not have repetitive meaningful exposure to the incidental use of objects, pictures, sign language, or speech as typical children. They need systematic support to learn and progress through concrete and abstract communication. Unfortunately, people who work with children who are deafblind are not typically trained in all the communication modalities these children may need, such as signals, cues, braille, sign language, and so on.

Children who are deafblind cannot completely overcome their isolation and learn to communicate on their own. To provide the level of understanding and response necessary for the development and use of communication skills, another person may need to be consistently available.

Conference story continued on page 2

Conference continued from page 1

The intervener can consistently recognize, respond, and reinforce the child's behaviors and attempts at communication.

Successful communication experiences will encourage the child who is deafblind to continue to interact. Any communication system that truly works for the child must be shared with everyone in contact with that child.

Linda reviewed the role of the intervener:

- Facilitate the access of environmental information usually gained through vision and hearing, but which is unavailable or incomplete to the individual who is deafblind.
- Facilitate the development and/or use of receptive and expressive communication skills by the individual who is deafblind.
- Develop and maintain a trusting, interactive relationship that can promote social and emotional well-being.

With such an intimate group, she was also able to discuss each family's situation and child in order to give suggestions and strategies for the families to use in working toward improving communication skills.

WESP-DHH is already busy planning next year's family conference for November 2017. WDBTAP offers scholarships for families interested in attending. Watch our Facebook page and website for details.

Having Fun in Appleton!

The WESP-DHH conference provides opportunities to make new friends and enjoy a day out in Appleton.



Raising a DeafBlind Baby

By Arika Okrent

This article originally appeared June 2nd 2016 on the website mental_floss at <http://mentalfloss.com/article/80906/raising-deafblind-baby>

Clarisa Vollmar is not quite one year old but already has a worldwide Facebook following of more than 30,000 fans. They are keeping up with her as she grows, learns, and explores her world as a DeafBlind baby.

That terminology is intentional, not a whim of random capitalization. Her parents, Justin and Rachel Vollmar, have introduced her to the world as DeafBlind, rather than deaf-blind or deaf and blind, in order to explicitly identify her with a community of DeafBlind people who are part of something called the pro-tactile movement. According to anthropologist Terra Edwards, who wrote a dissertation on the DeafBlind community, the pro-tactile movement is not quite an identity movement, but “a philosophy, which begins with the following axiom: Legitimate knowledge can be produced from a tactile perspective without first passing through visuality.”

In his book, *Where I Stand: On the Signing Community and My DeafBlind Experience*, DeafBlind poet and writer John Lee Clark talks about an unfortunate communication “bubble” that DeafBlind people have had to contend with. They have a “signing to the wall” feeling when they express themselves, not having access to any of the conversational feedback—nods, “uh-huh”s, smiles—that give an interaction vital energy. There are ways to convey those reactions through touch, and Clark describes a pro-tactile approach in terms of “tactile spaces, where DeafBlind people would enjoy equal access to information and participate fully.”

The Vollmars want to create such a space for Clarisa, and they have a special understanding

of what such a thing might mean to her. Both parents and all three of Clarisa’s older siblings Deaf in the “big D” sense of the, meaning they view their Deafness as a cultural identity, rather than a medical condition. The father, Justin Vollmar, was lucky to have been raised in a Deaf family, and never realized how lucky he was until he once stayed a hearing family for six weeks. He described the experience this way:

"It drove me crazy. I never felt so frustrated before in my life. I could not understand what was going on at the dinner table. Everyone except for my host brother could not sign. I missed what they said. All of them talked and laughed at each other's

jokes. I kept asking what they were saying. They kept saying, 'wait a minute, I will tell you later.' (They never did). I finally understood that is what many Deaf people grew up with. They get left out at family gatherings and holidays. They are usually behind with family news. They are not sure if their grandfather died of a heart attack or from cancer. They just never know until years later. Some just give up and lose touch."

The Vollmars never wanted their daughter to experience this type of isolation: “When Clarisa was born, my wife Rachel and I immediately agreed that we will modify our family to Clarisa's needs and make sure that she is fully involved with family at all times.” What is the best way to do that? They are figuring it out as they go along. Most DeafBlind people are born with some level of deafness and slowly lose their vision. They have early exposure to language and a visual concept of the world and social interactions.

Raising a Deafblind Baby continued on page 4





(Helen Keller also had this; she became DeafBlind as a toddler). A baby born DeafBlind doesn't have that, and the case of DeafBlind from birth is very rare.

The Vollmars have consulted with teachers, specialists, other parents of DeafBlind children, and importantly, DeafBlind pro-tactile advocates. They have made public their journey to find the best way for Clarisa, and it's a remarkable model of how a family can bring a child into their world by being truly attentive to her view of the world.

Clarisa's story is inspiring, but not in the way one might think. There is no typical narrative here of her "overcoming barriers" or of others "breaking through" to her. She is not achieving "despite the odds" or "by working 10 times harder." What's inspiring is the way her family has adjusted to her unique perspective, in order to give her the most natural and effortless upbringing possible.

2016 WDBTAP Child Count Underway

The national deafblind child count is underway and your help is needed. A google form has been emailed to all families on our registry requesting an update of your child's information. If you have not received this email please contact Jenny at jennifer.hudson-stanek@wesp-dhh.wi.gov or (608) 356-2023 and we would be happy to send it your way.

Families are required to complete the census if they want to continue participating in WDBTAP programming. The results of the census assists WDBTAP in receiving federal funding.



Easter Seals Provides Camp Opportunities for Deafblind Students

Time off from caring for another, a respite, is the number one need of families with a loved one with disabilities. To address that need, Easter Seals Camp Wawbeek and the Wisconsin Elks/Easter Seals Wisconsin Respite Camp (both located in Wisconsin Dells), offer well-deserved breaks for parents and caregivers while their loved ones enjoy innovative recreational opportunities in an accessible environment. Easter Seals provides a safe, educational environment that allows campers to have "the time of their lives at a place they'll never forget."

To learn more about Easter Seals or to visit a camp contact them at (608) 237-1979 www.eastersealswisconsin.com

2017 Preschool Family Conference

Friday March 31 - April 2, 2017
Green Bay Hyatt on Main,
Green Bay WI

The Wisconsin Center for the Blind and Visually Impaired is hosting the preschool family conference dedicated to families who have children from birth through age five with visual impairments.

This years conference will feature: What are They Thinking? Pediatric Brain Development by Dr. Brian Fidlin, PsyD, Clinical Psychologist. Dr. Fidlin's presentation will be a straight-forward discussion of brain development and the impact that this has on decision making, emotions and risk taking. You will gain a better understanding of student behaviors and find out about strategies that create conditions for learning and continuous development.

For more information go to:
<http://www.wcbvi.k12.wi.us/outreach/calendar2017-family-preschool-conference>

A Visit to Our Lending Library

The lending library is a service provided by WDBTAP and provides toys, learning aids and training manuals for parents and professionals. These items can be loaned for up to three months at no cost to you. Visit www.wdbtap.wi.gov/library to see these or any WDBTAP materials. Send us a message to make a borrowing request.



The Genesis LED Egg

The Color Change Waterproof LED Genesis Egg comes with a remote control featuring sixteen color options, 4 color changing modes, and a dimmer.



Star Projector

This sleep machine comes with a soothing light that projects stars and other shapes on the wall. It also plays a variety of nature sounds, or you can choose to play your own music by plugging in an MP3 player. You can easily turn the sound on and off, change the sounds and control the light and volume with the buttons on the side.



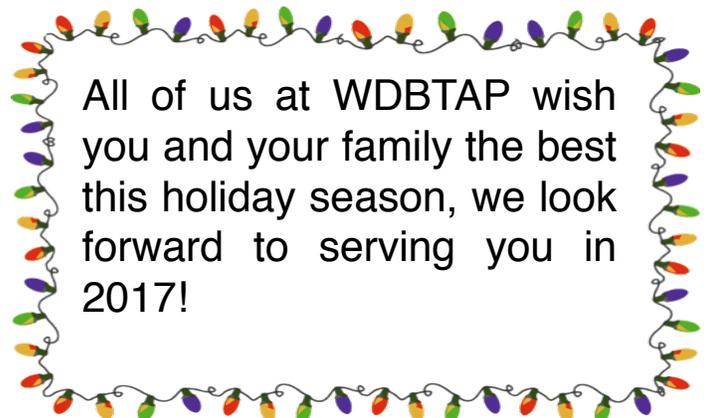
Handheld Rotation Board

Easily maneuverable with simple waist and arm motion. Helps increase upper-body strength while it targets the cerebral cortex.



Stay Connected

Join our family engagement coordinator, Jodi Anderson, and other WDBTAP family members on our private WDBTAP Facebook page. To become a member friend WDBTAP Anderson or send a private message to be included in the group.



What Types of Technical Assistance does WDBTAP Provide?

- Parent/Family trainings and assistance in connecting families with one another
- Statewide and regional workshops for service providers and families
- Observation, support and coaching in programming for children
- Intensive deafblind training series for paraprofessionals who work one on one with children and youth who are deaf blind
- Assistance in identifying children and youth who are deaf blind
- Referral to relevant local, regional and national agencies
- Lending library with materials, equipment and toys to benefit deaf blind children/youth on the Registry

WDBTAP STAFF

Marla Walsh, Project Director
Jolene Gruber, Grant Coordinator
Heidi Hollenberger, Deafblind Consultant
Jodi Anderson, Family Engagement Coordinator
Jennifer Hudson-Stanek, Office Associate

The contents of this newsletter were developed under a grant from the U.S. Department of Education, H326T130027. However, those contents do not necessarily represent the policy of the U.S. Department of Education, and you should not assume endorsement by the Federal Government. Project Officer, Louise Tripoli (Louise.Tripoli@ed.gov)

WDBTAP
124 2nd St. Suite 35
Baraboo, WI 53913

