

The Alaska Deaf-Blind Project

Quarterly Newsletter

The Alaska Deaf-Blind Project serves any individual from premature birth to age 22 with a hearing and vision loss. We serve those in urban and remote areas, as well as individuals not enrolled in school, those in secondary school, and those who have graduated. The Alaska Deaf-Blind Project's assistance is provided free-of-charge to families, schools, and community organizations.

A Letter from the Editor

Welcome Back!

Welcome back to the 2018-2019 school year. I hope that everyone had a nice summer, and if you haven't started back to school quite yet, are enjoying the last few days of your break. There was a good mix of sunshine and rain in Anchorage this summer; I spent most of my days out on the trails on my bike. For those of you who don't know me, biking is one of my passions, and every summer I try to get in more miles than the year before. This summer, I was just shy of 2200 miles! On super rainy days I enjoyed reading and working on a few puzzles. As much as I enjoy summer break, I am ready for the school year to begin! Please do not hesitate to contact me with any questions about your student or about the Deafblind grant.

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Deafblind Grant Information

The Alaska Deafblind Project is one of the grants that is housed at SESA. The services that are provided by the Deafblind grant are free of charge to eligible districts/students. The Deafblind Project serves individuals from birth to age 22 who experience both a hearing *and* a vision loss. Please note- a student does NOT need to be profoundly deaf or profoundly blind to qualify. Even a mild loss in each area can cause significant challenges. To qualify, a student must have:

VISON (at least one):

1. Visual acuity of 20/70 or less in the better eye as determined by an eye specialist
2. Functional vision with is virtually absent or immeasurable for purposes of learning as determined by an eye specialist
3. A need for special services requiring the use of nonstandard instructional material or aids designed to facilitate the child's learning as recommended by specialist
4. A temporary impairment or loss of vision due to illness, accidents, or temporary treatments
5. A diagnosis of a syndrome or disorder associated with vision loss
6. Be diagnosed with progressive vision loss

AND

HEARING (at least one):

1. Hearing impairment of 30db or greater unaided in the better ear
2. Recurrent otitis media or a documented history of otitis media affecting language or learning as indicated by a hearing specialist
3. A diagnosis of a syndrome or disorder associated with hearing loss
4. Functional hearing that is virtually absent or immeasurable for purposes of learning, as indicated by a hearing specialist, audiologist, or SLP

Note: A list of syndromes commonly associated with Deafblindness can be found at the end of the newsletter

Paraprofessionals Working as Intervenors

3 Day Training

In May, the Alaska Deafblind Project was able to bring participants from 6 school districts and Infant Learning Projects together to talk about students with Deafblindness, current needs, and ways to help support students in the educational setting.

At this time, Alaska does not have any intervenors; many of the students have 1:1 paraprofessionals assisting them. Using a combination of presentations, small group discussion, large group discussion, simulations, and printed material, the group discussed ways to use the paraprofessional or other school staff as an intervenor for the person with Deafblindness.

The hope is that Alaska will have trained intervenors in the future, but in the interim, there are a variety of staff that have the skills and knowledge to work successfully with a person with Deafblindness.

Resources:

[CEC Standards Specialty Set](#)- Special Education Paraeducator Intervenor for Individuals with Deafblindness.

[OHOA](#)- Open Hands, Open Access: Deaf- Blind Intervener Modules



Back Row: Jennifer Schroeder, Brooke Monro, Jenne Sipniewski, Janette Gagnon, Stephen Bailey, Kelli Creglow, Granger Nyboer, Jackie Kempf Middle Row: Robin McNeilley, Sarah Moreau, Chelsea Kercher, Christine Neely, Elissa Kaminsky, Charlotte Kimber Front Row: Dena Luschinger, Ellen Axmear, MaryClare Cable

Pictured Below: Participants moving through different social and academic activities during the simulation.



During the workshop, participants participated in a large variety of activities. One of the activities was a simulation exercise. This included some of the participants acting as "staff" and others acting as "students". While no simulation can be 100% accurate, the goal was to have everyone thinking about and seeing things in a different way.



Chelsea is leading Brooke around and taking her where she wants to go. Brooke has limited hearing and vision and is expected to just follow.



Meriah is in an unfamiliar environment and no one has given her any information; this results in her just standing there.



Ellisa has an unmodified cut and paste to work on. She has limited vision and no one is nearby to ask for help.

The group agreed- it was a struggle being the adult and being the student! For the "students", it was hard to be led places without being given any information, to complete activities that you could not see well, or to be expected to just hang out in a new environment with a lot of movement and noise. The group talked about how it did not feel good to lead people around, not be able to give them the information they needed, and to be told that they could not offer help. While this was done purposefully, and we can all see the challenges in this setting, schools are a busy place and teachers/paraprofessionals/related service providers can all feel pressure to "complete the activity", "work on the lesson", and "be on time". This can result in communication breakdowns, in student (and staff) frustration, and eventually in behaviors (one of the participants threw something at me!). This simulation was a great way to move into the topics of *Communication*, *Pacing*, and *Learning*. Just like our students who don't have all of the information- We don't know what we don't know!



Groups were given time to collaborate about specific students, challenges, or ideas that came up during the sessions. This led to some really nice discussion on how to do things differently, how to make sure that the student was actively involved, and how to help everyone remember that there are times (many times) when PROCESS is more important than PRODUCT.

Overall, the three days that participants spent together was a time of learning, great discussions, laughter, and really good problem solving. Having people from so many different areas of the school environment- teachers, parapro's, OT's, SLP's, TVI's, and audiology- really allowed the group to have in depth discussions and come away with a clearer understanding of what supports are needed when you are working with a student with deafblindness.

Deaf-Blind Intervener: Opening Activity Feedback

by Emily Berliner, SESA Executive Assistant/Grant Coordinator

I participated in the opening activity on the first day of the Deaf-Blind Intervener Training, held at The Chariot Group Conference Center in Anchorage, Alaska. Nearly 20 interveners from across the state participated in the training, led by SESA's Deaf-Blind Specialist, Jennifer Schroeder.

The opening activity was very clever! Participants were paired up – one person was asked to wear low vision simulation goggles and noise-cancelling headphones, while the other person acted as the teacher and instructed the "student" on specific tasks. The tasks included writing their name, coloring a picture, completing a puzzle, locating and putting on their jacket, and moving from one room to another. During the activity, one assistant walked around the room with a laptop playing music and another with a handheld fan to simulate the environmental factors of a classroom setting. Some participants became slightly frustrated with the excessive noise and fine motor skill tasks; others took things in stride and worked very quietly to maintain focus. When the activity concluded, participants breathed a sigh of relief – it seemed that the activity's objective hit home.

The interveners said the activity was both challenging and overwhelming, which was the instructor's intention. It truly set the tone of the training. My takeaway (as the handheld fan assistant), was that in order to successfully support and educate a student who experiences deaf-blindness, interveners need tools and strategies to simultaneously address issues they have with the students they currently serve, as well as gain a broader grounding in deaf-blindness. With this simulation activity, the instructor emphasized two critical components for working with individuals with deaf-blindness:

- 1) Developing and maintaining a trusting, interactive relationship between the interveners and the individuals they serve; and
- 2) Promoting social and emotional well-being.

Participant Feedback

"Great resources and teaching principles to draw from" --Jackie

"Very helpful to get a different view on the senses" -- Chelsea

"Definitely learned quite a bit more and refined the skills I already had!" --Sarah

"Some of the things that stuck out for me: tacs are not always the actual object but what the student perceives and there is more than one way of solving a problem" -- Christine

*"I've had limited experience/need, so far. This is all new to me, but amazing!"
--Granger*

"The group interactive activities really put perspective on how overwhelming a dual sensory impairment can be- it is Deaf X Blind, not Deaf + Blind" -- Nikki

"Communication discussion is very helpful just now" -- Dena

"I am ALWAYS learning" -- Robin M

Common Syndromes

Below is a list of syndromes commonly associated with Deafblindness. This is not an exclusive list, as there may be other causes for Deafblindness including pre-natal injury or illness, as well as birth injury or illness.

Alport Syndrom
Barrister Winter Syndrome
Cytomegalovirus (CMV)
CHARGE
Down Syndrome
Duane Syndrome
Goldenhar Syndrome
KID Syndrome

Lieber's Syndrome
Marshall Syndrome
Norrie Disease
Pierre-Robin Syndrome
Rubella Syndrome
Stickler Syndrome
Trisomy 13
Usher Syndrome