



Oregon Deafblind Project

Building Effective Programs

Greetings!



We hope you all had a wonderful summer and are enjoying the changing colors of Fall. We at the Oregon Deafblind Project are in the midst of renewal and change. After writing frantically on a proposal for another five years of the project, we are happy to announce that we got it! This means that thanks to funding from the Office of Special Education Programs at the Department of Education (as well as a smaller grant from Oregon Department of Education for the parent learning weekend), we will be able to continue providing technical assistance and training to families and educators of children who are deafblind in Oregon.

In addition to working with the Regional Consultants and educational teams, we will be able to continue providing support for families. The Oregon Department of Education, has informed us that they will continue supporting the Family Learning Weekend which has been held in the last few years at the Oregon Gardens (we have provided the weekend at other venues in past years as well). We look forward to working with our family volunteers to plan this and other events to bring together the families and specialists in the field of deafblindness who work with children. These events allow participants to share information and strategies and to learn how to best meet educational and life goals for children who are deafblind.

During this beginning stage of the next grant cycle, we are busy planning how to improve the services we provide and continuing the important work of the project. We would appreciate hearing from you about ways we can better support students who are deafblind along with their families and educational teams. We hope to provide opportunities for you to give us input over the next several months, so please let us know what you think.

Fall 2018

CONTENTS

Message from Project Staff	1
2018 Family Learning Weekend	2
Books Children Can Relate To	2
Usher Syndrome Overview	4
The Oregon Deafblind Workgroup	7
Oregon Deafblind Project Info	7

Family Learning Weekend

The 2018 Parent Learning Weekend was held once again at the Oregon Gardens in Silverton, Oregon. The 22 attendees spent time connecting with other families and sharing strategies and resources. Prior to the weekend, a group of parent volunteers worked with the project director to decide where to have the workshop, which topics were relevant to families and who should present. The presentation topics covered different levels of transition, legal issues, emergency preparedness, resources and information sharing. Presenters included parents, service providers and outside experts.



Linda McDowell (Director of the National Center on Deafblindness at Western Oregon University) presented information to assist parents in transition planning for their children.

Tracy Anderson, a Deputy Residential Facilities Ombudsman with the Oregon Residential Facilities Ombudsman Program presented information about that program and about advocacy issues for those transitioning into adult services.

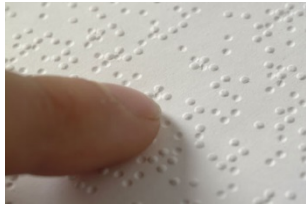
Lyn Ayer, the former Oregon Deafblind Project Director and Anne Olson-Murphy, Teacher of the Visually Impaired from Willamette ESD Regional Program, provided families with information on life transitions relevant for children of all ages.

Also, parents Chris Johnson, Rex Baker & Dave McCready provided insight and information on emergency preparedness and specifics related to caring for children with deafblindness who have multiple disabilities.

Our main partner, the Oregon Department of Education, continues to support the Project in hosting the annual weekend. Families spent the days learning and sharing information, and they spent the warm evenings relaxing and sharing the challenges and joys of raising a child who is deafblind with other families and specialists who were in attendance. In addition to the workshops, families and presenters were able to take walks or ride the tram to enjoy the beautiful gardens.



Books with characters children can relate to



own life experiences.

Families and educators often face challenges finding materials that are focused on or related to characters with deafblindness. Providing children who are deafblind with characters who are deaf/hard of hearing, visually impaired, deafblind or multiply disabled, can be important to their feeling of being included. Stories that involve situations and characters that children can identify with provide role models that children can draw from in their

The following is a short list of books that have characters that are deaf/hard of hearing, blind/visually impaired, or deafblind. More resources can be found on the Project website.

Elementary

A dog called Homeless, by Sarah Lean.

Fifth-grader Cally, who stopped talking for a day as part of a contest at school, continues her silence. But visions of her deceased mother; a new friendship with Sam, a deaf-blind boy; and the appearance of a huge dog keep her communicating. For grades 3-6. 2012.

Child of the silent night, by Edith Fisher Hunter (Nonfiction)

Tells the story of Laura Bridgman, blind and deaf since babyhood, who was successfully taught communications skills at the Perkins Institute almost 50 years before Helen Keller. For grades 3-6.

I am Helen Keller by Brad Meltzer: Engaging book tells how an ordinary person who had struggles in life was able to persevere by being courageous and by not giving up. Contains some braille. (K – 3)

Middle School

Can you feel the thunder?, by Lynn E. McElfresh

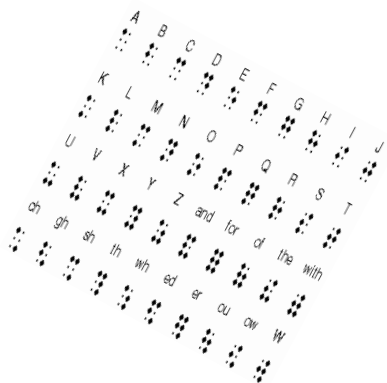
Thirteen-year-old Mic Parsons struggles with mixed feelings about his deaf and blind sister while at the same time he makes his way through the turmoils of junior high. For grades 5-8.

She Touched the World : Laura Bridgman, Deaf-blind pioneer, by Sally Hobart and Robert Alexander (Nonfiction): Biography of Laura Bridgman (1829-1889), the first deaf-blind child to receive a formal education--decades before Helen Keller. Discusses the causes of Laura's deaf-blindness at age two; her sponsorship at Perkins Institution; and her success at learning manual sign language. For grades 4-7. 2008.

High School

Not Fade Away: A Memoir of Senses Lost and Found by Rebecca Alexander & Sascha Alper: The memoir of a young woman becoming deafblind due to Usher Syndrome.

Miss Spitfire: Reaching Helen Keller by Sarah Miller: A book focusing on Anne Sullivan's early time at Ivy Green



More Books

The following list of braille books with a character who is blind and/or deaf for middle & high school was shared by Mary Dingus, Librarian from the Missouri School for the Blind. Most books available from **National Library Service(NLS)** <https://www.loc.gov/nls/> or **Seedlings Braille Books for Children**. <http://www.seedlings.org/>

- Blindsided: Priscilla Cummings:** Natalie finds out she will go blind at the age of 14 - she has to attend a school for the blind and learn many new skills.
- Firmament by Tim Bowler:** While struggling to cope with the death of his father, a gifted musician, fourteen-year-old Luke must deal with a dangerous bully, a lonely old woman, a blind young girl, his mother's romantic involvement, and his own musical talent.
- Light a Single Candle by Beverly Butler** Fourteen-year-old Cathy becomes increasingly despondent over the loss of her sight until a seeing-eye dog comes into her life.
- Follow My Leader by James B. Garfield:** At first eleven-year-old Jimmy is discouraged by losing his sight in a firecracker accident. Gradually he learns to read braille, use a cane, and do things for himself. But working with his own guide dog, Leader, makes the biggest and best change. For grades 4-7. (1957)
- Mirror, Mirror on the Wall: The Diary of Bess Brennan by Barry Denenberg:** In 1932, a twelve-year-old girl who lost her sight in an accident keeps a diary, recorded by her twin sister, in which she describes life at Perkins School for the Blind in Watertown, Massachusetts.

Resources:

DK Braille produces custom books with braille and tactile images for blind and partially sighted children. Books combine uncontracted Unified English Braille and large type with high-contrast colors, embossed images, and tactile cutout shapes for children to feel with their fingers. Available on Amazon or Penguin Random House <https://www.penguinrandomhouse.com/series/1DK/dk-braille>

Paths to Literacy: for students who are blind or visually impaired is a great resource for both children and families looking for books that are relevant, either about or in aid of individuals who are blind and or deaf.

http://www.pathstoliteracy.org/search-results?search_api_views_fulltext=deafblind

Their website also has a number of resources including:

Tips for families to create tactile books and other literacy materials

<http://www.pathstoliteracy.org/blog/you-can-do-it-tips-families-who-are-just-getting-started>

Using Tactile Sign Language to Read With a Child Who Is Deafblind

<http://www.pathstoliteracy.org/blog/using-tactile-sign-language-read-child-who-deafblind>

Story Boxes: Literacy Adaptations for Students Who are Deafblind

Ideas and strategies for creating story boxes for students who are deafblind, visually impaired, or who have multiple disabilities

<http://www.pathstoliteracy.org/blog/story-boxes-literacy-adaptations-students-who-are-deafblind>

What is Usher Syndrome?



Usher syndrome is a rare genetic condition that impacts more than 7,000 children in the United States (The Usher Syndrome Coalition.) Yet in 2015, the state deafblind projects funded by The Office of Special Education Programs (OSEP), which support families and educators of children who are deafblind, reported that only roughly 300 children with Usher syndrome were being served.

The lack of knowledge about this condition contributes to the disparity between the number of children with Usher Syndrome and the number of children receiving special services. Families, educators, medical professionals, related services personnel and others in the field of education often are unaware of the resources available to children and families. Having an understanding of the progressive effects on vision and hearing is a crucial first step to helping the child or young adult achieve the fullest potential in life.

Usher syndrome is an inherited condition that results in hearing loss and a progressive loss of vision from retinitis pigmentosa (also called RP). The hearing loss is thought to be congenital, and ranges from moderate to profound, and may or may not be progressive. There are major research efforts to find ways of preventing the vision loss. If you have a deaf or hard of hearing child and you have knowledge of Usher Syndrome, this may help you recognize the signs early; this allows for safety and educational benefits for you and your child and may allow for opportunities from the medical community to slow the rate of vision changes.

Does Usher syndrome always lead to blindness?

The extent and speed at which vision changes is extremely variable from one person to the next. In a few children the RP is so marked that by the age of six they require special education for the visually impaired. Many may not notice a serious restriction of vision until they reach their thirties. It is common for some people with Usher to retain their reading vision well into old age. Very few people with Usher will become totally blind - that is, to have no light awareness. Many children will become night blind in the beginning but in the long run will keep their vision for reading and seeing fine detail, so long as good lighting is available. Tunneling of the visual field is usually the hallmark of this condition, which means a person's ability to see to the side (peripherally) rather than straight ahead is affected.

What are the different types of Usher syndrome?

There are three clinical types of Usher syndrome:

- Type 1 - causes profound deafness. Poor balance is often associated with it which may result in delays in the age of sitting and walking. Narrowing of the visual field due to retinitis pigmentosa (RP) may be noticed before the age of 10. People with this type of Usher usually prefer to communicate using sign language (ASL in the U.S.) early on, then later use tactile sign language (via Tactile ASL – TASL – and/or Protactile Language) and identify themselves as Deaf and losing their vision.

- Type 2 - causes a moderate hearing loss and balance is not affected. RP may not become apparent until adolescence. Speech assisted by the use of lip-reading and hearing aids will usually be their first method of communication. People with this type of Usher may identify themselves as hard of hearing and losing their vision.
- Type 3 - is a rarer form of Usher syndrome. It does have a higher frequency in people of Finnish ancestry. Children usually have normal hearing and sight from birth, then develop a hearing loss and RP in adolescence or later. Hearing can change steadily over a period of ten or fifteen years, and some people also experience balance problems. Many of the young people with this type of Usher identify themselves as hearing and sighted until the hearing and visual changes occur.



Type 1

Severe to profound hearing loss at birth
Progressive vision loss begins in childhood



Type 2

Mild to severe hearing loss at birth
Progressive vision loss begins in adolescence or adulthood



Type 3

Hearing loss begins during childhood
Vision loss during late childhood or adolescence

What are the educational needs of a child with Usher syndrome?

Schools need to be aware when a child has Usher syndrome. It is important for educators to understand the needs of the child regarding access to language, access to the curriculum, and access to the environment and environmental information – including access to peers and others with Usher in consideration of the child’s social and emotional needs. Alternatives to printed material (such as large print, Braille) may be needed. Navigating safely may be an issue and educators and parents need to be sure that the child is receiving travel instruction from an orientation and mobility specialist who is familiar with Usher so the child can learn to navigate safely at school and in the community. Children with Usher syndrome have no additional learning problems or cognitive issues and should be expected to perform in school as well as any other child.

What are the important points a family should remember?

- Children with hearing losses have a 5 to 10% chance of having Usher syndrome.
- In the U.S., Usher types 1 and 2 account for up to 95% of instances.
- It is important to make the diagnosis early in the child's life.
- There are several different types of Usher syndrome.
- Children with Usher syndrome should be expected to perform in school as well as peers.
- Parents and teachers need to lead a child with Usher syndrome toward becoming self-sufficient and autonomous.

Information on Usher syndrome was gathered from the following:

<https://www.nidcd.nih.gov/health/usher-syndrome>

<https://rarediseases.org/rare-diseases/usher-syndrome/>

<https://www.usher-syndrome.org/what-is-usher-syndrome/usher-syndrome.html>

<http://thelighthousefortheblindinc.org/our-programs/deafblind-program/deafblind-education/>

<http://www.protactile.org/>

The Oregon DeafBlind Working Group

The DeafBlind Working Group has an essential role in extending the technical assistance provided by the Oregon DeafBlind Project to educators and families of children who are deafblind throughout Oregon. The group exists to work on identifying and promoting best-practices in the educational programs of children who are deafblind in Oregon and to assure every child who is deafblind receives optimal individualized services in early intervention, school-age (elementary, middle school, high school) and transition programs. Current members of the working group include:

Malina Lindell: Region 1, Eastern Oregon (Intermountain ESD)

J Beresheim: Region 2, Central Oregon (High Desert ESD)

Lynette Kleespies: Region 3, Southern Oregon (Southern Oregon ESD)

Jennifer Orton: Region 4, Cascade ((Linn/Benton/Lincoln ESD)

Anne Olson-Murphy: Region 5, Willamette (Willamette ESD)

Darlene Daniels: Region 6, Columbia (Portland Public Schools)

Julya Johnson: Region 7, Lane (Lane ESD)

JJ Isaacson: Region 8, Northwest (Northwest ESD)

Sharla Jones: Oregon School for the Deaf/RMT representative

Kathy Eckert-Mason: Department of Vocational Rehabilitation

Sarah Mora: Oregon Commission for the Blind

Jan Hearing (or new Director TBD): Oregon Deafblind Project, The Research Institute at WOU

Other regulars at the working group include:

Lisa McConachie, Senior Director Columbia Regional Program

Dr. Amy Parker, Coordinator Orientation and Mobility Program and Professor, PSU

A final note: Jan Hearing, who has been the Oregon DeafBlind Project Co-Director and Director over the past year has resigned due to family and health issues and will soon be leaving the Project. Currently, recruiting activities are under way at WOU to hire a new Project Director. Jan, you will be missed!



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