Dually Noted

News from the Pennsylvania Deaf-Blind Project

Weaving a Web of Connections

From the Director, Sue Ann Houser

The 2017-18 school-year is off and running. The Pennsylvania Deaf-Blind Project is committed to bringing families together through many formats: consultation, resources, Listserv, online training, and more.

In the article, Pennsylvania Deaf-Blind Project Family Learning Conference 2017 (see page 2), Patti McGowan and Molly Black, family engagement coordinators for the Deaf-Blind Project, describe the "web of connections" that was created between families, children, and educators during the opening event of the Family Learning Conference. This type of network-building plays a major role in the vision of the Project staff.

With the Project's support, strengthening the threads of these invaluable relationships will enable the sharing of information, experiences, and resources to be more fluid and accessible. We look forward to enhancing and expanding our web of connections with all families and educators of children who are deaf-blind.

The Pennsylvania Deaf-Blind Project was created to provide training, technical assistance, and resources to assist educators and families in the areas of assessment, instruction, and family involvement activities.

In this issue…

Pennsylvania Deaf-Blind Project Family Learning Conference 2017

PaTTAN Pennsylvania Deaf-Blind Project welcomed 27 Families to the 2017 Family Learning Conference at the Penn Stater Hotel and Conference Center in State College, Pennsylvania, on June 23-24, 2017. Seven of the families were new to our conference this year. The theme of the conference – Web of Connections – aptly highlighted the content of sessions and networking opportunities that provided strategies to address the needs that children and families face each and every day.

The conference began on Friday evening with a Welcome Networking Reception, during which five statewide agencies shared information and resources. The agencies were:

- Deaf-Blind Living Well Services (DBLWS), represented by Marsha Drenth
- Guide by Your Side of Pennsylvania, represented by Anne Gaspich
- Parent Education and Advocacy Leadership Center (PEAL), represented by Jeannine Brinkley and Lori Brew
- Pennsylvania Partnership for the Deaf-Blind, represented by Kristina Kezmarsky and Shelley Lill
- Special Kids Network, represented by Cindy Dollinger

Families expressed that the opportunity to meet with representatives of those agencies was a strong beginning to identifying key resources for their children.

The evening continued with the Pennsylvania Deaf-Blind Project's tradition of having each family introduce themselves and share a triumph or challenge they faced during the preceding year. A huge ball of yarn was passed to each family to symbolize the web of connections that were being created.

On Saturday, the families welcomed a guest speaker, Coach Cody Colchado, and his wife Jolee, from Texas. His message was, "Let your adversity make you stronger instead of weaker, and let your character be built through courage and tenacity." Coach Cody, who holds the title of America's Strongest Adaptive Athlete, openly shared how he has overcome barriers. His passion is to encourage families who are going through adversity to break through the barrier of fear associated with raising a child or youth with deaf-blindness. During his session, he shared his ABCs for Success.

In the afternoon, the men continued with Coach Cody for a session just for fathers and male guardians, while the women met for an afternoon of learning with retired teacher of the visually impaired, Tina Hertzog. Tina, who is an independent consultant in the state of Pennsylvania, gave a presentation called "Characteristics, Connections, and Community of Deaf-Blindness." The children and youth had a fun-filled day of activities provided by supervisors Dawn Moss and Cherie Neely, the wonderful childcare providers from IU 10, and university students from Clarion and Pitt!

The conference concluded with a family dinner and an opportunity to continue to network with the many families who may not see each other again face to face for another year. Both new and old friendships were solidified and embraced as everyone said goodbye.

When 27 families are brought together, each connected to 27 unique children of various ages and abilities, it is often a challenge to meet everyone's needs. However, we are all connected in the web of our deaf-blind community; and, we share an understanding of the value of lifelong friendship. How lucky we really are!

See you next year!

The 2018 Family Learning Conference will be held in Harrisburg on June 22 & 23. Mark your calendars. More information to follow.

IEP Letter to Families

From your Family Consultants, Molly Black and Patti McGowan

Dear parent or family member of a child or youth with deaf-blindness,

We want you to know that you are the most important person on your child's individualized education program (IEP) team. You are the most consistent IEP team member and you know the student (your child) the best! Set extra-ordinary expectations for both your child and your team. Allow the IEP to tell your child's story, set high goals, and utilize your child's strengths to support and overcome any weaknesses that may be discussed during your child's IEP meeting.

Your child's unique and specific needs, not his or her disability classification, should drive the IEP discussion. Keep in mind that you are the expert on your child. Be prepared to share your triumphs, challenges, hopes, dreams, observations, and concerns. Success for your child should be the goal of all IEP team members while developing your child's IEP.

If your child already has an IEP, make sure you review and familiarize yourself with his or her current IEP prior to the meeting. If your child does not yet have an IEP and is currently not receiving services, talk to other parents and families of children with deaf-blindness about related services and supports that have been beneficial to their child. Your child may attend and be present at his or her IEP at any age, when appropriate. In Pennsylvania at age 14, your child has the right and should fully participate in his or her IEP and be a valuable member of the IEP team.

An IEP meeting can be requested and held at any time during the school year, if necessary. Having regular team meetings (e.g., monthly, quarterly) in addition to your IEP meeting, to discuss progress or concerns can be advantageous for the entire team.

Having a strong IEP team and practical goals supported by educational services will allow your child to develop, learn, and be successful and happy. The IEP process can certainly be daunting at times, so hopefully the following links will help you during your own IEP "season." Remember – knowledge is power!

Here are two resources from the Pennsylvania Training and Technical Assistance Network (PaTTAN):

Parent Information: Individualized Education Program (IEP)
http://tinyurl.com/ybtv4hg3

Individualized Education Program (IEP) - (Annotated)
http://tinyurl.com/ycbs8uac

In Pennsylvania, we are fortunate to have the Parent Education and Advocacy Leadership Center (PEAL), a resource for disability information and referral. PEAL provides information and IEP trainings across the commonwealth:

Part III IEP Mini-Series: Know Your Parental Rights
http://tinyurl.com/y9dxlr27

Educational Rights and IEPs
https://pealcenter.org/education-rights/

The Office of Dispute Resolution has some really good resources, and a section devoted to IEPs:

Individualized Education Program (IEP)
http://odr-pa.org/parents/parent-resource-library/iep

Individualized Education Program Facilitation
http://tinyurl.com/yb9zmkcj

The Pacer Center has a wealth of information. Just search IEP at http://www.pacer.org.

This publication, *Developing Your Child's IEP*, from the Center for Parent Information and Resources is also great:
http://www.parentcenterhub.org/pa12/

Please feel free to reach out to Molly Black mblack@pattan.net and or Patti McGowan pmcgowan@pattan.net, your Family Consultants for the Pennsylvania Deaf-Blind Project, if you need additional support while navigating the IEP process.

Spotlighting a New HKNC Program - DBIS

Comprehensive vocational rehabilitation programs for youths, working age adults, and seniors who are deaf-blind are constantly evolving, and HKNC is committed to remaining the national leader in developing new and innovative ways of providing training to its consumers. In addition to HKNC's regular vocational and independent living skills training programs, in 2016 a new component was added – the Deaf-Blind Immersion Seminar (DBIS).

The DBIS was created for individuals who are deaf-blind and who have intellectual disabilities. The program offers a consumer and his/her three person support team a unique and individualized training experience during a five-day seminar. It provides vocational assessment and an array of work exploration opportunities for participants who have had minimal experience in the world of work.

The consumer participates in work experiences that match his/her interests, gifts, and abilities and develops a personalized communication system of sign language, object symbols, and touch signals for use at home, work, and the community. Consumers have the opportunity to learn adaptive skills in mobility, cooking, cleaning, laundry, and leisure time, along with an audiology assessment. HKNC staff interacts on a one-to-one basis with the consumer and the support team, modeling communication methods, teaching techniques, and proven strategies. An action plan is then developed by the support team, along with the HKNC instructors, for the consumer and the team to follow when they return home.

In 2016, two consumers participated in DBIS – the first was Kelly from New York with her job coach, and the second was Randy, an older gentleman from Iowa with his sister, community residence supervisor, and the director of his residential facility.

Kelly participated in a work experience learning about the vending machine business. In addition, she delivered mail to staff in their offices and participated in meal preparation. Kelly learned how to sign "more work" and began initiating this and other signs for the first time. She also learned several touch signals, which Kelly's mother has now implemented at home. The staff in Kelly's day program were receptive to setting up a snack machine at their site and will look into a work experience for her stocking the soda machines on their campus. In order to support Kelly in the community, the HKNC team introduced communication cards, which she was successfully able to use to order food and drinks at local restaurants.

Randy had lived in a state-sponsored residential setting for over thirty years and had no activities or ways to communicate to the staff. His sister became very frustrated by his situation. "I wanted to talk to him about fun things. I wanted to let him know where we were going."

Using object cues and touch signals, the HKNC team began to see Randy responding to simple requests and, by the end of the week, traveling independently in the HKNC Residence Building. A personalized book of object symbols was developed, and the home team learned how to use it effectively with Randy. Randy is currently living in a beautiful group home and, as a result of the DBIS, he is enjoying some preferred leisure activities. Now, when Randy's sister visits him, she is able to use the alternative communication methods she learned to discuss their plans and to make sure that he understands her.

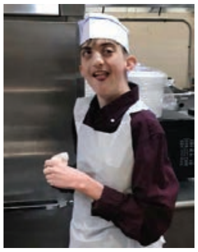
Support for this program comes from several sources. When the person is working or wants to work, the state vocational rehabilitation agency can be a funding source. Another resource for funding is the agency that provides the consumer's residential supports. One example is the Home and Community Based Services (HCBS) waiver funding. Other teams apply for grants from their county or state.

The best scenario is to have three people accompany the focus person in this journey, either in NY or in the home community. Those three people can be family members, residential support staff, job coaches or friends in the focus person's life. If you are interested in the DBIS, please contact your HKNC regional representative. https://www.helenkeller.org/hknc/nationwide-services.

CONNECT!, a publication of the Helen Keller National Center for Deaf-Blind Youths and Adults Spring 2017. Reprinted with permission.

National Center on Deaf-Blindness

Jacob's Journey



In this story, Emrick Jones describes his son Jacob's experience with HKNC's Deaf-Blind Immersion Seminar. June 2017.

During March 27–31, 2017, Jacob Jones's North Carolina based team had an opportunity to participate in HKNC's Deaf-Blind Immersion Seminar (DBIS), an assessment and training program for individuals who are deaf-blind and have intellectual disabilities. Jacob's team includes Emrick and Kathy Jones (parents), Cassie Black (caregiver), Dreama McCoy (Section Chief, Supporting Teaching and Related Services, Exceptional Children Division, North Carolina Department of Public Instruction), Dorothy Snyder (Educational Consultant for Deaf-Blind, Department of Public Instruction, NC Project for Children and Young Adults Who Are Deaf-Blind, Exceptional Children's Division), and Alex Velez (North Carolina Department of Human and Health Services, Deaf-Blind Specialist). Thanks to Marilyn Trader (HKNC, Regional Representative Southeast) for organizing this opportunity.

DBIS facilitates an intensive evaluation by HKNC specialists focusing on vocational exploration, lifestyle assessment, individualized communication systems, low vision and audiology assessment, and environmental modifications. In addition, support staff receive hands-on training and mentoring specific to individuals who are deaf-blind. This seminar is a one of a kind experience where two parallel evaluation/training paths coincide—one oriented to the focus person and one oriented to the support staff.

From our first arrival on HKNC's campus, we were warmly welcomed by the dorm staff who introduced us to our "home" for the next 5 days. Jacob, who is 22, was curious and excited about what was forthcoming. Following breakfast on Monday, we were met by some fantastic HNKC staff (Laura Rocchio, Mike Richardson, and Kathy Anello). Their plan was to make formal introductions, give an overview of the week, and gracefully begin the week's journey. Ultimately, Jacob had another idea . . . . He promptly approached Mike and Kathy and asked very enthusiastically, "When and where am I going to work?" With that said, he quickly gathered his belongings and instructed Mike that it was time to go.

During the next 5 days, Jacob had an opportunity to experience a variety of vocational opportunities including:

- Laundry Services at St. Francis Hospital
- Mail Services at St. Francis Hospital
- Cafeteria at St. Francis Hospital
- Shredding documents at a local law office
- Dietary Services, Industrial Dishwashing
- Food Services, preparing measured servings of juice and fruit at HKNC
- Managing vending and drink dispensing machines at HKNC
- Janitorial Services at HKNC

Intermixed with this vocational work, Jacob also received numerous evaluations by HKNC staff.

Throughout the week, Jacob's NC team members met with HKNC staff to:

- Discuss common practices and strategies to implement in Jacob's community upon their return to NC
- Observe classroom instructions
- Observe and learn best practices for individuals wo are deaf-blind

From Jacob's mother's and my perspective, there were two significant points that I believe set the foundation for a successful outcome. First, we were humbled by the hundreds of years of experience represented by the HNKC staff and by the compassion and personal commitment each person has for the deaf-blind community. It was quite a remarkable experience to have such a rich knowledge base in a single concentrated area and we were blessed to have open access to it all. Second, was to be immersed in a rich environment where all persons interacting with Jacob **only** spoke and acted upon his **abilities**. From these two perspectives alone, a whirlwind of discussion, learning, and experience took place.

A quote from Helen Keller appropriately summarizes the week:

> *Optimism is the faith that leads to achievement. Nothing can be done without hope and confidence.*

From the **Jones** family, a great big **thank you** to Jacob's North Carolina based support staff and to all HKNC staff who made this a very productive week.

> *As a representative of the North Carolina Project for Children and Young Adults Who Are Deaf-Blind (NCDBP), I found this experience to be one of the most valuable activities I have ever had the opportunity to observe. It was a pleasure meeting the HKNC staff and watching them document Jacob performinga variety of tasks. Following the immersion seminar, NCDBP continues to offer support where we can and to watch as the family and team pursues avenues of meaningful employment. We are planning to develop training opportunities for other teams in our state built upon the HKNC experience.*
>
> *– Dottie Snyder*

OHOA Kickoff 2017-2018 Training

On Thursday September 7, 2017, the Pennsylvania Deaf-Blind Project kicked off their 4th annual year-long Open Hands Open Access (OHOA) Deaf-Blind Intervener Learning Modules training. Over 50 participants attended the kick-off, which was video conferenced at all three PaTTAN sites. Those attending included parents,classroomteachers,paraprofessionals,interpreters, Teachers of Visually Impaired Students, Teachers of the Deaf and Hard of Hearing, Speech and Language Pathologists, and administrators.

The day-long training introduced participants to the unique learning needs of students with deaf-blindness, which included a deaf-blind simulation experience. In addition, the role of the intervener was explained, and information was shared on the process of obtaining national intervener certification (NICE). Lastly, the participants practiced interfacing with the online modules through the Welcome and Orientation Module.

Throughout the 2017-18 school year, these participants will engage in Modules 1 to 8 which include topics such as: Introduction to Deaf-Blindness, The Role of the Intervener, Sensory Systems, Trusting Relationships, Availability for Learning, and Emergent and Complex Communication.


OHOA participants at the PaTTAN Pittsburgh site sit quietly classroom style under simulations experiencing having no sight or hearing.

What is a Pennsylvania ABLE Savings Account?

A financially secure future is something every family wants for their child, especially families of children with disabilities and special health care needs who are saving for disability-related expenses. The Pennsylvania Achieving a Better Life Experience Act (PA ABLE) provides individuals with qualified disabilities, and their families and friends, a tax-free way to save private funds to support disability-related expenses for health, independence and quality of life, while maintaining government benefits.

Enrollment

Eligible Individuals who are adults (+18) and have the legal capacity to contract must open an account for themselves. A parent or guardian, or power of attorney of the Eligible Individual may open an Account on behalf of an eligible Individual who is a minor, or an adult who lacks the legal capacity to contract. To see if you or your family is eligible go to www.paable.gov/eligibility/.

Contributions

The PA ABLE Act allows people with disabilities and/or their families to open investment and checking accounts—tax free and without impacting any other government benefits. The PA Treasurer's Office manages the funds and provides oversight. PA ABLE savings account benefits may include:

- Save up to $14,000 each year
- Savings grow tax free
- Use account to pay for a wide range of disability-related expenses
- Withdrawals will be exempt from federal and state income tax when used for qualified disability expenses
- ABLE account holders can save up to $100,000 without affecting eligibility for Supplemental Security Income (SSI) benefits. ABLE savings are also excluded from other means-tested* federal and state programs, such as Medical Assistance.

The Program offers investment vehicles that are similar to mutual funds and other investment products. Customer service agents are available to assist with the enrollment process, which includes how you want your contributions to be invested using investment vehicles that are similar to mutual funds and other investment products. There is also an FDIC-insured interest-bearing checking account option. See Appendix B of the PA ABLE Program Disclosure Statement.

Since April, only a fraction of eligible families set up ABLE accounts in Pennsylvania. There are most likely 500,000 to 800,000 people in Pennsylvania who may be eligible to create an ABLE savings account. Learn more about the PA ABLE Savings Program at www.paable.gov.

Benefits Exclusive to PA ABLE Savings Program

Several benefits are available only through the PA ABLE Savings Program, exclusive benefits include:

- ***Pennsylvania Income Tax Exclusion.*** For PA taxpayers, the earnings in an Account are tax deferred for state income tax purposes and, if used for Qualified Expenses, tax exempt
- ***Pennsylvania Inheritance Tax Exclusion.*** Assets held in an Account are not included in a deceased's assets. The inheritance tax rate varies depending on the relationship between the deceased and the heir.
- ***Protection from Creditors.*** In PA state proceedings, assets held in an Account are protected from creditors of the Account Owner or contributor.
- ***PA ABLE Account Control.*** Parents or guardians who opened an Account as an Authorized Individual for their minor child may retain control of the Account until the Account Owner can independently manage his or her own finances. The Account Owner does not automatically assume control of the Account at age 18.

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*A **means test** is a determination of whether an individual or family is eligible for government assistance, based upon whether the individual or family possesses the **means** to do without that help.

The Pennsylvania ABLE Savings Program is administered by the Pennsylvania Treasury Department. Before investing, please carefully read the Disclosure Statement (available at PAABLE.gov or by calling 855-529-2253) to learn more about the program, including its effect on federal and state benefits, investment objectives, risks, fees, and tax implications.

PEAL Center newsletter (shared with permission).

iCanConnectPA

iCanConnectPA, the National Deaf-Blind Equipment Distribution Program in Pennsylvania, is now a permanent program. This federal program provides communications technology free of charge to low-income people who have both vision and hearing loss. People who are eligible for iCanConnectPA receive: a free assessment to determine the appropriate technologies that will meet their needs; equipment that meets their goals and needs for distance communication; and, equipment installation and training as needed.

If you were already familiar with iCanConnectPA, please go to the website (http://disabilities.temple.edu/icanconnect) and download a new application, which has been updated to incorporate requirements outlined in the FCC's rules for the permanent program. You can also contact iCanConnectPA at 800-204-7428 (voice), or iCanConnectPA@temple.edu (email).

iCanConnectPA
THE NATIONAL DEAF-BLIND EQUIPMENT
DISTRIBUTION PROGRAM IN PENNSYLVANIA

Daring to Dream: Using Discovery to Plan for Transition

There is a subject that triggers anxiety in all parents of children with disabilities. The anxiety is magnified when the child has significant impact of disability – like multi-sensory impairments. That subject is transition. Thinking about and planning for what comes next when school ends for our children can be a consuming process – where will they live? Did we complete all the enrollments and applications for supports? As parents of children with significant disabilities, do we think about employment in this planning and exchange? Too often, we don't. It's easy to understand why not – traditionally, the employment supports for individuals with disabilities often did not include supports or services for our children with dual sensory impairment and other significant disabilities.

The Office of Vocational Rehabilitation, OVR, may complete an assessment and often the findings would identify that our children were not eligible for employment support services. When we planned at school, the evaluation identified all the areas that we, as a team, needed to work on as we planned for the future with our youth with disabilities, and that usually didn't include employment.That has changed, and continues to change. In 2014, the U.S. Congress passed the Workforce Innovation and Opportunity Act (WIOA), which placed greater emphasis on employment for individuals with significant impact of disability. Transition age students and young adults up to age 26 cannot be considered for placement in a sheltered work setting until they have first been considered for employment.

> *"Discovery consists of looking at the same thing as everyone else and thinking something different."*
>
> *– Albert Szent-Gyorgyi*
> *(Nobel Prize winner)*

Albert Szent-Gyorgyi discovered vitamin C. His definition of "discovery" led to a new way of looking at individuals with disabilities and employment. Discovery is a nontraditional, noncomparative alternative to the ways we have always conducted work assessments for students and adults with disabilities, including those with the most significant disability. Discovery is completed over a period of up to 20 weeks. During that time, someone certified to conduct Discovery assessments will spend time observing and interacting with the individual with disabilities in their home, at school, in the community while they are doing the things they do in everyday life. They will conduct interviews with those who know the individual best – and who are "champions" of the individual who can share and describe their strengths. The key to Discovery comes in the act of translation. The process involves taking all the things an individual does in everyday life and translating them in to potential work tasks that can be offered to an employer.

In Discovery, we don't look at readiness, or even specific job titles – we look at what a person can do, what interests them, and what conditions are in place that make them successful in the things they do. These three things lay the groundwork for employment planning. Here is an example: "Joanie" is one of eight siblings. During the process of Discovery, one of her younger brothers shared a vital clue about Joanie. When asked what his sister does really well, he thought about it, and he replied, "Joanie opens Christmas presents faster than anyone else in the family!" Imagine that being the clue that, in part, led Joanie to her first job! As it happened, there was a company in Joanie's town that had an unmet need – something to unpackage boxes of products to run through an embroidering machine to create promotional products. One of Joanie's tasks at her first job was to unpackage those boxes of shirts and hats and other items to ready them for personalization.

When we think in terms of task, work tasks, and use translation, we open up a range of employment options for people with disabilities that have not before been considered. This is part of what we mean when we talk about Customized Employment. It is a very different approach from what has traditionally been offered through OVR and ODP waiver funded employment services. Typically, support has been provided in the form of work assessments – looking at how someone completes work at a job site, or formal testing; job development support is someone assisting a job seeker to look at job postings, writing a resume, going to a job interview. Those things typically don't work for many individuals with significant disabilities, who may have dual sensory impairment, be nonverbal, or otherwise do not do well with traditional testing and would not fair well at a job interview.

WIOA includes language that allows a job seeker with a disability to choose a representative to act on their behalf during job development – and that is how we conduct job development. An employment specialist acts on behalf of the job seeker to meet with employers, explain exactly what customized employment is, and can be, and works to negotiate an individualized job/job description for the individual. During negotiations with a potential employer, an employment specialist is seeking to match a business's needs with the tasks that the job seeker with

Daring to Dream,

continued from page 7

a disability can contribute to the business to create a mutually beneficial employment relationship. The employment specialist has the information from the Discovery profile and the Customized Plan for Employment – which identify those tasks the job seeker can offer and what conditions should be in place when considering potential employment. The richer and more robust the information in those documents is, the more likely a good fit for employment can be secured. Addressing barriers, such as communication issues, sensory impairments, access to transportation, etc. are all things that are covered in the Discovery profile and planning process. Rather than focusing on barriers that prevent access to employment, the Discovery and customization process focuses on conditions – for learning tasks and achieving success – that must be in place in a work setting to make employment success achievable for individuals with significant impact of disability.

When we think about finding employment from a different perspective – consider building a job position from tasks, rather that traditional job descriptions – we open the doors of opportunity. Everyone has something to contribute, and there are many stories of success. You can learn more about some of these success stories by visiting the National Center on Deaf Blindness' publications page. Here is a link to an issue of *Deaf-Blind Perspectives*, which offers some specific examples of those successes: http://tinyurl.com/yddhxyhz.

If you would like to learn more about these efforts in Pennsylvania, I hope you will join us as we present sessions on Discovery and Customized Employment at the HELIX Conference, The Pennsylvania Transition Conference, or visit an exhibit table and talk with us at these conferences or at the Pennsylvania Department of Education Conference. You can also visit our website: http://tinyurl.com/ycb2pzfs. There is information about Discovery and Customized Employment, as well as a schedule of trainings that we are hosting across Pennsylvania in partnership with Marc Gold & Associates (MG&A). For more information about Marc Gold & Associates and a wealth of publications and resources related to Discovery and Customized Employment, visit the publications and resources page on the MG&A website: www.marcgold.com.

– Nicole Turman, Program Manager, Arc Discovery Employment Transitions (ADEPT)Discovery/Customized Employment Program Specialist

Experience Books

Fall and winter are wonderful seasons to make memories. There are many great events over theses months that include holiday celebrations, family gatherings, school parties and concerts, fun exploration of fall foliage, and winter shenanigans in the snow. Tactile experience books are wonderful ways to commemorate these times together with your child. These active/live books take real objects/artifacts from activities and events and incorporate them into parts of a storybook that you and your child create of that activity/event.

Together with your child create a tactile experience book of a fall or winter memory that your child would like to remember. Encourage your child to participate as much as possible in the creation of the experience book. Have your child pick out the activity that he or she wants to remember. You might be surprised by their choice! Discuss with your child the list of items he/she might want to use as illustrations. Then give your child the mission of helping to collect those items. Have your child tell you in his/her words about the activity and use this as a base for your story (progression/line). Create the experience book together as a fun "craft" project. Finally, and best of all, snuggle together, read your experience book, and remember! (Repeat last section as often as possible!)

– Jennifer Edgar

For more information and resources on creating tactile experience books see list below:

Paths to Literacy

- Tactile Experience Books – http://bit.ly/2w3pDIo
- Tactile Books for Students with Visual Impairments (includes creating tips) – http://bit.ly/2vJQqqr
- Experience Stories and Tactile Books - http://bit.ly/2wgrHwh
- All Aboard! Experience Book About Trains – http://bit.ly/2x5JGCY
- Decorating the Christmas Tree: An Experience Book Tradition – http://bit.ly/2vJCiNR
- Winter Tactile Experience Book: Snow, Snow, What Do You See? – http://bit.ly/2vEEojM

Washington Sensory Disability Services

Experience Books FAQs – http://bit.ly/2x5gKe0

Texas School for the Blind and Visually impaired

- Experience Stories for Functionally Blind Pre-Readers – http://bit.ly/2i8ZemS
- Creating and Using Tactile Experience Books for Young Children With Visual Impairments – http://bit.ly/2wgwhuj

Perkins School for the Blind – YouTube Videos

- Supermarket Tactile Book with Ira Padhye – http://bit.ly/2v2MXR0
- Brushing Teeth with Ira Padhye – http://bit.ly/2v35Zrp

dblink.org PDF

National Center on Deaf-Blindness





Families Matter to NCDB!

NCDB knows that families are the one consistent influence in their children's lives and the true experts in what they need for learning and development. To help families support their child's educational journey, NCDB, in collaboration with state deaf-blind projects and national family organizations, has developed a number of resources.

Visit our site to find the most current information on deaf-blindness and explore multiple learning opportunities in the following areas:

- **Family Engagement** – Family-to-family connections and support
- **Early Identification and Referral** – Finding and serving children early
- **Literacy** – Early communication and literacy development
- **Transition** – Preparing for a happy, successful adult life
- **Interveners and Qualified Personnel** – Knowledgeable teachers and other serviceproviders

Ways to Engage and Learn

NCDB Library (nationaldb.org/library)

A large collection of online resources on all aspects of deaf-blindness. Browse by topic or research specific questions.

Recursos En Español (nationaldb.org/pages/show/recursos-en-espanol)

NCDB Library resources translated into Spanish.

Open Hands, Open Access: Deaf-Blind Intervener Modules (moodle.nationaldb.org)

A series of 27 online modules designed to train interveners. Also a great resource for parents—you can sign up for free and work through them at your own pace.

For Families (nationaldb.org/families)

Links to resources especially for families, including state and national organizations and state deaf-blind projects and our Families Matter video series (each featuring a different family).

Facebook (https://www.facebook.com/nationaldb)

Follow NCDB on Facebook! We post stories, interesting resources, and "family fun facts."

Children Who Are Deaf-Blind

Although the term deaf-blind implies a complete absence of hearing and sight, in reality it refers to varying degrees of hearing and vision loss. The type and severity differ from person to person, but the key feature of this condition is that the combination of losses significantly limits an individual's ability to access auditory and visual information. The majority of children who are deaf-blind also have additional physical or cognitive disabilities or health problems.

When both vision and hearing are affected, especially from birth or early in life, natural opportunities to learn and communicate are severely limited. As a result, children who are deaf-blind require specialized teaching methods and intensive, individualized education and accommodations from infancy through young adulthood.

It is essential that families and educators have access to training and support regarding the assessment and education of infants, children, and youth who are deaf-blind. Each state has a federally funded technical assistance project to provide this training and support. You can find contact information for the deaf-blind project in your state at nationaldb.org.

Create a profile on our site to Bookmark, Share, Connect!

https://nationaldb.org/wiki/page/10/800

National Center on Deaf-Blindness

Deaf-Blind Network
Technical Assistance Across the Nation

IDEAs that Work
Office of Special Education Programs

The contents of this document were developed under a grant from the U.S. Department of Education #H326T130013. However, those contents do not necessarily represent the policy of The Research Institute, nor the US Department of Education, and you should not assume endorsement by the Federal Government. Project Officer, Jo Ann McCann.

Family Engagement Update from the National Center on Deaf-Blindness (NCDB)

NATIONAL CENTER ON DEAF-BLINDNESS

NCDB is a national technical assistance center, funded by the Federal Department of Education, that works with state deaf-blind projects and national family organizations to improve quality of life for children who are deaf-blind and their families. We have six areas (or initiatives) where we focus our efforts:

1) Early Identification and Referral – finding the children as early as possible and connecting families and providers to needed resources

2) Family Engagement – connecting families to information and one another

3) Literacy – how to promote early communication and literacy development

4) Interveners and Qualified Personnel – working to get more people trained to support learners with deaf-blindness

5) Transition – promoting quality planning as children grow

6) National Child Count – making sure we know where the children with deaf-blindness are located, their ages and primary etiologies

In an age where there's numerous ways in which you can find information and connect, we wanted to share with you some ways that we think you'd enjoy learning and sharing. We encourage you to check out the following:

Create a Profile on the National Center on Deaf-Blindness Website: nationaldb.org

NCDB wants you to join our national initiatives! As parents, you are the key voice in everything we do. We have set up the site so that you can create a profile and then join groups that interest you. Here's how you join . . .

Step 1: Go to nationaldb.org

Step 2: Click on "Make a Profile" in the upper right-hand corner of the screen

Step 3: Fill in the information requested and click on "Create My Profile"

You're in! Now you can join the Family Engagement Group!

Step 4: From any screen on the website click on the "Connections" tab (it's in the bar across the top of the page) and choose "TA Initiative Groups"

Step 5: Click on the "Family Engagement" link

Step 6: In the upper left-hand corner of the screen click on "Join Group"

Now you are a member of the Family Engagement Group and can post to the forum. Remember that although you have to be a member to post, this is a public group and posts can be read by anyone, so take care not to post personal details.

The next time you come to the website, it is less complicated and you don't have to go through the 6-step process. Instead, just follow these steps:

Step 1: Login (in the upper right-hand corner of the screen) using the username and password you chose when setting up your profile.

Step 2: You will then see your name (also in the screen's upper-right corner). Click on the "down" arrow next to your name. The names of any groups you belong to will appear.

Step 3: Click on Family Engagement to go directly to the group.

For Families (nationaldb.org/families)

We have begun to collect stories from families of children with deaf-blindness that we hope will be a source of inspiration for others. Once you check them out, if you are interested in telling your story, please let us know. It is our hope that over time we will compile a large collection of stories that demonstrate how incredibly diverse this population of learners truly is and allow others to be learn and be inspired.

Online Parent/Family Training: The Role of Interveners in Educational Settings

NFADB (National Family Association for Deaf-Blind) and NCDB have teamed up to offer training that provides an introduction to the role of interveners in the educational setting. The training uses Module 3 from the Open Hands Open Access Intervener Learning Modules. Patti McGowan (NFADB) and Peggy Malloy (NCDB) have been hosting these trainings online, free to families. If you are interested in joining the next group, please contact either one of them (malloyp@mail.wou.edu or pmcgowan@pattan.net).

Friday Family Fun Facts

Every Friday NCDB posts a new Friday Family Fun Fact on our Facebook and Twitter accounts from a family in the deaf-blind network about something they have done in the home, school, or community with their child. If you have Facebook or Twitter, you'll want to check them out! It's really awesome to see the array of things families do to support their child. And, we'd love to feature some families in Hawaii (hint, hint!). If you'd like to share some with us, please send them to: megan.cote@hknc.org

Family 2 Family Communities (F2FC)

F2FC are online groups that bring family members together across state lines to get to know one another, share information and resources and offer support. Interested? Contact Carol Darrah at cdarrah@uga.edu. There will be a new group offered in the Fall of 2017.

Open Hands Open Access (OHOA) Deaf-Blind Intervener Learning Modules

OHOA is a national resource designed to increase awareness, knowledge, and skills related to the process of intervention for students who are deaf-blind. They are free self-paced modules that you may want to use yourself and/ or share with providers who work with your child. For more information, please go to: ohoamoodle/

We hope you like these resources and that we've enticed you to join the fun! Please let us know if you have any questions!

– Megan Cote
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Literacy for Children With CVI

Are you a parent or an educator of a child with CVI (cortical visual impairment)? You may know that CVI is now the most common cause of visual impairment in children in the developed world. While there have been significant strides in intervention, there is still concern about how to introduce books and other educational materials.

We're happy to announce that Diane Sheline has created a new section on Literacy and CVI on Paths to Literacy: http://www.pathstoliteracy.org/topic/cvi/overview You will find an overview and implications for the 3 phases of CVI, as well as guidelines for modifying books for children in Phases I, II, and III. Find out how to create your own book, with 8 new examples for young children.

Try these general tips for promoting literacy with children with CVI:

1. Know where the child is on the CVI Range.
2. Determine what the child is interested in looking at (preferred visual target).
3. Identify the child's preferred color.
4. Use a solid colored background that makes the items "pop" in contrast.
5. Use page fluffers to separate the pages and make it easier for the child to turn them.
6. Minimize print and visual targets on the pages until the child is ready for more complexity.
7. Use a flashlight shining on the visual target on the page to draw the child's visual attention.
8. After a book is made, send it back and forth between home and school, so the child has access to literacy materials everywhere!
9. Begin with real objects before introducing pictures.
10. Collaborate with families, teachers, OT, PT, Speech when creating literacy materials.

Paths to Literacy is a joint project between Texas School for the Blind and Visually Impaired and Perkins School for the Blind focusing on all aspects of literacy for children with visual impairments. We invite you to register on the site to find out about new ideas!

– Charlotte Cushman, Project Manager
Training and Educational Resources
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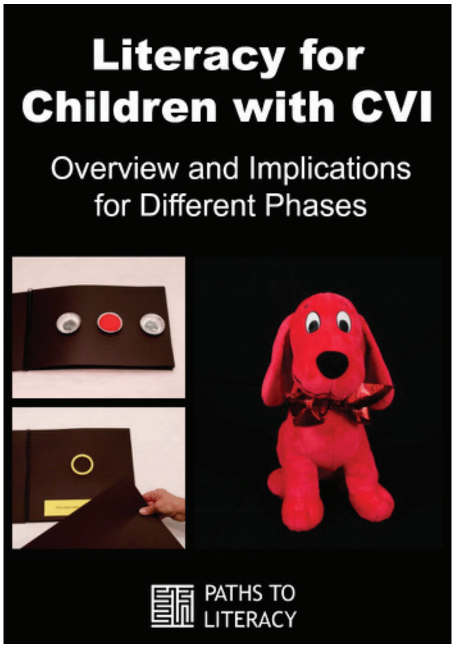

Literacy for Children with CVI

Overview and Implications for Different Phases

PATHS TO LITERACY

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IDEAs that Work
Office of Special
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