Dually Noted

News from the Pennsylvania Deaf-Blind Project

Message From the Director

In the Fall/Winter 2015 issue of Dually Noted, we included information on the Alice Cogswell and Anne Sullivan Macy Act, which, at the time, was a draft bill designed to strengthen the Individuals with Disabilities Education Act (IDEA) to improve results for children who are deaf, hard of hearing, blind, visually impaired, and deaf-blind. Many schools are not prepared to support children who are deaf-blind in developing to their full potential. On February 16, 2017, the Alice Cogswell and Anne Sullivan Macy Act was reintroduced in the House as H.R. 1120. There have been a few additions to make the bill stronger. These are highlighted in the bill summary located on page 2.

The need for highly qualified personnel working in our schools cannot be stressed enough. The National Center on Deaf-Blindness (NCDB) has identified Interveners and Qualified Personnel as one of their national initiatives. The focus of this national initiative continues to be the implementation of the 2012 Intervener Service Recommendations, which describe the need for qualified interveners and for those interveners to have access to qualified supervisors, coaches, and teachers. This work is also guided by the recognition of the specific needs for qualified personnel in deaf-blindness and the integration of the Council for Exceptional Children (CEC) competencies. Parties who are supporting this initiative include practitioners in the field, teachers, interveners, state deaf-blind project staff, university faculty members, family members and representatives from professional organizations. According to The Conference of Educational Administrators of Schools and Programs for the Deaf, (www.ceasd.org) if passed, H.R. 1120 will: promote and ensure the delivery of high quality special education and related services to students with visual disabilities, or students who are deaf or hard of hearing or deaf-blind, through instructional methodologies meeting their unique learning needs; and, enhance accountability for the provision of such services. Qualified personnel are the only people who can assure that high quality education and services are provided for your children who are deaf-blind.

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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.

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What happens next? According to the American Foundation for the Blind (www.afb.org), the U.S. Congress must review and amend IDEA as part of Congress's periodic reauthorization of that law. The Cogswell-Macy Act can be passed by Congress at any time in advance of IDEA reauthorization, or it can be incorporated, in whole or in part, into reauthorization itself. In either case, the Cogswell-Macy Act represents our community's unified voice in support of much-needed improvements to IDEA. By calling on Congress to promptly pass the Cogswell-Macy Act now, we communicate our sense of urgency and that the changes we seek are long overdue. Should Congress ail to act on the Cogswell-Macy bill itself, the bill will continue to be the source from which Congress will draw the specific proposals for the changes we are requesting.

To find out more, including what you can do to support the passing of H.R. 1120, please visit http://www.afb.org/cogswellmacyact or http://www.ceasd.org/child-first/alice-cogswell

Alice Cogswell and Anne Sullivan Macy Act, H.R. 1120

Named for the first student with deafness to be formally educated in the U.S. and for Helen Keller's beloved teacher, respectively, the Alice Cogswell and Anne Sullivan Macy Act will strengthen the Individuals with Disabilities Education Act to improve results for children who are deaf, hard of hearing, blind, visually impaired, and deaf-blind, including those with additional disabilities. Among other things, this Act will:

- Require states to identify, locate, and evaluate children who are deaf, hard of hearing, blind, visually impaired, or deaf-blind regardless of formal disability category or classification so that all of these students, including those with additional disabilities, are counted and properly served.
- Expand knowledge about the scope and quality of special education and related services provided to students who are deaf, hard of hearing, blind, visually impaired, or deaf-blind through refined data collection that tracks these students, regardless of formal disability category or classification.
- Expect states to conduct strategic planning and commit such planning to writing, to guarantee that all students who are deaf, hard of hearing, blind, visually impaired, and deaf-blind within each state receive all specialized instruction and services needed, provided by properly trained personnel.
- Enhance existing "special factors" provisions to ensure that they provide for: the language, communication, and other unique learning needs of children who are deaf and hard of hearing; the needs of children who are blind and visually impaired related to the Expanded Core Curriculum; the body of services that teachers of students with visual impairments and related professions are expertly trained to provide; the language, communication, access to environmental and educational information needed by students who are deaf-blind for learning and interaction, and other needs.
- Ramp up U.S. Department of Education responsibilities to monitor and report on states' compliance with their obligations with respect to instruction and services specifically provided to students who are deaf, hard of hearing, blind, visually impaired, or deaf-blind.
- Assist parents and educators of students who are deaf, hard of hearing, blind, visually impaired, or deaf-blind through regular and up-to-date written policy guidance from the U.S. Department of Education.
- Improve educational outcomes for students who are deaf-blind by updating relevant terminology, including intervener services as a related service, and ensuring the availability of trained and qualified personnel.

- Establish a national collaborative organizational resource, the Anne Sullivan Macy Center on Vision Loss and Educational Excellence, to proliferate evidence-based practices in the education of students with vision loss, to keep special educators current with the latest instructional methods, and to supplement state and local educational agency provision of the instruction and services of the Expanded Core Curriculum.

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The Family Engagement Coordinator Scarf is on the Move!

In July 2016, the National Center on Deaf-Blindness (NCDB) hosted a training for the state Deaf-Blind Project Family Engagement Coordinators. For many of the attendees, it was their first time to meet in person. As an ice breaker activity, a ball of yarn was tossed across a circle as each state representative introduced themselves. Each time someone would toss the yarn, they would hold onto of a section of the string, thus creating a large web. The web then became a symbol of the support that Family Engagement Coordinators receive from NCDB, from each other and ultimately the support they give to families in their state. After the training, a young woman from Texas (who experiences combined vision and hearing loss) took the string and wove it into a scarf. Now the scarf is taking a trip around the nation so Family Engagement Coordinators can take it to events and activities in their state. Why are we doing this, you ask? So that, over time, the connection formed by the people serving in this vital role continues, and others can learn more about the array of activities and supports that they provide to the amazing families in their state. Your Pennsylvania Family Consultants, Patti McGowan and Molly Black attended this training and will be bringing the scarf to our Family Learning Conference 2017 in State College, Pennsylvania, June 23 and 24. Let's add "our" story and add to the legacy of the scarf! Join us in June as we create our own "Web of Connections."

Grief Support for Families of Children With Deaf-Blindness

With great thoughtfulness, the National Center on Deaf-Blindness (NCDB), the National Family Association for Deaf-Blind (NFADB), and state deaf-blind project personnel have been collecting grief resources for families related to child loss. As you can imagine, death is a very traumatic experience for families. When coupled with a secondary loss of connection to the deaf-blind community, healing can be even more challenging.

To help, we've created a list of resources where family members can obtain information and support.

Resources for Grieving Families:

https://nationaldb.org/wiki/page/10/753

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Next, we are excited to announce the launch of a Parent and Guardian Grief Support Group. We will be offering a series of web-based, peer- to-peer meetings where parents who have lost a child will have an opportunity to process their grief and learn about coping strategies that have helped others. **We are asking interested parents and guardians to commit to the entire 5-month series**. Enrollment is free. New groups will form as needed.

How to Join

If you are interested in joining the Parent and Guardian Grief Support group, please contact:

- Megan Cote, Family Engagement Initiative Lead at NCDB, megan.cote@hknc.org
- Molly Black, Family Consultant for the Pennsylvania Deaf-Blind project, mblack@pattan.net

Or register on-line at:

http://www.surveygizmo.com/s3/3370521Peer-Grief-Support-Program-Registration-Form

NCDB NFADB IDEAs that Work Office of Special Education Programs

pennsylvania
DEPARTMENT OF EDUCATION
Bureau of Special Education
Pennsylvania Training and Technical Assistance Network

From Your Family Support Group – Pennsylvania Partnership for the Deaf-blind (PPDB)

Pennsylvania Partnership for the Deaf-blind (PPDB) is pleased to announce the new Executive Offices of the PPDB Board and new and returning General Board Members, as of March 2017.

It is a great pleasure to introduce Kristina Kezmarsky, elected PPDB President and Tammy Kitterman elected PPDB Vice President.

Kristina Kezmarsky

I live in Pittsburgh, Pennsylvania, with my 10 year old son Shane. I have a Bachelors in Law and Society from Penn State University. I work full-time as a paralegal, focusing on family welfare and helping to ensure the permanency of children in foster care. Shane was born at 33 weeks and weighed 3 lbs. 8 oz. He was diagnosed at birth with Cornelia de Lange Syndrome, deaf-blindness, gerd, mitral valve stenosis, left ventricular hypertrophy, aortic insufficiency, and GI complications. Shane is nonverbal and uses a Dynavox, gestures, and some modified ASL to communicate. He has been active with Special Olympics for 6 years and he takes weekly swim lessons. Shane has overcome innumerable obstacles over the years but, with his tenacity and me as his voice, we can get through anything.

Tammy Kitterman

I live in Bethel Park, Pennsylvania, with my husband Grant and my son, Brock. Brock is 12 years old and is deaf-blind. He was diagnosed with Bilateral Retinoblastoma when he was 12 weeks old. The chemo that he received to save his life damaged his hearing. Brock is academic and is very active in many blind sports, as well as typical sports. I work part-time as a school bus driver and full-time as Brock's advocate and personal trainer.

PPDB also welcomes new General Board Member Jodi Reeves, and returning Board Members Molly Black and Gordon Boe.

The PEAL Center Welcomes New Director

January marked a bittersweet yet exciting moment for the Parent Education and Advocacy Leadership Center (PEAL). Our founder and first Executive Director, Liz Healey, retired after eleven dedicated years of service for families of children with disabilities and special health care needs. As the organization transitions to its next leader, Jeannine H. Brinkley, we look forward to our continued mission of education, advocacy, and leadership for families of children with disabilities and special health care needs as we work toward building communities across Pennsylvania that include all children.

In 2005 Liz wrote and received the grant to start the PEAL Center, an organization of parents of children with disabilities who provide support for families to obtain high quality inclusive educational services for their children. Liz quickly grew the organization to meet the needs of families to address special health care and extended services and support across the entire state of Pennsylvania. She has guided the PEAL Center in taking on new projects while staying true to its original mission.

On June 14, 2016, we announced that Liz was going to retire at the end of the calendar year. PEAL's Board of Directors conducted a search to identify Liz's successor, and in September we announced Jeannine H. Brinkley as the new Executive Director. Jeannine brings to PEAL more than three decades of expertise in inclusive practices, special education, and supporting school teams to transform service delivery, as well as personal experience supporting family members with disabilities. As Executive Director, Jeannine will oversee PEAL's statewide organization, which provides information, resources and training, as well as individual assistance to families. The PEAL Center focuses on strategies to develop inclusive education and effective health care for children with disabilities, as well as developing innovative resources and supporting system level improvements.

"On behalf of the Board of Directors of the PEAL Center, I am delighted to welcome Jeannine Brinkley as the new Executive Director," commented Board President Dr. Linda Rhen. "Her wealth of experience and demonstrated leadership in helping to create new possibilities for children and youth with disabilities will help the PEAL Center move forward in its mission to ensure that all children, youth, young adults, and adults with disabilities or special health care needs lead rich active lives and participate as full members of their schools and communities."

As our leadership transitions, PEAL will continue to serve its mission through face-to-face workshops, web-based training and resources, one-on-one parent advising, and the development and distribution of resource materials. Contact info@pealcenter.org for additional information.

PEAL
Center

When People Who Are Deaf-Blind Fly Alone

By S.M. Stoffel

Recently, a friend of mine who is deaf-blind was rudely informed by American Airlines that she was not allowed to fly by herself. She had been flying the exact same route for years without any complaints from what used to be US Airways airlines. Why did a change in ownership cause this sudden bias against a passenger? Similar incidents have occurred with other individuals who are deaf-blind flying American or another airline. This situation is not new to the deaf-blind community.

So what do we do about this injustice? The first step in solving any problem is to understand the problem itself. Do you know why some airlines have kicked (or tried to) passengers who are deaf-blind off flights? Here's the reason American Airlines gave:

It is crucial for the flight crew on an aircraft to be able to communicate with all passengers when an emergency occurs. Flight personnel are not required by law to know sign language, nor are they required to have an interpreter on board (no, the ADA does not apply). So, if a passenger can't hear spoken words and can't see visual cues, the passenger is at risk of not understanding and following instructions during an emergency situation. This failure of the passenger to respond correctly may also endanger other passengers in a crisis.

That is what the airline says. And how do they address this issue? Sometimes, they just ignore it and hope nothing bad will happen during a flight. Sometimes, they deny people who are deaf-blind the right to fly alone. In the latter case, a passenger who is deaf-blind would be allowed to fly only if accompanied by a hearing person. However, neither of these responses are what the airlines should be doing.

Obviously, ignoring a potential problem is never a good idea. If an emergency situation does arise, and the flight crew can't communicate sufficiently with a passenger, things could go terribly wrong.

On the other hand, denying an adult the right to travel without a babysitter is unfair. It is certainly not a simple matter to find a travel companion to go with you every time you fly, even if the airline is required to pay for the extra ticket. It's also unnecessary.

What should the airlines be doing, then? Consider the following:

- Airlines should make it clear in their passenger guidelines that the flight crew must be able to communicate information and instructions to all passengers during an emergency. It must also be stated plainly that the flight crew is not required by law to know sign language or have an interpreter on board during a flight.
- The guidelines should encourage travelors who are deaf-blind (and any other travelers who can't understand spoken instructions) to prepare a simple and quick communication system that the flight crew can use during an emergency, such as cue cards or a paper describing some tactile cues.
- The guidelines should include a list of statements that the flight crew may need to communicate to a passenger during an emergency, so that the passenger can prepare a cue system that covers all of those important statements.
- Personnel encountering a passenger with deaf-blindness attempting to board a flight should not deny access on the spot. They should attempt to work out an emergency communication system, if the passenger does not already have one ready.

What should you, the passenger with deaf-blindness, do to prepare for flying alone? Here are some things to know and do:

- When told you can't fly alone, don't cite the ADA. The ADA doesn't cover flying. The law you should be familiar with is the Air Carrier Accessibility Act (ACAA).
- Prepare a simple and quick communication system that someone who doesn't know sign language or Braille can use to tell you things during an emergency on the aircraft. Slow systems, such as Print On Palm, may not be quick enough in a crisis. Make some cue cards or a list of tactile cues that allow the flight crew to quickly tell you things like

"Emergency! Stay in your seat," or "Emergency! Go to the nearest exit," and so on. Cue cards should have the emergency statements printed in text and Braille form. Give the flight crew a paper with tactile cues described, such as: "Draw an X on my shoulder with your finger to say emergency." Remember that speed is important, so make your cues simple.

- Always request that the flight safety guide be available in Braille or large print for you. You must make this request several days before the flight, because they generally don't keep such materials on hand.
- If you have a way to access text, such as an iPhone with Braille, a Braille machine with a regular keyboard, or a dry-erase board, bring it with you on the flight and explain how the flight crew can use it to communicate more complex information to you, such as sending you a phone text to tell you that the plane had to land at a different airport due to bad weather.
- Be sure to identify yourself as a person with deaf-blindness at every step of the process—booking the flight, requesting disability services, getting your boarding pass, etc. This is an important step in order to get the law behind you.
- If you are prepared for emergencies, but the personnel still want to deny you access to your flight, demand to speak with a Conflict Resolution Officer (CRO). It is your legal right to do this, and doing it shows them you know the law. When you meet with the CRO, request to fill out a formal complaint form and explain the situation.

Airlines and travelers who are deaf-blind need to work together to improve flight accessibility, safety, and convenience. Never forget: We're people, too.

Pennsylvania Partnership for the Deafblind

Pennsylvania Partnership for the Deaf-blind (PPDB) is an organized network of individuals with deaf-blindness, their parents and family members, friends, service providers and other interested people. PPDB supports their members as they deal with the daily issues of life, such as relationships with family and friends, health, education finances, employment, insurance, service agencies and others. PPDB exists to provide support for individuals with deaf-blindness and their families through a family –driven network from birth to earth.

PPDB is a 501©(3) organization. Contributions are tax deductible. PPDB one of four State Affiliates of the National Family Association for Deaf-Blind (NFADB) and the first to do so.

Membership is minimal and for more information on PPDB, it's activities, and how to become a member, please visit our website www.papdb.org

Your PPDB Board is working hard for you and your family! We would love for you to become a member and join one of our committees! Please feel free to contact any board member at any time.

PPDB Board of Directors

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Visit Active Learning Space at www.activelearningspace.org!

Active Learning is an approach based on the work of Dr. Lilli Nielsen. It is not just a piece of equipment, such as a “Little Room” or a HOPSA dress, but rather it refers to a total approach for instructing individuals with severe multiple disabilities. It contains an assessment, a curriculum, specifically-designed equipment, and instructional strategies that support learners to be active participants in their surroundings.

This approach is closely tied to evidence-based research, such as the work of Jean Piaget’s developmental stages of learners. It views the child’s development holistically, including not only motor, cognitive, and sensory skills, but also social and emotional development.

The Active Learning approach can be used in conjunction with other approaches, such as the strategies of Dr. Jan van Dijk. Though initially this approach was designed for individuals with visual impairments and deaf-blindness, it has proven to be effective with individuals with other significant disabilities, such as autism and cerebral palsy.

It is an approach that can be used with all learners, but is most effective for those who have significant multiple disabilities and are functioning in the 0 to 48 month developmental level. The Active Learning approach can be used with individuals with various visual conditions, such as CVI (Cortical Visual Impairment) and ONH (Optic Nerve Hypoplasia), as well as with those who are deaf-blind or medically fragile.

We invite you to explore the world of Active Learning! You can also add us to your Pinterest Page or sign up for our e-newsletter at http://www.activelearningspace.org.

Penrickton Center for Blind Children

Perkins elearning

Texas School for the Blind & Visually Impaired

Open Hands Open Access Deaf-Blind Intervener Learning Module Training Kick Off

September 7, 2017; 8:30am – 3:30pm

PaTTAN – East, Harrisburg, and Pittsburgh

The Open Hands Open Access (OHOA) Deaf-Blind Intervener Learning Modules are a national resource designed to increase awareness, knowledge, and skills related to intervention for students who are deaf-blind and are being served in educational settings. This will be a 10-month training hosted by the PA Deaf-Blind Project for both educational teams and interested individual participants with the desire to understand the unique educational needs of students who experience deaf-blindness.

Presenters: Tina Hertzog and Patti McGowan

Audience: Teams and Individuals working and/or interested in professional development of students who are deaf-blind, including parents, teachers, paraprofessionals, administrators, and other service providers, including those who are not seeking to become interveners.

Agenda:

8:30-8:45: Introductions, Learning Objectives
8:45-10:00: Complex and Unique Effects of Combined Vision and Hearing Loss on Learners who are Deaf-Blind
10:00-10:45: Simulation/Reflection/Break
10:45-12:00: The Importance of Collaborative Teaming
12:00-1:00: Lunch
1:00-1:30: The Development/Purpose of the OHOA Modules
1:30-2:30: Welcome and Orientation Module/Break
2:30-3:30: OHOA Timelines/Guidelines/Wrap-Up
There will be two 15-minute breaks

Registration Information: Please register for this event by visiting our homepage at www.pattan.net

For content questions, contact: Patti McGowan at pmcgowan@pattan.net or 724-864-2553

For registration/cancellation questions, contact: Kristi Simpson at ksimpson@pattan.net or 800-441-3215 x 7241

Credits: Act 48 Clock Hours- 5 hours; ASHA - 0.5; RID CEUs - 0.5

APPROVED PROVIDER
ASHA CONTINUING EDUCATION
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PA Training and Technical Assistance Network is approved by the Continuing Education Board of the American Speech-Language-Hearing Association (ASHA) to provide continuing education activities in speech-language pathology and audiology. **See course information for number of ASHA CEUs, instructional level and content area.** ASHA CE Provider approval does not imply endorsement of course content, specific products or clinical procedures.

PARID is approved by the RID CMP to sponsor Continuing Education Activities. This program is offered for 0.5 CEUs in the Content Area of General Studies and has a Content Knowledge Level of Some.

This course is offered for .5 ASHA CEUs (Advanced level, Professional area).

Act 48 Clock Hours

Individuals attending this event must arrive on time and stay the duration of the event to receive Act 48 Professional Education hours. Requests for exceptions must be brought to the attention of the individual's superintendent or IU Director prior to the event. [5] Act 48 hours are offered for this event.

pennsylvania
DEPARTMENT OF EDUCATION
Bureau of Special Education
Pennsylvania Training and Technical Assistance Network

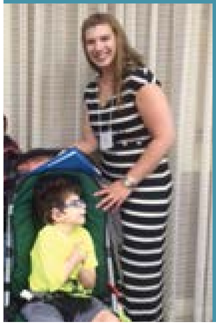
2017 Family Learning Conference

June 23 and 24, 2017

Penn Stater Hotel and Conference Center

215 Innovation Blvd.
State College, PA 16803

Come experience sharing, caring, and learning together with staff from PaTTAN and the Pennsylvania Deaf-Blind Project and other families living with deaf-blindness.



If your child has both a vision and hearing loss, your family (parents/guardians, siblings and child with deaf-blindness) may be eligible to attend a weekend learning conference. Although the period for registering for this year's event has passed, check with staff to see if there is still room, or a recent cancellation. We'd love for you to join us!

Molly Black, 724-863-1283, mblack@pattan.net, or

Patti McGowan, 724-864-2553, pmcgowan@pattan.net

Online Resources for Families of Children Who Are Deaf-Blind

Compiled by Elizabeth Bell, NCDB Information Specialist

CHARGE Syndrome Foundation (www.chargesyndrome.org)

A nonprofit organization that works to improve the lives of people with CHARGE syndrome, through outreach, education, and research. Supports families via a director of outreach, webinars, a provider database, extensive online resources, and an international conference every 2 years.

Center for Parent Information and Resources (www.parentcenterhub.org)

Every state has at least one federally funded parent center, which provides parents of children with disabilities information about local educational services and their child's rights under IDEA. Visit this site to find your local parent center and browse general resources about special education.

FamilyConnect (www.familyconnect.org)

A site from the American Foundation for the Blind for parents of children with visual impairments.

National Center on Deaf-Blindness (nationaldb.org)

A national technical assistance center funded by the U.S. Department of Education. Visit the site to find extensive information on deaf-blindness and keep up with current initiatives.

- NCDB Library (nationaldb.org/library)
  A large collection of online resources on all aspects of deaf-blindness, organized by topic. Some of the resources are aimed at families; others at professionals or researchers.

- Recursos En Español (nationaldb.org/pages/show/recursos-en-espanol)
  Many of the resources from the NCDB Library 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)
  Page with resources especially for families, including the new Families Matter video series (a new video story will be posted every few months, each featuring a different family).

- Families Lead (familieslead.org)
  A tool to train family leaders, which includes personal stories and a wealth of resources on all aspects of leadership.

- Facebook (www.facebook.com/nationaldb)
  Follow NCDB on Facebook! We post news stories, interesting resources, and a weekly literacy tip (Tuesdays), personnel highlight (Wednesdays), and family fun fact (Fridays).

National Family Association for Deaf-Blind (nfadb.org)

A nonprofit organization empowering families to advocate for individuals who are deaf-blind. Connects families through Facebook, webinars (in English and Spanish), a toll-free number, and a semiannual online course on the role of interveners in educational settings.

Perkins eLearning (www.perkinselearning.org)

Videos, webinars, online courses, and other resources designed to provide professional development to teachers of children with visual impairments or multiple disabilities. A lot of the content is also useful for parents, especially the following microsites:

- Activity Bank (www.perkinselearning.org/activity-bank): Ideas for fun and educational activities to do with your child, from texture matching to creating a solar oven.

- Paths to Literacy (www.pathstoliteracy.org): Strategies and resources for teaching literacy.

- Paths to Transition (www.perkinselearning.org/transition): Information about how to prepare your child for adulthood, including work and independent living.

- Paths to Technology (www.perkinselearning.org/technology): Information for parents, educators, and students about assistive technology in educational settings.

Usher Syndrome Coalition (www.usher-syndrome.org)

An advocacy and support organization where you can connect with other families, find information on the latest research and legislation, read blog posts, sign up for the newsletter, and join advocacy efforts.

WonderBaby (www.wonderbaby.org)

An excellent site for parents of young children with visual impairments or multiple disabilities. It's made up of articles and blog posts written by parents on a wide range of topics and includes many tips and activities. It also has a section where parents can ask and answer questions.

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IDEAs that Work
Office of Special Education Programs

The contents of this newsletter were developed under a grant from the Pennsylvania Department of Education (PDE). However, the contents do not necessarily represent the policy of PDE, and you should not assume endorsement by the federal government.

OSEP Project Advisor: Susan Weigert

Grant# H325T130083

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