



Special Symposium Edition

Fall 2012

National Family Association For Deaf-Blind

NFADB exists to empower the voices of families of individuals who are deaf-blind and to advocate for their unique needs.



NFADB Symposium

Preparing Leaders for Today and Tomorrow: Family Leadership in the 21st Century



It was hot and balmy in Austin during the NFADB Symposium this past July. But that didn't stop the family leaders, NFADB Board members and the collaborative partners that gathered together to attend "Preparing Leaders for Today and Tomorrow: Family Leadership in the 21st Century". The symposium was held in Austin, on the campus of Texas School for the Blind and Visually Impaired.

There was a sense of camaraderie and respect between all who attended. The genuine sense of wanting to learn and to share was unbelievable. Resources and information presented were of high quality and the presenters were outstanding. Everyone left the symposium wanting to personalize the missions and goals and make an impact in their own communities. This is what you can expect when a great group of individuals who are deaf-blind, their families, and people who work with persons who are Deaf-Blind come together. We all left feeling inspired and rejuvenated! In the years to come, NFADB will continue our efforts to provide opportunities for sharing knowledge, community, and collaboration. A webinar is in the future.

As your new president, along with the NFADB board members, we look forward to working with you on our mission to empower the voices of families of individuals who are deaf-blind and to advocate for their unique needs.

Welcome to all of the new members and to those of you who have been continuing members of our common cause, thank you for all of your work.

~ Elisa

Elisa Sánchez Wilkinson
President
National Family Association for Deaf-Blind



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THE NATIONAL FAMILY ASSOCIATION FOR DEAF-BLIND (NFADB)

SUPPORTING PERSONS WHO ARE DEAF-BLIND AND THEIR FAMILIES. A non-profit national family organization established in 1994. The philosophy of the Association is that "Individuals who are deaf-blind are valued members of society and are entitled to the same opportunities and choices as other members of the community."

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Sending a Special Thank You

to all of our Symposium speakers and presenters. Your passion and knowledge for your subject was apparent and made the symposium an invaluable learning experience for all.

Thank You....

Tracy Inman (FL)
Kim Powers-Smith (TX)
Melanie Knapp (TX)
Vivecca Hartman (TX)
Beth Mount (NY)
Linda Alsop (UT)
Sally Prouty (MN)
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Amy Parker (OR)

*"Alone we can do so little,
together we can do so much."*

Helen Keller

A Big Thanks to our Collaborative Partners

This Symposium would not have taken place without the generous help of our collaborating partners. Your support was, and always will be, invaluable to NFADB.

Thank You....

Perkins School for the Blind
National Consortium on Deaf-Blindness (NCDB)
Helen Keller National Center (HKNC)
Texas School for the Blind and
Visually Impaired

Connecting with Families at the Symposium by Cyndie Pfolher

I would like to share my experience attending the 2012 National Family Association for Deaf-Blind (NFADB) Symposium "Preparing Leaders for Today and Tomorrow: Family Leadership in the 21st Century". It was an amazing conference listening to deaf-blind presenters' talk about interveners, interpreters, and Support Service Providers (SSP) and how important it is to have these services in place for individuals with deaf-blindness.

It was moving to hear families sharing stories about their deaf-blind children and individuals that were also deaf-blind sharing how these interventions positively impacted their lives. I had many opportunities during this symposium to connect with families that have children that are deaf-blind and to share experiences with one another. I really got excited to meet other families that also had children with CHARGE Syndrome.

My son, Joshua is eleven years old, has CHARGE Syndrome, and is deaf-blind. Josh currently has a teaching assistant that works with him 1:1 at school and has taken the intervener online courses through Utah State University. Josh's communication has improved greatly and his negative behaviors have decreased tremendously at school having his 1:1 trained in deaf-blindness. Although Josh has an intervener, that title is not recognized by New York State and by many other states in the educational system, so that position (Intervener) cannot be written on his IEP and its being classified as 1:1 educational support. This type of classification needs to change in the near future so that it is not such a struggle for families to include the word "interveners" in their children's IEP to obtain the needed support and services by a specially trained professional on deaf-blindness.



At the NFADB Symposium, parents were encouraged to educate others about these important and needed services and to get involved in local, state, and national committees/special education advisory panels to have these services recognized and offered to all individuals with deaf-blindness. I felt so empowered with the support of other families and professionals that I feel now it is the time to strongly advocate for these positions to be included in the law for the benefit of children and individuals who are deaf-blind. Our voices will be louder if we work together in each state to make

this happen! I plan to do all that I can to be a voice for my child and other children who are deaf-blind so critical supports such as having Interveners are in place to help our children be successful and live a life full of enriching opportunities.

-What Leadership Means to Me-

"Parents Have the Power"

The Mary O'Donnell Social

In 1996, the deaf-blind community lost a very special person in the passing of Mary Margaret O'Donnell. Mary's "career" in deaf-blindness spanned more than thirty years during which she was a driving force in the creation of the New Jersey Association for the Deaf-Blind, served on numerous advisory committees at the state and national level and helped found the National Family Association for Deaf Blind (NFADB). In 1992, Mary was awarded the prestigious Anne Sullivan Medal at the National Conference on Deaf-Blindness, the first parent to receive this award. At the time of her death, Mary was serving as president of NFADB.



A private, understated person who shunned the spot light and preferred working behind the scenes, she somehow always seemed to end up in a leadership position. For those lucky enough to have known her personally, it was easy to see why. She possessed a wealth of knowledge but never tried to impress others with it—she simply offered them her support and counsel. She had an inner strength and tenacity that enabled her to stay focused, even in times of great confusion. She was a great listener who was open to differing points of view and never failed to recognize the contributions of others. Mary was a lovely, thoughtful lady who carried herself with class and dignity in all she did. She is greatly missed. *(Excerpted from the September 1996, Deaf-Blind Perspectives)*

On Saturday night, all of the Symposium participants enjoyed spending time together at the Mary O'Donnell Social. This is an opportunity for networking and support in



a fun and relaxed setting. Our thanks go out to Mary's family, who has graciously donated to support this social since the late 1990s. She will forever be remembered and be an inspiration to the deaf-blind community.



During the social, NFADB had the pleasure of recognizing another great friend and leader in the field of deaf-blindness. Steve Perreault has dedicated much of his career to supporting families in the United States and around the globe. Thanks, Steve, for your belief in and commitment to families!

A Dynamo Texas Family Leader Shares Her Symposium Experience

The NFADB Conference this summer was a wonderful opportunity to join with other families across the nation! We got to say hello and put faces with names we have seen in emails and rekindle relations made long ago. It was such a reassuring atmosphere of belonging and being part of a bigger group ~ THANK YOU NFADB!

I was also excited to participate in the opportunity to help motivate other families with our personal family journey that led us to be so driven in the Intervener movement. I cannot reiterate enough, how our lives improved after learning from having a well-trained Intervener stay in our home for a few months and teach us and set-up routines that we have kept in place over 5 years later!

Quite honestly, having chosen the path to stick with staying in our local school district has been good for our family and we have benefited from our districts realization that a stronger commitment to deaf-blind training was needed. I did not get to expand on this during the presentation due to time restraints, but as I did open my story with, I am extremely grateful to the Texas Deaf-blind Outreach Project for being a lifeline for us over the years! This is the state's Deaf-Blind Project offering technical assistance and outreach to individuals with deaf-blindness and their families. We also had successful state level advocacy through my involvement with DBMAT, my state family organization. So when my district was ready to make a stronger commitment, the Outreach Team were there and ready to offer more help and support to our educational team! As some of you know now, at age 15, things are going very well at school for Christopher ~ Thank you Outreach for getting us where we are!

I want all families that could benefit from a well-trained Intervener to have the same opportunities early on in their child's life!



At the NFADB Conference there was a break-out session where the choices were: School District Level, State Level and National Level Advocacy learning sessions, and Adult Services. Having had successful opportunities thus far on the school district and state levels in my child's 15 years of life, I chose to attend the National level session. It was so informative. As with anything, you have to start with the basics. You have to learn the set-up and foundation of a system before you can start planning a strategy to help educate yourself as well as others about how to effect a change in a positive and diplomatic manner. I learned so much and yet, it was a seed to help me realize how much more I have to learn! Fortunately, they gave many resource ideas of places to find more information.

Shortly after the NFADB Conference, NCDB announced their plan to start collecting information in planning the development of a national Intervener college level curriculum! I look forward to helping in any way possible and to the future when our nation has this readily available to all!

I am so excited about the National plans, which NFADB has the opportunity to support! This can only help us all by making more information and training opportunities available to, not only the families, but the professionals that work with our loved ones as well!

NFADB – You Rock in keeping us all connected for the betterment of our National Deaf Blind Community!
I look forward to a gathering of celebrations of our stories and successes someday soon!

Vivecca Hartman

My Experiences: The Good, The Bad, And the Ways of Interpreters by Quinn Burch

(Quinn was a presenter at the Symposium. She inspired the participants with her personal experiences. The following is her presentation printed with her permission.)

Due to the fact that I have been deaf-blind since a very young age, I have grown accustomed to developing and maintaining close relationships with interpreters. They have become a significant part of my educational career. I'm going to share my experiences with you, the good and the bad experiences I've had with interpreters and the qualities in interpreters which have helped me the most in my academic career up to the present.

The most important thing for me, of course, is that an interpreter ALWAYS, ALWAYS, ALWAYS has on BLACK or if not black, a really dark color top/jacket. It also helps me if it is a modest cut, NOT low cut, or if the interpreter is wearing a dark colored scarf. When there is too much light skin, this gets in the way of the solid dark color background, which hampers my seeing their hands, and therefore their signing.

Due to lack of vision, I cannot see far, so I need an interpreter to be VERY close. A good interpreter friend of mine has joked: "You want me on your lap??" That's how close I need the interpreter to be. It may not be comfortable for some, but it's what it has to be. I do use some tactile sign, but I'm not proficient and have a hard time reading tactile signing. My vision requires that an interpreter keep their signing in an exact location so I can see their hands, which is about chin height and also does not impede my seeing the movement of their mouth, preferably higher up in front of the upper body but not too high, I need the background of the dark colored clothes to be able to see the signing. Without good contrast I have a hard time seeing the hands which is my way of getting the information I need.



I grew up in a hearing culture signing mostly Signed Exact English, this is what we signed at home. At school it was Contact Signing or more Pigin this is a form of sign that is a little of ASL but more in the English word order form, so I'm unfamiliar with the language of the deaf as in pure ASL. Some interpreters are so used to interpreting in ASL; I'm a tough client because I need them to interpret in SIGNED EXACT ENGLISH. I'm also very different from most deaf clients because I know most interpreters are used to translating ASL to English when voicing something for a deaf person. When interpreters voice for me for the first time without knowing anything about me beforehand they are often caught off guard because I do not sign OR think in ASL. I use many expressions and idioms that most deaf people are not familiar or comfortable with, such as "in one ear, out the other". Because I'm the only deaf person in my family, went to public schools, and was mainstreamed, I haven't been exposed to much ASL at all. I am an avid reader, and that helps to contribute to my "thinking like a hearing person" as an interpreter friend of mine puts it. I'm not trying to be boastful; it's true for everyone who is a strong reader: strong readers have strong minds, and are usually very good writers too. .

I've had some bad experiences with interpreters refusing or being unable to switch from ASL to English when interpreting for me, or in some other way being unable to conform their style to my needs. For example there is one interpreter at a

camp for blind young athletes which I coach at. She's a nice woman, but she persisted in slouching when she interpreted, so it seems as though she is interpreting for her lap. I tried a few times to ask her to straighten up so I could see her hands, but to no avail.

Another woman I had in college persisted in using ASL, however, I continued to ask her to sign in English. She used certain ASL signs which are especially hard for me to see. Another interpreter friend tried to help me out and explain my problems to this woman, but she continued to sign her way.

I know this isn't something interpreters can help sometimes, but physical stature plays a major role in my ability to work well with an interpreter. I work better with a person who is slim because that way we can sit closer together and this helps me to see their hands easier. Also height matters. I have one interpreter at school who is REALLY short, and I was a little nervous when I found out she would be interpreting a walking tour of a college for me. I would have a hard time seeing her sign because I would have to look down to see her hands. I work better with a person who's my height or taller, at least if we have to be standing.

From the time I was in kindergarten, up to my high school graduation in 2009 I had the same interpreter. She was more than just an interpreter, though. She was a mix of interpreter, aide, mentor, and friend. She interpreted my classes, but she also did other things to help me, such as making sure I had my work in Braille or in another accessible format. In math classes she wrote the problems on a whiteboard for me because I couldn't see the blackboard the teacher was writing on. She was always there for me, if I needed anything. If I didn't know where to go I knew I was always welcome in her office. We even hung out outside of school, going on trips, such as shopping, I stayed with her when my parents were in Boston for several weeks when Dad was getting treatment for his cancer. She's one of my biggest advocates, and I'd say she's a surrogate mother, we end our text messaging conversations the same way my MOM and I do! Simple: xoxoxox.

The sad thing is, once I graduated from high school my golden years with Mrs. Masick had to end. I REALLY wanted her to go to college and interpret for me there, but she's not a college interpreter. So my time with Mrs. Masick had to end. I was SO scared. I'd been depending on her for a lot for the longest time, and I didn't know what I would do without her. It HAS been hard without her. The director of the students with disabilities office at my college does not know how to do her job, and always has a bee in her bonnet. I really believe I would have had a far less stressful and far smoother college career so far if Pam Masick Lane were still with me, or at least if she took a new job as the director of academic support at St. Rose!!! That's where I'm at school now.

So now it's a new arrangement. The college uses independent interpreter services. The college and my commission of the Blind share the price for the interpreting services. Standard procedure, if I need an interpreter, is to email the head of the office for students with disabilities, and she contacts the head of the interpreter agencies so that interpreters can be booked for the time I requested. My first two years of school I was working with an interpreting agency headed by a woman who was strict and unfriendly, and often did not listen to what I had to say. She was coldly professional about rules, procedures, and what not. I was very unhappy because she didn't make an effort to schedule my preferred interpreters, and I was missing a lot of information because I didn't work well with most of the people she booked for me. I launched a campaign to switch to a different agency. I worked with this agency a little back then, but only for services that were not academic. I finally succeeded in getting the powers above to listen to me, and we got the switch. I've been a LOT happier since then. The head of the new agency I work with is the complete opposite of the first head I worked with. She's SO friendly, energetic, bubbly, and chatty. She is willing to listen to what I have to say and listen to my suggestions: she always loves my feedback and advice. Most important, she makes an effort to see if my preferred interpreters are available to book them to work with me, and not booking new people I've never met before unless it's a last resort, and checking to make sure the arrangement is to my satisfaction. She's awesome. Thanks to her, I've been working with my favorite interpreters a lot more in the past couple years and am much happier.

Exciting news from The National Consortium on Deaf-Blindness

Greetings Family Leaders-

We would like to invite you to a national web meeting focused on developing free, nationally available, intervener training modules.

Why: To invite your participation as a team member in creating high quality, open access (free for all to use), intervener training modules

When: September 13th at 4 PST---5 MST---6 CST---7 EST

How: The meeting will include a conference call and an online portion; however, the online portion is not mandatory to participate.

Duration: 90 minutes

Log-In Information:

- 1) Connect your browser to: <http://hknc.adobeconnect.com/interveners-2>
- 2) Type, your name, log in as a guest and enter.
- 3) Once inside the room, you will be prompted to enter the phone number where you would like to be called. You will receive a phone call shortly thereafter. This is the best way to join the audio portion of the call.
- 4) Please note, however, that if you are at a phone extension, or the prompt does not display, you will need to dial in to the webinar at 1-888-757-2790 and when prompted enter the Participant Code of 810131.

As many of you know, the National Consortium on Deaf-Blindness (NCDB) has just released *Recommendations for Improving Intervener Services*, available at www.interveners.nationaldb.org. Many of you completed the family survey or participated in the family member panels that contributed to these recommendations. Thank you for sharing your feedback in this process! These recommendations were developed in response to a direct request from the Department of Education's Office of Special Education Programs (OSEP).

We are now working with OSEP to identify strategies to support our deaf-blind network -- all of us -- including parent partners; state deaf-blind projects; university faculty; teachers and interveners, to work together in moving forward with the recommendations. In particular, we are moving forward with the recommendation to facilitate a team, made up of our network members, to create open access national training modules to help states prepare and train interveners.

The content of the modules will be largely based on existing intervener training resources. We are already working with several members in our community, including Linda Alsop, Alana Zambone and a number of state deaf-blind projects, to identify the best ways to organize and move forward with this work. Because no open-access curriculum/intervener modules currently exist, creating a high quality resource will meet the needs of states that have had no access to interveners or adequate training resources. The modules may also be used by existing training programs as a training component or resource for students. All of the modules will be transcribed into Spanish and all videos will have captioning and video description to be accessible to all individuals who would like to use the modules. In addition to the modules, the team will develop a companion guide that explains how the modules and materials should be used to ensure that high quality training occurs for interveners.

Here's where you fit in! We would like to invite you to participate in this national web-meeting for family leaders to learn

National Family Association for Deaf-Blind

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Supporting Persons Who are
Deaf-Blind And Their Families

This newsletter supports “person first” language. All submitted articles will be edited accordingly. This publication is supported in part by the Helen Keller National Center, Sands Point, NY, and the Hilton/Perkins Program of Perkins School for the Blind, Watertown, MA. The Hilton/Perkins Program is funded by a grant from the Conrad N. Hilton Foundation of Reno, Nevada. Opinions expressed in the newsletter do not necessarily reflect the opinions of NFADB, HKNC or Hilton/Perkins. Newsletter is available in braille, large print or electronically upon request. NFADB exists to empower the voices of families of individuals who are deaf-blind and advocate for their unique needs.



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about and discuss the module development process, to help us think about how to best organize this effort, and how you could become involved in creating this much-needed resource. Not everyone may be able to commit to a high level of involvement and that's okay. Some may want to work on content development with other team members. Some may want to serve on an advisory committee. Some may want to contribute ideas more generally. And some may want to help find high quality video clips of interveners and students. Others may just want to be aware of the activities to share information with others. All of the above are fine options. You may come up with other ideas of how to contribute as well (theme music, graphics, or ideas we have not thought about).

Please let us know that you are joining this meeting by clicking the link and registering.

Link to register: <http://www.surveymoz.com/s3/1003655/Family-Leader-Intervener-Module-Workgroup>

Thank you and we look forward to your participation on September 13th.

Sincerely-

NCDB Team

Nuts & Bolts: Symposium Demographics

Total Number of Participants: 77

Number of Family Leaders: 51

Number of Self-Advocates: 4

Number of States Represented (Family Leaders only): 24
states, Puerto Rico & Washington DC



Annual PPDB Helen Keller Award Presented To Mr. Gordon Boe

The Pennsylvania Partnership for the Deafblind (PPDB), an organized network of parents, family members, and individuals with deafblindness, has awarded the 2011 Annual PPDB Helen Keller Award to Gordon Boe, Past President and current Board member of the PPDB. The Helen Keller Award is given in recognition of contributions made to the deafblind community.

Gordon and his wife Mary, live in North Wales, PA. They are raising their deafblind granddaughter, Brittany. Their work with Brittany led Gordon to recognize the need for a parent-led organization that could support family members as they struggle to cope with the daily challenges of life with a child who is deafblind. In 2007, he led the founding group that created PPDB. He served as its first President until 2011. During his term, Mr. Boe obtained the organization's 501(c)3 status and was involved in establishing PPDB as the first state affiliate to the National Family Association for Deaf-Blind (NFA DB). He also successfully applied for over \$15,000 in grants from the Commonwealth of Pennsylvania.

Gordon is the primary author of "Hop Scotch Your Way through Transition," a guide developed by PPDB that provides assistance to parents and families of children with deafblindness in developing an organized approach to transitioning their children from school to the adult world.



Pennsylvania Partnership for the Deafblind is a private, non-profit organization, which exists to provide support for individuals with deafblindness and their families through a family-driven network. If you would like more information regarding PPDB, or are interested in joining us, please contact Susan Shaffer, PPDB President, shaffers@dickinson.edu, or visit the PPDB website at www.papdb.org

Intervener Information by Susan Morgan Morrow

Dear Friends & Colleagues, I am writing to you from the perspective of the state deaf-blind technical assistance (TA) projects (federally funded grants serving the needs of children with combined hearing and vision loss between the ages of 0-21) to request input on a critical topic. Some of you on these respective listservs may be familiar with the term 'intervener' while many others are not. Allow me to explain..

As defined on the intervener website: www.intervener.org:

An Intervener is a person who:

Works consistently one-to-one with an individual who is deafblind

Has training and specialized skills in deafblindness

An intervener provides a bridge to the world for the student who is deafblind. The intervener helps the student gather information, learn concepts and skills, develop communication and language, and establish relationships that lead to greater independence. The intervener is a support person who does with, not for the student. Specialized training is needed to become an effective intervener. Training should address a wide range of topics necessary to understanding the nature and impact of deafblindness, the role of the intervener, and appropriate educational strategies to work with students with combined vision and hearing loss (Alsop, Killoran, Robinson, Durkel, & Prouty, 2004; McGinnes, 1986; Robinson et al., 2000).

An intervener is not a traditionally known paraprofessional or one-to-one aide.

Those respective roles do not possess the necessary knowledge and skills specific to the learning and developmental needs of children and young adults who are deaf-blind.

An intervener is not an interpreter.

An educational interpreter is as a facilitator of communication/information between hearing and deaf/deaf-blind individuals. That role

has been more clearly defined with more specific boundaries (see http://www.rid.org/UserFiles/File/pdfs/Standard_Practice_Papers/K-12_Ed_SPP.pdf).

An intervener is not a Support Service Provider (SSP).

An SSP functions specifically outside of the educational environment, making linkages within the community and vocational environments, outside the arena of K-12 (see <http://aadb.org/information/ssp/ssp.html>).

The role of an intervener has gained great momentum and national recognition within the last 10 years, more specifically within the last 2-3, obtaining national recognition and credentialing through the National Resource Center for Paraprofessionals and Related Service Providers (NRCP). With professional recognition comes the need for sign language vocabulary that conceptually and accurately reflects this unique role. It is critical that such a sign is created in a unified manner with broad and thoughtful input.

Signs currently being used

There are four signs that have been seen most consistently throughout various parts of the country

1. 'IV' in the open palm of the supporting hand (similar to the sign of 'help')
2. 'IV' in between the thumb and pointer finger on the top of the supporting hand (related in some way to 'intervention' or 'interruption')
3. # 1 handshapes, facing each other, palms in, moving from side to side (indicating equal partners, working one-on-one, swaying movement)

1 handshapes, supporting hand in front, dominant hand slightly behind, pushing slightly forward (similar to the sign for 'mentor', with the learner in front with support), then hands drop down to the closed '5' handshape indicating person (such as the ending for 'teach-er').

For those of us who are signers, many would agree that the first two are less respectful and do not capture the full philosophical and theoretical meaning of the role. The third sign, while more respectful, may not accurately define the role and cause confusion of the meaning. The last sign choice (similar to 'mentor') is respectful and is probably being used more frequently but, too, may fall short of accurately representing the full role of an intervener.

What is of highest desire is direct input from deaf-blind individuals themselves, particularly, deaf-blind students who have had direct experiences working with interveners. Unfortunately, many of the students who benefit from the services of an intervener have not or may never acquire language fluency that would allow direct expression to this degree. Of equal desire, is input from deaf-blind adults, however, it is not to be confused with the role of a Support Service Provider (SSP), as this is a role unique to that within the K-12 educational environment.

Professionals on these listservs who are hearing/sighted are welcome to provide input and perspective but, again, it is of most desire to hear directly from individuals who are deaf-blind and others who are native signers. If you know of students/young adults who have benefitted from the services of an intervener please forward this request to them. TA providers of the state projects are anything but respectful of the needs and wishes of children and young adults who are deaf-blind and their families, thus needing direction from the field and communities that we serve. This is where the field, as a whole, needs your input.

Thank you, for your time and thoughtful consideration. *Susie*

Susanne Morgan Morrow, MA, CI, CT - Project Coordinator

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Phone: 718.997.4854



Bookshare Online Library – FREE Digital Books and Reading Technologies

Many parents and educators are unaware of Bookshare, a nonprofit online library offering a vast collection of accessible ‘digital’ books for individuals with print disabilities, including students who are blind and Deaf-Blind. Bookshare’s digital formats and free reading technologies can make all the difference in long-term independence for a child at school and at home. Using the library, children who are Deaf-Blind can get their reading assignments on time, attend more general education classes and enjoy more meaningful reading and learning opportunities.

Bookshare is free for U.S. students of all ages who are blind, have low vision, a severe reading/learning disability, or a physical disability. The library is funded through awards from the U.S. Department of Education, Office of Special Education Programs. Memberships enable students and educators to download digital books for school work and recreational reading. The collection includes over 150,000 titles in K-12 and postsecondary textbooks, children’s literature, reference information, bestsellers, and periodicals and newspapers. In addition to English, there are books in Spanish, Arabic, and other languages.

Bookshare has a dedicated collection of Deaf and Deaf-Blind (DB) titles that’s growing. Teen and transition-aged Deaf-Blind students can learn about their culture and history in many books about deaf-blindness that are currently out of print. The easiest way to see the combined Deaf and Deaf-Blind collection is to go to the Bookshare [home page](http://www.bookshare.org), (www.bookshare.org), tab to “Advanced Search,” and enter the word “deaf” in the “synopsis” field. You don’t have to be a member to use the search functions or to download public domain books from Bookshare.

*FREE Membership Options

Schools and organizations can sign up students who qualify or parents can sign up their child with proof of disability directly for one or both of these two types of memberships at no cost:

Organizational membership – Any U.S. public school who serves children with qualified print disabilities may obtain a free organizational membership to Bookshare. Having your child on a school membership is necessary so that teachers can download K-12 ([NIMAC](#)) textbooks for your child. Schools may sign up as many teachers or sponsors as required to download books on behalf of students. With this type of membership, a qualified professional in the school or district certifies that a student is eligible.

Individual membership – You’ll want to sign your child up for an individual membership in addition to having your child on the school’s membership. An individual membership establishes a habit for lifelong learning and reading. With an individual membership, students download as many books as they want on any and all subjects of interest. This extends their learning and the ability to read books for pleasure. Individuals wanting to sign up submit a proof disability signed by a qualified professional, such as special education teacher, assistive technology specialist, physical therapist, speech and language teacher, occupational therapist, medical doctor, and more.

Reading Technologies

Members can download titles in digital text, audio, and digital braille formats. There are two free reading technologies that offer text-to-speech for hearing books read aloud or seeing large print on a computer screen. You can learn more about Bookshare's free reading tools at <http://www.bookshare.org/readingTools>.

Braille readers can download books directly to some braille displays to read with refreshable braille or transfer books to a braille display from a computer. In this [video](#), an Alabama student demonstrates reading with his braille display. Depending on the device used, two audio formats, mp3 and DAISY audio, read books aloud and offer another option for reading. The digital text format can be used to generate hard copy large print.

This year, Bookshare also introduced two 'on-the-go' reading apps for visually impaired readers:

Read2Go for iOS devices has a wide range of font sizes and colors for reading in large print. It offers two built-in voices for reading books, as well as the voice that comes with the device. It works with or without Apple's accessibility software called VoiceOver. It can connect to braille displays via Bluetooth – a favorite option of one deaf-blind member. Read2Go is available in the Apple iTunes Store for \$19.99.

Go Read, a free Android app, also offers text-to-speech using whatever voices are available on the device. It is optimized for readers with visual impairments.

When selecting assistive technology software or a device for reading, parents should research the options and talk with teachers and specialists to select the right device that works best for a child's needs.

Knocking down barriers for students

Sabrina (in photo with her parents) developed an eye condition and has physical limitations that affect her ability to read print materials. To accommodate her needs, her school provides a laptop equipped with the Bookshare free reading technology, Victor Reader Soft Bookshare Edition. Sabrina uses switches to start, stop and pause digital text; now she can keep pace with her reading assignments. Her father said, "Bookshare and a computer opened up a new world for my daughter. She had limited access to books, but now can read on her own and turn pages forward and backward with a switch. She can also review text she doesn't understand through the text-to-speech. This is a big benefit."



Krystian (in photo with his teachers and aides) is legally blind. He is learning to use a Braille Note so he can read more digital books without having to carry heavy braille volumes. "I am discovering new adventures in reading," he said when asked about Bookshare.

Bookshare's goal is to break down barriers to reading access and bring reading to life for students who cannot read standard print. Now in its 10th year (2012), Bookshare serves over 200,000 U.S. students and the schools who serve them. In 2011, attendees at the 2011 [American Association of Deaf-Blind symposium](#) learned about the benefits of Bookshare and through this article, we hope that NFADB families will too!

Visit us at www.bookshare.org



New Federal Program Set to Distribute Communications Technology to People With Vision and Hearing Loss

*Perkins School for the Blind, Helen Keller National Center, and FableVision
Will Lead the **iCanConnect** Campaign*

Watertown, MA – Many thousands of Americans who have combined loss of hearing and vision may soon connect with family, friends, and community thanks to the National Deaf-Blind Equipment Distribution Program. Mandated by the 21st Century Communications and Video Accessibility Act (CVAA), the Federal Communications Commission (FCC) established this new program to provide support for the local distribution of a wide array of accessible communications technology.

The FCC is also funding a national outreach campaign to educate the public about this new program. The iCanConnect campaign will be conducted jointly by Perkins School for the Blind, Watertown, MA, the Helen Keller National Center in New York City, NY, and FableVision of Boston, MA. iCanConnect will seek to ensure that everyone knows about the free communications technology and training that is now available to low-income individuals with combined hearing and vision loss. From screen enlargement software and video phones, to off-the shelf products that are accessible or adaptable, this technology can vastly improve their quality of life.

iCanConnect seeks to educate people about the availability of communications technology for this underserved population so they can remain safe and healthy, hold a job, manage a household, and contribute to the economy and the community.

As of August 7, 2012, information about the new equipment distribution program will be available online at www.iCanConnect.org or by phone at **1-800-825-4595**. Additional information is available through the FCC at <http://www.fcc.gov/encyclopedia/national-deaf-blind-equipment-distribution-program>.

“With the right technology, people with disabilities can link to information and ideas, be productive, and move ahead,” said Steven Rothstein, President of Perkins. “Perkins’ most famous student, Helen Keller, exemplified the potential of a person who is deaf-blind. We are proud to have a role in this transformational program.”

The CVAA, championed in Washington, DC, by Congressman Edward J. Markey of Massachusetts and Senator Mark Pryor of Arkansas, acknowledges that advances in technology can revolutionize lives. Nearly one million people in the United States have some combination of vision and hearing loss. Persons with combined loss of vision and hearing as defined by the Helen Keller National Center Act whose income does not exceed 400 percent of the Federal Poverty Guidelines are eligible to participate in the new program.

“The mission of the Helen Keller National Center is to enable each person who is deaf-blind to live and work in his or her community of choice,” explains Executive Director Joe McNulty, adding, “This critical technology access program accelerates those efforts, but only if people know about the resources. iCanConnect is poised to get the word out, coast to coast.”



“One of the marvelous things about community is that it enables us to welcome and help people in a way we couldn’t as individuals. When we pool our strength and share the work and responsibility, we can welcome many people, even those in deep distress, and perhaps help them find self-confidence and inner healing.” — Jean Vanier, Community And Growth

NFADB thanks all the families that have joined this association and those that continue to support, contribute, and inspire those around them. Below you will find information regarding membership. To continue to receive up to date information regarding legislative issues, medical information, notices of upcoming events, families sharing information, and more, your membership needs to be current. NFADB is an outstanding association. Being a member brings each of us a sense of pride and satisfaction to know that we are working together to help our family members with deaf-blindness achieve success in their lives. Please share this with family and friends. **THANK YOU!**

SUPPORT NFADB!

MEMBERSHIP: For any person/family who has an interest in deaf-blindness. All memberships include all family members living in one household.

- ☐ One Year: \$15
- ☐ Three Year: \$35
- ☐ Lifetime: \$100

(*U.S. FUNDS ONLY)

Members are eligible to serve on the NFADB Board of Directors, within the limits of the organization’s by-laws.

All members automatically receive our NFADB newsletter which is also available by request in BRAILLE, LARGE PRINT or electronically. Indicate your preference on the application.

CONTRIBUTING SPONSORS: For those interested in pledging your support through monetary or other gifts of value to the Association.

Your Contribution: \$_____

We are on the Web:
www.nfadb.org

And Facebook too!

Name: _____
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Information about person who is deaf-blind

Name: _____
Birth date: _____
Relationship to you: _____
Cause of deaf-blindness: _____

I give permission to share my name with other families whose children have similar etiologies or disabilities.

☐ Yes ☐ No

Please return with check or money order payable to: "NFADB" at:

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