# **Dually Noted**

# News from the Pennsylvania Deaf-Blind Project



# Families Create *One-Page Descriptions* for Their Children at the Annual Family Learning Conference

The PaTTAN Pennsylvania Deaf-Blind Initiative hosted its annual Family Learning Conference (FLC) June 27-28, 2014, in Hershey, Pennsylvania. The Deaf-Blind Initiative welcomed 31 families to the Deaf-Blind Family Learning Conference. This year's conference theme, "Set the PATH Chocolate Style," featured sessions and networking opportunities that provided families with strategies to address the impact of deaf-blindness on their child and family.

The guest speakers of the conference were Melissa Mecke and Christy King from the Office of Developmental Programs Consulting System. Their session focused on Person Centered Practices, and each family was engaged in creating a *One-Page Description* for their child with deaf-blindness.

One-Page Descriptions consist of person-centered information focused on three areas – an appreciation for the child as an individual, what is important to the child, and how to support the child. A One-Page Descriptions are typically used in three ways:

 To share information about someone, for example in new situations or meeting new people, or at the beginning of the person's records

Continued on page 2

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...

- Intervener Services in Educational Settings
- Open Hands Open Access Intervener Learning Module Training
- NCDB Family Engagement Update
- PPDB Helen Keller Awards





### Families Create One-Page Descriptions continued

- As the beginning of a more detailed, person-centered description
- As the basis for action

Prior to the end of the summer, two families had already used the *One-Page Description* tool and found it to be very helpful for their children. Thomas's family shared his *One-Page Description* with medical and teaching staff when he was transitioning out of the early intervention (EI) to a new pre-school environment—

We just wanted to let all of you know that we went home after the F.L.C. in June and developed a One-Page Description for our son. So far, we've given it to his education team members, a few of his doctors and even some new friends we've made! All of them have expressed their appreciation for the "little introduction to Thomas," as one of them called it. No one knows our children as well as we do, so using this great tool helps us to share that knowledge with others who would find it helpful. Using a template, it took us no time at all and was actually pretty fun! We hope you all consider using it too!

- Scott & Shelley Lill

Thomas's One-Page Description is to the right.

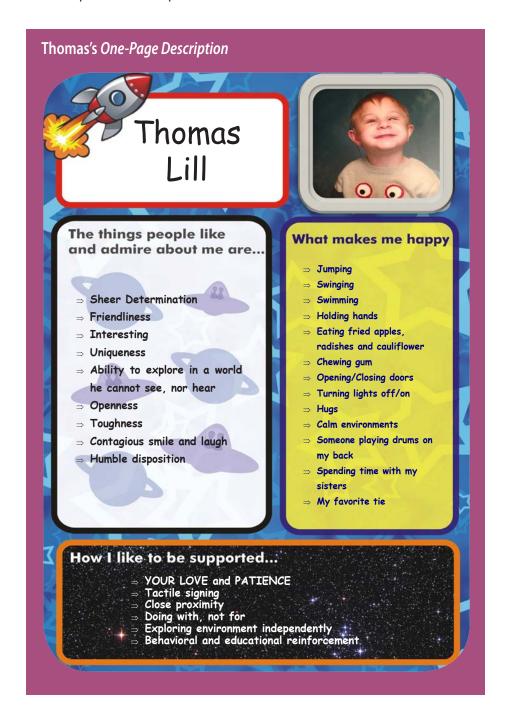
Julia's family shared her *One-Page Description* when she went away to summer camp—

A one-page profile is great resource for teachers, camp staff, caregivers, babysitters and family members. I am so glad we had an opportunity to make one for Julia. After attending the Family Learning Conference this year, we worked together with Julia to create a one page information sheet for her to take when she went to summer camp. Dropping her off with the one page made it so much easier on her mom. Julia had a much better experience at camp this

summer because the camp staff was able to refer to her one page. We also created a one-page profile for her new fifth-grade teachers. Julia is looking forward to a great school year.

- The Murrays

Julia's One-Page Description is on the following page.



Page 2 Fall/Winter 2014

## **Online Parent Training: The Role of Interveners in Educational Settings**

The National Family Association for Deaf-Blind (NFADB) and The National Center on Deaf-Blindness (NCDB) are currently collaborating to sponsor an online family/parent training called The Role of Interveners in Educational Settings. The training uses Module 3, The Role of Interveners in Educational Settings, from the Open Hands Open Access (OHOA) Deaf-Blind Intervener Learning Modules. Family/parent participants learn about the role of interveners, the principles of intervention, and how interveners function as members of a student's educational team.

Together, NFADB and NCDB feel that this endeavor will advance their shared goals of empowering parents and increasing recognition and acceptance of the use of intervener services for students with deaf-blindness.

The Pattan Pennsylvania Deaf-Blind Initiative would like to congratulate the following families from across the Commonwealth of Pennsylvania for their interest and participation in this national online training:

The Brundage Family - Philadelphia

The Burke Family - Doylestown

The Johnson Family - Blandon The Kitterman Family - Bethel Park The McMurtie Family - Centre Hall

If you have any questions or know of other parents in the state who may be interested in participating in this training opportunity in the future, please do not hesitate to contact:

Patti McGowan, NFADB pmgowan@pattan.net or

Peggy Malloy, NCDB malloyp@wou.edu

### Julia's One-Page Description

I *love* to talk to people-especially my peers! Please encourage them to talk to me- please help them understand how to communicate with me!

I may not know you are talking to me if you're not nearby. I'm not being rude, just touch my arm and say my name to get my attention.

I sometimes have trouble hearing in noisy situations. Please be patient with me.

I love to learn new things and appreciate when people take the time to teach me!

I love sports. I can swim, bowl, ski, canoe, rock climb, and play the violin and harmonica for fun. With help I can do almost anything. Please don't assume I can't do something take some time to explain it to me and show me and just see how I do.

### Julia Murray



I can only see about 4-6 feet in front of me. I need some guidance getting from place to place in unfamiliar places or in the outdoors where the terrain is uneven. I have a lot of trouble seeing in bright sunlight, so I might need to be reminded to make sure I have my sun glasses and some extra help.

I should use my iPad camera to help me see what is going on around me or up on stage.

I love to be included in activities.

I like to know what is going on- if possible explain what I can't see.

I can read large print and braille. I know some sign language.

People like me for my personality and my drive to do new or challenging things. I'm a motivator. I love to encourage others to try new things and to do their best.

Page 3 Fall/Winter 2014

## **Intervener Services and Interveners in Educational Settings**



## A message from Jay Gense, director, and Peggy Malloy, coordinator, concerning Intervener Services Definition

We are writing to ask for your assistance in disseminating the attached definition of intervener services in educational settings, as appropriate, and in using it in your day-to-day work with school, families, and others. Using a consistently applied definition is important.

As part of a nationwide needs assessment conducted prior to developing the *Recommendations to Improve Intervener Services* (interveners.nationaldb.org), we found that the lack of a consistently applied definition likely contributes to widespread misunderstanding of intervener services among families and educational personnel who have not previously been exposed to the concept. To address this concern, the attached definition was developed as a result of a) an extensive review of existing publications that described intervener services, b) consultation with numerous stakeholders, and c) a survey disseminated to all state deaf-blind projects to obtain feedback. We believe that this definition represents the best knowledge of intervener services that is available at this point in time.

Please join with us in using and disseminating this definition. Consistent messaging is key to advancing recognition of interveners as a model of individual support. Clear and consistent communication will help us transcend the lack of understanding that exists in the broader field of special education regarding educational strategies that are effective for this population of children.

The definition is also available online https://nationaldb.org/library/page/2266.

Please contact Peggy Malloy, NCDB Intervener Services Team Lead (malloyp@wou.edu; 503-838-8598), with any questions or comments.

Page 4 Fall/Winter 2014



## **Intervener Services and Interveners in Educational Settings**

#### Definition

Interveners, through the provision of intervener services, provide access to information and communication and facilitate the development of social and emotional well-being for children who are deaf-blind. In educational environments<sup>1</sup>, intervener services are provided by an individual, typically a paraeducator, who has received specialized training in deaf-blindness and the process of intervention. An intervener provides consistent one-to-one support to a student who is deaf-blind (age 3 through 21) throughout the instructional day.

Working under the guidance and direction of a student's classroom teacher or another individual responsible for ensuring the implementation of the student's IEP, an intervener's primary roles are to (Alsop, Blaha, & Kloos, 2000):

- provide consistent access to instruction and environmental information that is usually gained by typical students through vision and hearing, but that is unavailable or incomplete to an individual who is deaf-blind;
- provide access to and/or assist in the development and use of receptive and expressive communication skills;
- facilitate the development and maintenance of trusting, interactive relationships that promote social and emotional well-being; and,
- provide support to help a student form relationships with others and increase social connections and participation in activities.

### **Teaming**

An intervener does not work in isolation. Instead, he or she:

- participates as an active member of the student's educational team,
- attends and participates in IEP meetings,
- attends regularly scheduled planning and feedback meetings with the teacher and other team members,
- is actively supervised and supported by the classroom teacher and other professionals responsible for the child's IEP, and
- receives ongoing support from professional educators with expertise in deaf-blindness.

Page 5 Fall/Winter 2014

### **Training**

In the absence of specific state standards to the contrary, training programs should comprehensively model the Council for Exceptional Children's (2009) "Specialization Knowledge and Skill Set for Paraeducators Who Are Interveners for Individuals with Deaf-Blindness." These standards should be used by all programs that train paraeducators to be interveners.

<sup>1</sup> Although this definition focuses on intervener services in educational settings for students ages 3 to 21, it is important to note that interveners also provide services to individuals in early intervention and community settings.

### References

Alsop, L., Blaha, R., & Kloos, E. (2000). *The Intervener in early intervention and educational settings for children and youth with deafblindness*. Monmouth, OR: Western Oregon University, Teaching Research, National Technical Assistance Consortium for Children and Young Adults Who Are Deaf-Blind.

Council for Exceptional Children. (2009). Specialization knowledge and skill set for paraeducators who are interveners for individuals with deaf-blindness. *What every special educator must know: Ethics, standards, and guidelines*, 6th ed., pp. 195-201. Arlington, VA: CEC.

Additional references and information about the process used to develop this definition can be found in the following report:

National Center on Deaf-Blindness. (2013). *Definition of intervener services and interveners in educational settings: Technical report*. Available at http://documents.nationaldb.org/Intervener%20Services%20Definition%20Technical%20Report.pdf

# National Center on Deaf-Blindness (NCDB) Intervener Services Initiative nationaldb.org/pages/show/intervener-services-initiative



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**July 2013** 

Note: This definition was updated with references in November 2013.

Page 6 Fall/Winter 2014

## School Teams "Kick Off" Open Hands Open Access (OHOA) Intervener Module Training

During the summer PaTTAN Low Incidence Conference 2014, the Pennsylvania Deaf-Blind Initiative "kicked off" the Open Hands Open Access Module Training for interveners and educational teams with six teams across the commonwealth. The Open Hands Open Access (OHOA) 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 (ages 3 through 21).

The idea of intervention and interveners with students with deaf-blindness is not new to Pennsylvania. In 2010, the Pennsylvania Deaf-Blind Initiative began team training and direct technical assistance to students with deaf-blindness and their educational teams. This endeavor from our state was recognized by the National Center on Deaf-Blindness (NCDB) as they were preparing to develop the OHOA Modules and including states that supported intervention for their students with deaf-blindness. The development of the modules is in response to Recommendation 3 of the Recommendations to Improve Intervener Services (NCDB, 2012). Recommendation 3 is one of a set of recommendations intended to establish a strong national foundation for intervener training and workplace supports.

The module content was created by a diverse group of experts in the field of deaf-blindness, including state and national deaf-blind project staff, parents of children who are deaf-blind, higher education faculty, teachers, educational interpreters, and interveners. Each module includes a variety

of accessible videos, photographs, slide presentations, and learning activities. The development of the modules was guided by an advisory committee and was reviewed by a variety of experts in deaf-blindness and the process of intervention, experts in module design, and field-test participants.

Pennsylvania was asked to be a part of this network and the development of these modules. Staff members from the PaTTAN Pennsylvania Deaf-Blind Initiative were included in both the advisory committee, as well as the creator/writing teams. A teacher of the visually impaired from Berks County and parents from both central and southwestern Pennsylvania were involved and pleased to be a part of this diverse group in the field of deaf-blindness.

The Pennsylvania Deaf-Blind Initiative agreed to adopt these modules as a tool of learning. The Initiative wanted to include all members of the educational teams on behalf of students with deaf-blindness, as well as share

resources and information specific to the state of Pennsylvania. This included parents on the teams. This innovative approach to the modules, designed specifically as a training tool for individuals functioning as the students' interveners, provided an opportunity for collaborative teaming around students with deaf-blindness where members of the educational teams gain knowledge and skills in providing for the needs of their students. The teams can support each other while supporting the students.

The six teams that began the Open Hands Open Access Intervener training at the Low Incidence Conference ranged from four members to a team of eight members. This included:

- Special Education Directors
- Teachers of the Visually Impaired
- Teachers of the Deaf Hard of Hearing
- Interveners
- Paraprofessionals in the role of Interveners

Continued on page 10



Page 7 Fall/Winter 2014

## **NCDB Family Engagement Update**

Hello Pennsylvania!

A lot has been happening in NCDB's Family Engagement Initiative! For those interested in learning more about these activities, the update that follows will give you a snapshot of what has taken place over the past nine months and what we have planned for the coming months and next year. I would love to hear from you if you have any thoughts to share or questions to ask.

All the best,

Kathy McNulty

# Goals and Objectives of NCDB's Family Engagement Initiative

The overarching goal of NCDB's Family Engagement (FE) Initiative is to improve opportunities for high-quality family engagement and partnerships, including enhanced collaborations with the parent centers.

Anticipated outcomes for this five-year initiative include:

- The Deaf-Blind Network, the parent centers, and national family organizations will develop partnerships with increasing levels of collaboration.
- Parents of children who are deaf-blind will be able to effectively advocate for their child.
- Parent leaders will be able to effectively advocate for all children with deaf-blindness at the local, state, and national levels.

The FE work is guided by three objectives and a series of supporting activities.

### **Objective 1:**

Alignment of efforts between the National Center, State Deaf-Blind Projects, Regional Parent Technical Assistance Centers (RPTAC), state Parent Training and Information Centers (PTI), national parent organizations, and other state-level partners to leverage resources and integrate technical assistance.

Ongoing and/or planned activities to accomplish this objective include:

# Family Engagement Technical Work Group (FE TWG)

A FETWG was formed and held its first meeting on May 28, 2014.
Members of the FETWG are:

Diana Autin, Director, R1PTAC

Jan Serak, Director, R4PTAC

Liz Healey, Director, PA State PTI

Kelly Orginski, MI PTI

Jennifer Bigelow-Stambaugh, Family Specialist, MI DB project

**Egenie Bellah**, Family Specialist, TX DB Project

**Sue Ann Houser**, Director, PA DB Project

Patti McGowan, Secretary, National Family Association for Deaf-Blind (NFADB)

**Sheri Stanger**, Director of Outreach, CHARGE Syndrome Foundation

The FE TWG will convene quarterly to strategize how members can increase awareness of each other's programs, leverage limited resources to support families and identify successful examples of collaborative partnerships between and among the DB and PTI Networks.

In year two, with guidance from the FETWG, NCDB will look to expand the number of successful collaborative partnerships. Intensive technical assistance will be offered to a small number of State Deaf-Blind Projects and PTI Centers interested in increasing levels of collaborative activity in their state.

### **Partners in Action Campaign!**

NCDB and NFADB have joined forces to raise awareness on the critical importance of providing individualized supports to children and adults who are deaf-blind. As part of a yearlong action campaign, a series of webinars will be conducted on three specific aspects of individualized services: the role of interveners, improving access to information through technology, and the impact individualized services can have on quality of life issues for the individual who is deaf-blind.

The first of these webinars, Looking to the Future of Deaf-Blind Services and the Role of the Intervener, was held on February 12 and the second, The Impact of Technology in the Life of a Person who is Deaf-Blind, was held on June 24 as part of Helen Keller Awareness Week. Recordings of both webinars can be found on the NCDB website at https://nationaldb.org/library/page/2372 and https://nationaldb.org/library/page/2427. The third webinar will be announced soon.

## Free Training for Parents on Interveners

A very positive and exciting outcome of the webinar on interveners has been the collaborative effort of NCDB and NFADB to offer online parent trainings of the Open Hands Open

Page 8 Fall/Winter 2014

# Pennsylvania Partnership for the Deafblind Announces Helen Keller Award Recipients

Access (OHOA) Module 3: The Role of Interveners in Educational Settings. In an effort to stay connected and supportive of the participants who have completed the training, NCDB and NFADB send each parent a bimonthly email that contains one or two useful resources and contact information if they should have any questions.

Additional information on this activity can be found at https://nationaldb.org/pages/show/online-parent-training.

# New Liaison Position in the CHARGE Syndrome Foundation

Over the last three months, NCDB has worked closely with the director of outreach of the CHARGE Syndrome Foundation to launch a pilot project to establish the position of CHARGE liaison to the State Deaf-Blind Projects. Technical assistance has included support in developing the job description and recruitment materials.

The primary function of the liaison will be to:

- Share the latest CHARGE resources with the state projects and the families
- Assist in helping both the Foundation and the state projects in identifying families
- Update the Foundation on available state resources
- Promote connections among the CHARGE families in the state

CHARGE liaisons will be sent to all of the state DB projects as well.

Continued on page 11

The Pennsylvania Partnership for the Deafblind (PPDB) is proud to announce the two Annual PPDB Helen Keller Award Recipients who received their awards in 2014 – Mindy Radzik from York, Pennsylvania and Coach Neil Rushnock from White Oak, Pennsylvania. The PPDB Annual Helen Keller Award recognizes people who make significant contributions to the deaf-blind community in Pennsylvania.

Mindy Radzik is a teacher of the blind and visually impaired (TVI). Mindy knew from a young age that she wanted to work with individuals who are blind and deaf-blind. After the birth of her younger brother, Noah, who was deaf-blind since birth, Mindy began to talk to his teachers about the work they did with students who are blind and, eventually, she went to school to become a TVI. Although Mindy's brother and grandparents, who were also blind, have passed away, they continue to inspire her. Mindy's genuine love of her family and her work with individuals who

are blind and deaf-blind has given her a unique perspective and concern for all children with disabilities. She has become a very special teacher with a strong belief in the abilities and possibilities of all her students.

**Neil Rushnock** is a general educator and Head Swim Coach for Norwin High School Boys Swim Team. For the last four years, Coach Rushnock, who had not previously been exposed to the disability of deaf-blindness, has naturally supported a student with deaf-blindness as a member of Norwin High School Varsity Swim Team. Coach Rushnock modeled leadership, kindness, and the benefit of peer supports. He was instrumental in the four-year success of Hunter McGowan, a swimmer with deaf-blindness who was fully included on the swim team. Coach Rushnock set a precedence that the team followed in supporting their teammate with deaf-blindness.

*Visit PPDB at http://www.papdb.org/* 

Helen Keller

**Award** 

**Recipients** 



Mindy Radzik and her brother, Noah



Coach Neil Rushnok and Hunter McGowan

Page 9 Fall/Winter 2014

### **Intervener Module Training continued**

- Classroom Teachers
- Occupational Therapists
- Physical Therapists
- Life Skill Support Teacher
- Speech-Language Pathologist
- Personal Care Assistant/Aide
- Supervisors
- Parents

All that came to the table brought their expertise and played a vital role to the team learning the intervention and the role of the Intervener in the educational setting.

With onsite technical assistance from Nancy Steele, from the National Center on Deaf-Blindness, and Tina Hertzog, facilitator and co-host to the Intervener Module training for the PaTTAN Cohort, the Pennsylvania Deaf-Blind Initiative staff began the pioneer efforts of leading teams through the module study.

From August 2014 through July 2015 these six teams will be participating in the first eight modules. In addition to the Welcome and Orientation Module, they include:

- Module 1: An Overview of Deaf-Blindness and Instructional Strategies
- Module 2: The Sensory System, The Brain, and Learning
- Module 3: The Role of the Intervener in Educational Settings
- Module 4: Building Trusting Relationships and Positive Self-Image
- Module 5: Availability for Learning
- Module 6: Understanding Communication Principles
- Module 7: Emergent Communication

 Module 8: Progressing from Non-Symbolic to Symbolic Communication and Complex Language

This year-long study will provide teams the opportunity to develop strategies based on best practices in the field of deaf-blindness. Another unique component of this approach to the modules is the use of Google Drive's file sharing capabilities. Each team can complete knowledge and skill based activities in a secure, confidential, collaborative environment, allowing for team discussion on the application of those learned strategies. In addition, the use of a collaborative teaming model will be encouraged through ongoing support by PaTTAN educational consultants. This model's elements include shared: planning time, resources, meaningful goals and unity of purpose, leadership, values and trusting relationships, and interdependence. Collaborative teaming is essential in meeting the educational needs of a student with deaf-blindness. The Initiative hopes that this effort will be a model for other states nationally working with educational teams.

In this team approach to the modules, parents play a critical role. *Parents are* their children's first teachers. Research proves that when family members are involved in the planning and instruction of their children's education alongside the school, academic outcomes increase. The PaTTAN philosophy of training always includes the parents as full members of a school team. Likewise, the national effort to create the Intervener Modules always included a parent partner. As we roll-out training to teams across the commonwealth, it requires parent participation to ensure quality delivery. Best practice always includes the team members who know and understand

the student and especially one who is in it for the longest, that being the family.

The teams began their work in Module 3, The Role of the Intervener in Educational Settings. As the teams work their way through that module, each participant is required to complete several types of assignments, including; journaling, participating in discussions, reflecting on readings and slide presentations, watching videos and experiencing dual sensory loss through simulation. Read below some of the insight the participants have shared concerning the role of the intervener:

A speech and language pathologist shared, "Interveners provide valuable information about the student; likes/ dislikes, strengths/weaknesses that other team members need to know when planning lessons are making educational decisions. Interveners translate directions/instruction given by other team members so that the student understands and fills in missing information that the student needs to understand the task. All individuals working with a student should feel comfortable sharing concerns, successes, and suggestions within the team when planning instruction for the student."

A teacher of students with visual impairments said, "It is vital the intervener and the rest of the team work together in providing any information they have about the child. As the child is continually learning to communicate, the whole team is continually learning more and more about the child. It is important, therefore, for the team to provide each other with information not only about the student's responses and communication, but also about the content of the lessons and teaching tips/strategies that are found to be successful."

Page 10 Fall/Winter 2014

Concerning a dual sensory loss simulation experience, a parent stated, "I did the optional activity for parents/family members, entitled "Sharing a Pleasant Activity at Home." I knelt beside (my child) on the couch as he held onto the back and jumped. I've often wondered why he loves this so much—now I know. If one were to stand back and look at him doing it from some distance, one would not be overly impressed. After all, it looks like only an inch or so and he's holding on very tightly. However, after having done it beside him while blindfolded and ear-plugged, it seems like an entirely different activity!"

A classroom teacher shared, "I found myself looking for other sensory input. I listened to my breathing, began rubbing my fingers together, and tapping my feet. I think it's important to remember that without the sensory input of sight and hearing, (the student) will need other opportunities to engage in to get the input she desires."

It is evident from the above testimonials that collaboration of teams is vital for the student with deaf-blindness. This same collaboration is best practice in our network community of deaf-blindness through the technical assistance from our National Center

on Deaf-Blindness down to the state deaf-blind projects to our educational teams under the educational system. We all know what works is a trusting relationship between all the team members involved, being available to assist when needed and an understanding of the educational needs of children and youth with deaf-blindness.

For more information on the Open Hands Open Access (OHOA) Modules and training for teams, contact: Sue Ann Houser, shouser@pattan.net

### **NCDB Family Engagement Update** continued

The Foundation is currently finalizing its selection of liaisons. Once completed, NCDB will assist the director of outreach in conducting an orientation session for the new liaisons. An announcement of the names of the CHARGE liaisons will be sent to all of the state DB projects as well.

#### **CHARGE Webinar Series**

NCDB is a member of the CHARGE Syndrome Foundation's Education Committee and has assisted in the planning and provision of technical support for the three to four CHARGE Webinars the Foundation conducts each year.

#### **Objective 2:**

Create an online repository of parent leadership training materials, providing open access to all families and partners.

Ongoing and/or planned activities to accomplish this objective include:

## Website on Parent/Family Advocacy and Leadership

For the past nine months NCDB has worked on completing the development of the new www.familieslead. org website. This website will house all of the parent leadership training materials created during the 2006-2011 funding cycle of the NCDB. It will also include materials developed by the state deaf-blind projects, NFADB, CADRE, PTIs, Parents as Collaborative Partners Project, PACER and much more.

The website will offer visitors opportunities to:

- Meet Parent Leaders\* in the community and read their story of advocacy and change;
- Learn more about the Power of Families\* through actual examples of how parents brought about change;

- Find Family Leadership Learning Materials that will help to develop the fundamental knowledge and skills needed to create change;
- Discover Training Tools to assist trainers and organizations to plan and deliver family leadership training.

In year two of the NCDB grant, technical assistance will be provided to a small number of interested State Deaf-Blind Projects and PTI Centers to pilot the use of the website materials to design and conduct parent leadership trainings.

NCDB launched a pilot version of this website in September 2014.

Continued on the back cover

Page 11 Fall/Winter 2014

<sup>\*</sup> Much of the current information under Meet Parent Leaders and the Power of Families comes from parents of children who are deaf-blind. It is hoped that once the website is launched, community partners beyond deaf-blindness will join in efforts to expand and enrich the content of the website.

## NCDB Family Engagement Update

continued

### Objective 3:

Identify parent leaders throughout the country and develop an online support group for them.

Ongoing and/or planned activities to accomplish this objective include:

# On-Line Forum to Provide Coaching and Mentoring Efforts

NCDB will look to its partnerships within the Deaf-Blind Technical Assistance Network, the PTI Network, and national parent organizations, to help identify parents who currently serve in leadership positions around the country, (e.g., members of task-forces or advisory panels, organizational leaders). The NCDB website will be used to create an online forum for coaching and mentoring of parent leaders. This activity is in the developmental stages.

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