



Volume 16 Issue 1

SUMMER FALL 2011

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News From Advocates for Deaf-Blind

A Publication of the National Family Association for Deaf-Blind

NFADB UPDATES

Linda Syler, President, NFADB



For most of us summer is a busy time with our children home from school or some programs closed down for vacation. Many organizations hold their conferences during this time. Members of our board have been representing you and your child (children) at several of these events. Susan Green attended the CHARGE conference and set up a display with information about NFADB. She also attended the Deaf-Blind session at the OSEP Project Director's Meeting. Pearl Veasart traveled to Kentucky to the AADB symposium. During the month of July, Janette Peracchio had attended Area 4 NCDB meeting in DC, followed up with PDM DB Day and National Leaders Consortium for Sensory Disabilities (NLCSD).

Your Board and EC have continued to meet via phone conferencing throughout the year. Discussions have covered various topics, the most recent being fundraising. Any ideas you may have on this topic will be appreciated and should be forwarded to our treasurer Cynthia. The conference committee has been active and as soon as the dates and location are finalized they will appear on the website and listserv. Please keep next summer on your calendar for our symposium. The activity will be for family leaders. The next newsletter will have all the information about this exciting event.

I have been involved in NFADB for seventeen years, and have served as president for the past five years. It has been an honor to serve you. On Sept 1, 2011 Susan Green will become the president of NFADB. Susan has served as a member of the Board and as Secretary of NFADB. She is a great asset to our organization. Others elected to the Board are Janette Peracchio - Vice President, Paddi Davies - Secretary, and Elisa Sanchez-Wilkinson - Board member. The support I have received from the Board and EC is greatly appreciated. To our advisors and administrative assistant (Lori) a big thank you for your help, support and guidance. ♥



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."

NFADB EXECUTIVE COMMITTEE

Linda Syler
President

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Vice President

Cynthia Jackson-Glenn
Treasurer

Susan Green
Secretary

BOARD OF DIRECTORS

Edgenie Bellah - Texas
512-563-3676
Bellahbunch@yahoo.com

Patti McGowan - Pennsylvania
724-989-4640
pmcgowan@pattan.net

Veronica Castillo - Arizona
602-454-7692
Bunnycast@aol.com

Monica Quesada - Puerto Rico
787-315-3411
itziamonique@gmail.com

Paddi Davies - Oregon
503-838-6408
daviesp@wou.edu

Sheri Stanger - New York
914-478-7248
SheriME@aol.com

Erma Hill -Virginia
804-282-0239
Hill2C@aol.com

Blanche Stetler - New Jersey
732-721-5448
JTMommy@aol.com

Pearl Veesart - California
805-528-5673
pearlve@sbcglobal.net

International Liaison
Clara Berg - New York
718-428-1591
Clara.Berg@qc.cuny.edu

Lori Bookstaver
Administrative Assistant
800-255-0411
mfnfadb@aol.com

Special Advisors - Betsy McGinnity, Kathy McNulty, Nancy O'Donnell

Newsletter Editor - Lori Bookstaver

Editorial/Technical Support - Allison Burrows, Nancy O'Donnell

Please address all correspondence to: NFADB Newsletter Editor, 141 Middle Neck Road, Sands Point, NY 11050-1299. Voice/TTY: (8:00 a.m. - 3:45 p.m., EST) 800-255-0411; Fax: 516-883-9060; E-mail: NFADB@aol.com

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. ♥



Find us on
Facebook



SUBMITTED BY
PADDI DAVIES

Just a little heads up to all of you social-networking enthusiasts out there - **WE'RE ON FACEBOOK!** Come join our group by logging on to Facebook and searching for "National Family Association for Deaf-Blind." Click on the "Like" button to the right of our name and you'll be our friend. Jump in on a conversation or start your own. We'd love to hear from you!

To join Facebook, go to www.facebook.com. Sign up and create your profile. ♥

SAVE THE DATE!

NFADB Symposium

July 20-22, 2012 - Austin, TX



For information contact Janette Peracchio at jperacchio@gmail.com ♥

COMMIT TO NFADB



NFADB has several areas of activities that help keep the organization viable. We welcome your participation in any of these following areas. Please contact our main office at 800-255-0411, if you would like more information about these activities and/or are interested in lending a helping hand. Thank you.

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iPad 101: Where to Even Start

By Paddi Davies

iPads are all the rage these days. These amazing little tablet computers are flying off the shelves. They're being used for business, fun, everyday living and education. So...what is the big deal about the iPad? They're small, light and portable and have pretty incredible visual capabilities. Pictures and video are crystal clear and the touch screen makes it easy to pinch or pull to adjust the size of an image. Combine that with adequate sound capabilities and you've got a powerful little tool.

It's very exciting to explore how the iPad can be used by children with special needs, including those with vision and hearing impairments. Unlike a regular computer, which focuses mainly on documents, an iPad uses mini software applications, or "aaps" that have a specific, limited purpose. Each of the small squares on the iPad picture represents a link that opens a specific app. For instance, a calculator app is designed to function only as a calculator. A popular children's magazine has an app that has several games to play, stories to read and pictures to color. The user can download as many apps as the iPad's memory can hold. There are thousands upon thousands of apps available for free or purchase. Most apps can be downloaded from the iTunes App Store, where you can also read a description and see pictures of the app, contact the app developer with questions and read reviews from other app users.

New apps are constantly being developed to help children with special needs develop communication, literacy and self-care skills, as well as all sorts of other skills needed to be successful in the school, home and community. The mind-boggling thing for parents and providers is keeping up with the variety of apps available. Some common questions are:

How do I know which apps are best for my child?

Which apps are best for "insert your focus" here (communication, choice making, motivation, etc)

Where do I find these "apps?"

How do I find out about new apps coming out?

Like anything else you research on the Internet, the resulting list of resources can be overwhelming. Who has the time?! The goal of this article is to get you started with just a few helpful resources. Start with these and then expand from here.

#1 Moms with Apps (www.momswithapps.com)

Moms With Apps is a collaborative group of family-friendly app developers seeking to promote quality apps

for kids and families. This site isn't specific to kids with special needs, but they do have a page that focuses on applications that are designed specifically for children with all sorts of disabilities (<http://momswithapps.com/apps-for-special-needs/>). This page lists the apps, gives a brief description of the purpose and provides a link to the iTunes App Store where you can download the app. If you're like most families, your iPad may be used for multiple members of your family. The Moms with Apps website is family-focused. Other pages on the site include: Apps for Family Fun, Apps for Fun & Creativity, Apps for Parents, Apps for Learning and Apps for Reading. This can be a one stop shop for your whole family.

#3 Babies with iPads (<http://babieswithipads.blogspot.com/>)

This blog focuses on the use of iPads to promote the development of infants and toddlers with disabilities. There are articles and suggestions on how iPads can help develop communication, play, pre-literacy, cognitive, visual/auditory and motor skills. The webpage authors share their top 10 apps and highlight new apps as they come out.

#2 Apps for Children with Special Needs (<http://a4cwsn.com/>)

This website allows you to view videos of apps before you download or purchase them. The videos demonstrate how products really work from a user perspective. The goal is to provide you information and advice from an independent source, will provide you valuable insight into whether an app would work for your child.

As you begin to think about your child's developmental and educational needs, consider the value and usefulness of an iPad. You may want to discuss this with your child's intervention or educational team. If you have questions about the use of an iPad for your child or the usefulness of specific applications, here are a few places to start.

1) Your state deaf-blind project.

Contact information:
www.nationaldb.org/ppStateDBProjects.php

2) The National Consortium on Deaf-Blindness (NCDB)

Website: www.nationaldb.org,
info@nationaldb.org, 1-800-438.9376

These resources may not have all the answers, but they can help you find them! ♥



AFFILIATE UPDATE



New York Parent Network

By Barbara Loughran

New York Parent Network's Board of Directors met with Kathy McNulty, our Professional Consultant, to revise our goals and priorities for the upcoming year. NYPN renewed our affiliation with NFADB for the next three years and reviewed possible ways for us to work together on our common goals.

NYPN sponsored two events recently, NYPN CHARGE Family Picnic and O&M Workshop for Families.



The number of families in our CHARGE Syndrome Support Group has increased so much that we will likely divide the group in two. The members wanted to meet face-to-face to get to know each other and their children better. NYPN's CHARGE Facilitator, Suzanne Chen, coordinated the picnic with great success. The picnic was held on June 4 at the Queens Farm Museum. Eight families gathered with blankets, food and drinks, toys and children in tow to spend an afternoon together. It was a fun day for everyone.

New York Parent Network collaborated with the Helen Keller National Center to present an Orientation & Mobility Workshop for Families on June 12. The presentation by Dr. Eugene A. Bourquin, DHA, COMS, CI & CT, CLVT included information and videos about O&M, and demonstrations of sighted guide techniques. Family members and professionals expressed their appreciation to Gene for sharing his expertise with us at this insightful workshop.



New York Parent Network sponsors monthly conference calls for our support groups: Usher Syndrome, CHARGE Syndrome, and Spanish speaking families. The Cornelia de Lange Syndrome support group is on hiatus. Our newest support group is for families of children with deaf-blindness ages Birth to Six. Clara Berg will facilitate this group to help new families.



We are working on our Spring/Summer Newsletter; *NYPN e-news* supplements the newsletters with updates twice a month to inform families of events, webinars, articles, and things of interest in New York.

Please visit our website: www.nypn.net for more information about NYPN. ♥

Adaptive Equipment Websites/Phone Numbers

Compiled by Elisa Sanchez Wilkinson

Abilitations: Providing products that may be solutions for balance, mobility, positioning, play communication, sensory solutions, find motor and body works. 1-888-388-3224 website: www.abilitations.com

Ableware: Maddak Inc. is a manufacturer of home healthcare products for seniors, people with disabilities and people recovering from injuries and illnesses. The products make daily living activities easier enabling you to remain active and independent. 1-973-628-7600 website: www.maddak.com

Access to Recreation: Providing customers with products that give them the ability to enjoy activities that they once thought impossible. A wide range of products from fishing aids to crochet aids, exercise equipment to rehabilitation equipment, wheelchairs to ramps and hundreds of other items. 1-800-634-4351 website: customerservice@accesstr.com

Beyond Play: Extensive selection of products for young children of all abilities. They carry a wide selection of fun and educational products in child development, specialized products for early intervention and special needs. 1-877-428-1244 website: www.beyondplay.com

Enabling Devices: Assistive Technology—Products for People with Disabilities. Communication devices and sensory input, push buttons, plush moving toys and more. 1-800-832-8697 website: enablingdevices.com

Giant Leaps (formerly Special Populations): Special Needs Products for ages 5-20. Featuring sensory solutions, Snoezelen, motor skills and rehab, developmental and learning aids, positioning and mobility, daily living and recreation 1-800-332-9410 website: giantleaps.com

Going Strong (formerly Special Populations): Special Needs Products for young to senior adults. Featuring recreation and leisure, independence and everyday life, wellness and rehab, environments, sensory solutions, and more 1-800-334-1969 website: GoingStrongStore.com

MaxiAIDS: Products for independent living. Thousands of products specially designed for the arthritic, diabetic, blind, low vision, visually impaired, deaf, deaf-blind, hard of hearing, and individuals with special needs. 1-631-752-2-0521 website: www.Maxiaids.com

Rehabilitation and Long Term Care: Southpaw Enterprises has dedicated itself to developing and manufacturing sensory integration dysfunction (DSI) and neurodevelopmental products that help therapeutic professionals, people with special needs, their families, and other professionals, solve problems or meet new challenges. 1-800-228-1698 website: www.southpawenterprises.com

Special Needs Toys: We present a range of Special Needs Toys, from mobile Multi-Sensory, to Swings, Trampolines and other Sensory Integration kit, Switches, Rewards and small Sensory toys. 1-800-467-6222 website: www.specialneedstoys.com

Catalogs are available from many of these websites. Order forms are available to print from many of the above sites. ♥



Just Talk About It writer B Rose Huber

(Published with permission from the PEAL Center)

For Alexander Black, 20, life is as sweet as a candy bar – stocking candy bars, that is.

While in school, Alex ran his own vending machine, donating proceeds to a local church. Now that he's graduated – he will continue to run the machine, but with more responsibilities.

"Before he added pieces of candy with the help of a vocational consultant," said Molly. "Now we're hoping he can help stock it and get really involved with the process."



In the upcoming year, Alex will learn all the steps involved in running a vending machine. His vocational consultant has already videotaped the entire process to use as a teaching strategy.

Although the vending machine is in current operation, starting the process wasn't easy. It required planning, dedication and most importantly – communication. Alex has multiple disabilities related to Cornelia de Lange Syndrome, and his own communication is limited. Throughout his life, his parents and two sisters openly discussed his needs and goals. That talking helped open the doors for Alex's vocational life.

"If there was ever anything I wanted to help Alex accomplish, I would just talk about it," said Molly Black, Alex's mother and PEAL Board Secretary. "The vending machine is a perfect example. We just talked about it and talked about it, and one day a vending machine was donated."

In addition to his vending machine, Alex also volunteers at a nursing home. He removes activities from the calendar of events in resident rooms and delivers items from a cart. And, despite his degree of hearing loss, he also has a great passion for music. He hopes to work in a local music store, putting together drum kits. He's also learning how to string guitars.

Along the way, Alex had instrumental supports in his life. He's been involved in three major person-centered plans with people present from various support systems. He's worked with the same three community supports most of his life (which is not always common). He has a great music teacher and through his vocational consultant has learned how to assemble drums. His family is supportive – he especially has a strong bond with his younger sister Abbey.

"Abbey has always treated Alex as if he can do anything," said Molly. "He has no limitations to her."

What's next for Alex? He and his family are hoping for a home of his own. With more communication, talking and sharing, the Black family is hoping to help Alex make that dream a reality. ♥



THE MAGIC "HAPPENED" HERE

Submitted by Susan Green

Everyone has heard of the Magic Kingdom at Disney World. For approximately 850 people there was a much more magical place in Orlando, Florida. The 10th International CHARGE Syndrome Conference was at the Rosen Shingle Creek Resort on July 28-31, 2011. There were participants from around the world, which consisted of individuals with CHARGE Syndrome, families, friends and professionals.

The conference kicked off with a professional day. This was open to all. Many of the experts in the field attended. CHARGE Syndrome was first recognized in 1981 and has been the focus for research. There were 41 breakout sessions throughout the weekend. Sessions consisted of CHD7 (gene) research, toilet training, transition, and family sessions, to name a few. It was difficult to decide which session to attend because they were all good.

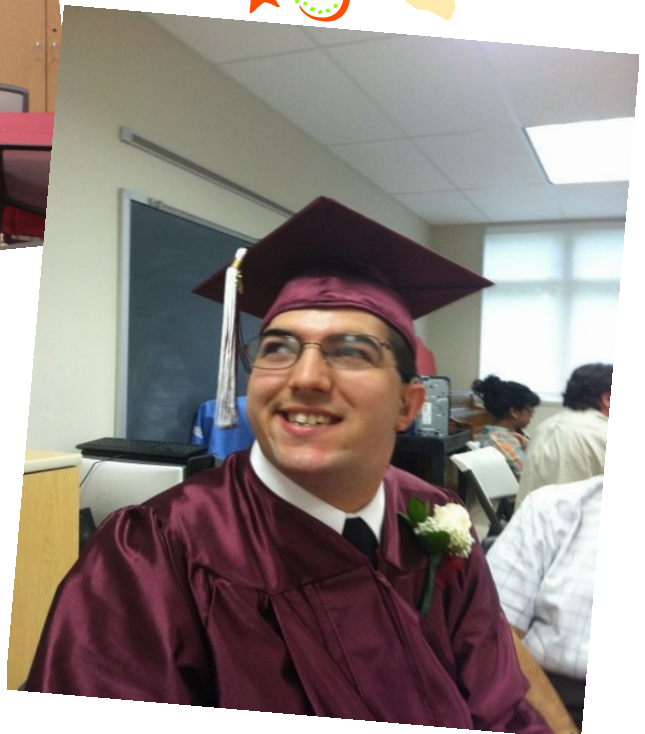
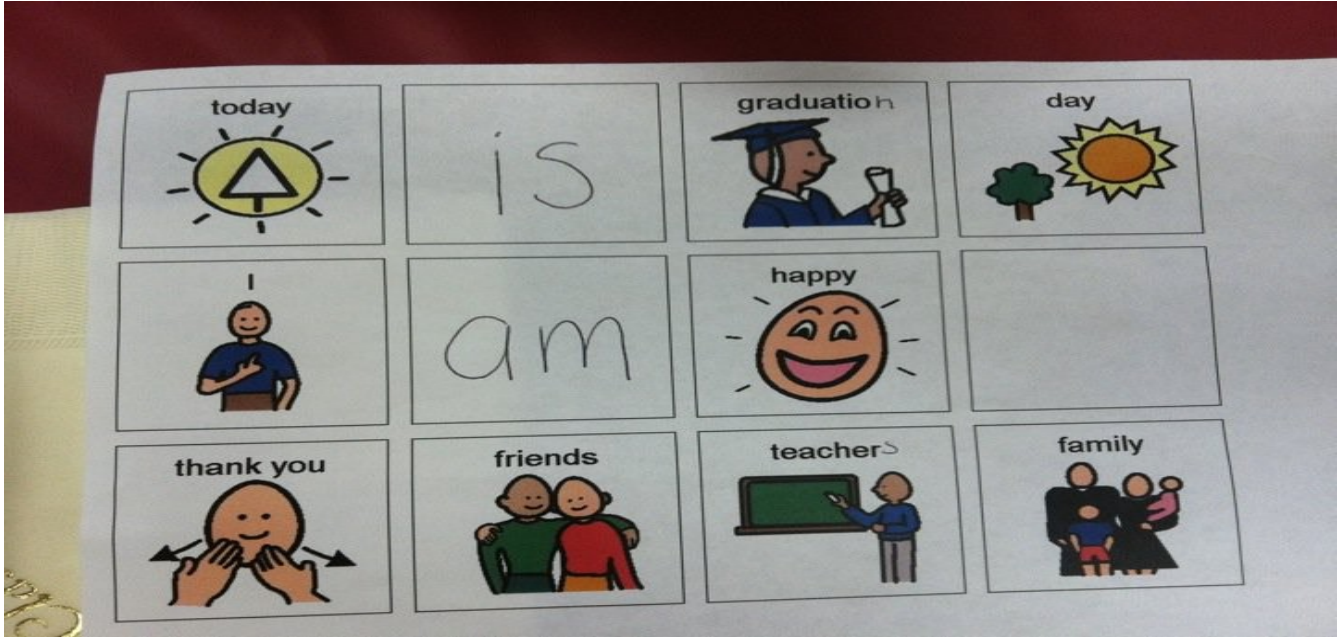
In 1998 I attended "my first CHARGE conference." There are no words to describe my whole experience. It was a very educational, emotional and wonderful conference. For many, this is the first time to connect with another individual with CHARGE and their family members. This year I attended the conference as a representative for National Family Association for Deaf-Blind, also known as NFADB. NFADB is the largest nonprofit national organization of families of individuals who are deaf-blind. CHARGE Syndrome is one of the leading causes of deaf-blindness, at this time. With that being said, the two are a great fit. NFADB can collaborate and advocate together with the CHARGE Syndrome Foundation and its members at the national level. There were many members of NFADB that stopped by the exhibit to say hello. It was a perfect opportunity to renew memberships or join for the first time.

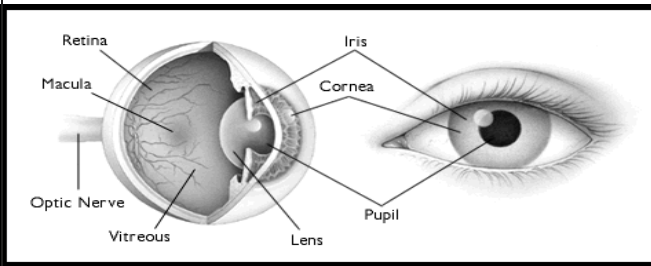


The CHARGE Syndrome International Conference is a biennial (every 2 years) event that takes place the last weekend in July. It was announced over the weekend that the next time we meet again will be July 25-28, 2013 in Scottsdale, Arizona at the Fairmont Scottsdale Princess. I am sure that the magic will happen there, as well! ♥



TIM STETLER'S GRADUATION





The Eyes Have It

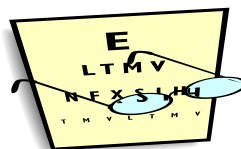
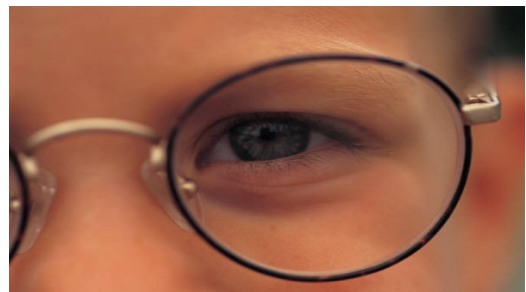
*compiled by Cynthia Jackson-Glenn, M.S., COMS,
NFADB Treasurer*



**According to the Foundation Fighting Blindness (2011),
there are things you can do to keep your eyes healthy.**

Top Ten Things You Can Do to Keep Your Eyes Healthy

1. Always wear sunglasses when you are outdoors
2. Always wear eye protection when:
 - playing sports,
 - mowing your lawn,
 - working with tools,
 - using household chemicals, etc.
3. Always work and read in well-lit rooms
4. Use antireflective coatings on computer screens and glasses
5. Eat a balanced diet that includes fruit and vegetables rich in lutein and zeaxanthin and foods high in omega-3 fatty acids
6. Don't smoke
7. Exercise regularly and generally maintain a healthy weight
8. Keep your blood pressure, cholesterol and blood sugar within healthy limits
9. Limit your alcohol beverage consumption as these drinks dehydrate your body, including your eyes
10. See your eye care professional regularly to monitor your general eye health ▼





Countdown to School...Don't Forget Routines

Submitted by Paddi Davies



The days are getting shorter. Newspaper ads are highlighting school clothes and lunch boxes. Summer will soon be over and all of us will be switching up our daily routines. This can be unsettling. Our internal clocks need readjusting. We have to rearrange our evening hours to allow for baths, homework and making lunches for the next day. Our days are organized by a series of simple and complex routines that begin when we get up in the morning and carry on throughout the day. The following article, taken from the Washington Sensory Disability Services website, shares the importance of consistent, meaningful routines for children with sensory impairments. Additional information and videos showing children engaged in routines are available at: <http://www.wsdsonline.org/deafblind/routines/video.html>

The Power of Routines

Have you ever been frustrated when your favorite, regularly scheduled TV show was replaced by a news or sports event? Had your morning ruined when you discovered you were out of coffee? Your routine was thrown off!

All people depend on routines. Routines provide a predictable framework to our days and reduce stress. Changes or unexpected events can cause stress.

For children—and especially for children with deaf-blindness—routines provide consistent, repeated experiences that allow them to anticipate what is about to happen, communicate in a structured and familiar setting, and actively participate to the greatest extent they can.

In a routine, the steps happen in the same order, in the same way, at an expected time, and at a good pace for the child. Through their regularity and familiarity, routines provide additional information that may not be available to children as a result of their hearing loss and visual impairment. As children learn routines, they also learn about the world (concept development). The stability of the routine creates an environment in which children are available for learning. Without routines, children may react negatively out of fear because they don't know what might happen or be done to them next.

Formalizing an activity into a routine may be referred to as “routine-based intervention” or “activity-based learning.”

Why use routines?

- Routines provide "a systematic approach that is individualized to meet the child's skills and preferences" (FACETS, 1999).
- Routines provide opportunities for consistency, predictability, anticipation, and repeated practice (Smith, 2002).
- Using routines creates stability (Aitken et al., 2000).

Through a routine, the student has the best chance of recognizing an event, feeling secure, learning, and responding (Aitken et al., 2000).

What does it mean to identify an activity as a routine?

To be identified as a routine, the steps in an activity must be formalized. In the beginning, the structure and sequence must be identical each time the steps are performed. For an activity to be considered a routine, it should initially meet the following criteria (Smith, 2002, p. 1):

- There is a clear signal to the student that the activity is starting. The steps of the activity occur in the same sequence.
- Each step is done the same way each time (same materials, same person, same place).
- Assistance is given in the same way each time until the student is ready for a lower level of prompting.
- The pacing of instruction is precisely maintained until the activity is finished (no side conversations, no going to

(Continued on page 10)

get something you forgot, or spontaneously adding new or different steps that won't happen the next time the activity is done).

- There is a clear signal to the student that the activity is finished.

Once a child is familiar with a routine, it may be possible to vary the materials, the person helping the child, or where the routine takes place. As a child is able to accept small changes, he becomes capable of generalizing concepts and activities. Parents and teachers must assess each child's readiness for changes to a particular routine.

For more help with routines

We all deal differently with changes in our daily routines. Some of us are more laid back some get all bent out of shape. Children are no different. However, all children benefit from the use of consistent routines. Start the school year off on the right foot by thinking about ways to develop meaningful routines for your child. To learn more about setting up routines in the home and at school, contact your state deaf-blind project or the National Consortium on Deaf-Blindness.

Your state deaf-blind project.

Contact information: www.nationaldb.org/ppStateDBProjects.php

National Consortium on Deaf-Blindness (NCDB)

Website: www.nationaldb.org

Email: info@nationaldb.org

Phone: 1-800-438.9376



References:

Aitken, S., Buultjens, M., Clark, C., & Eyre, J. T. (2000). Teaching children who are deafblind: Contact communication and learning. London: David Fulton Publishers.

FACETS (1999). Tip sheet: Considerations for planning routines based intervention.

[<http://tactics.fsu.edu/pdf/HandoutPDFs/TaCTICSHandouts/Module2/Considerations.pdf>]

Smith, M. (2002). Routines. [<http://www.tsbvi.edu/component/content/article/64-mivi-general/1733-routines>] ♥



OSEP/NCDB/State Deaf-Blind Projects Deaf-Blind Project Directors' Meeting

Submitted by Susan Green

This year the Deaf-Blind Project Directors' Meeting, also known as PDM, took place July 17, 2011 in Washington, D.C. Over 100 participants, mainly DB Projects, NCDB, OSEP DB Project Officers, gathered to share brain storming ideas. NFADB was represented, as well. The topic of discussion was "Enhancing Deaf-Blind Network Connectivity: Applications of Web Technology." Many of the DB Projects are faced with the "new normal" of doing more with less. This includes large geographic areas to cover with less staff and money. One solution to address some of the challenges is utilization of web-based technologies to increase collaboration.

A targeted content area identified as high need was Central Auditory Processing Disorder (CAPD). The presenter was Charles I. Berlin from Tampa/St. Petersburg, Florida.

Overall, it was a packed full day with NFADB collaborating and advocating for individuals who are deaf-blind and their families. It is imperative that we are present and our voice be heard at the national level. ♥



Commit to an NFADB Committee!



NFADB has several committees working behind the scenes all year. We welcome your participation on any of the following committees. Please contact the committee chairs, as indicated, or our main office at 800-255-0411, if you would like more information about the committees' activities and/or are interested in lending a helping hand.

COMMITTEES & EXECUTIVE COMMITTEE (EC) LIAISONS:

Membership Coordinator: Paddi Davies e-mail: davi-esp@wou.edu; Erma Hill e-mail: HILL2C@aol.com; Patty McGowan e-mail: pmcgowan@pattan.net, ph 724-989-4640.

Affiliate Coordinator: Blanche Stetler e-mail: JTMommy@aol.com, ph: 732-822-3423; **EC:** Janette Peracchio e-mail: jbperacchio@gmail.com, ph: 860-558-7648.

Newsletter Coordinator: Cynthia Jackson-Glenn e-mail: Cynthia.jackson-glenn@rsc.ohio.gov, ph: 513-504-8597.

Fundraising Coordinator: Vacant; **EC:** Cynthia Jackson-Glenn e-mail: Cynthia.jackson-glenn@rsc.ohio.gov, ph: 513-504-8597.

Interpreter Coordinator: Pearl Veasart e-mail: pearlve@sbcglobal.net, ph: 805-528-5673; **EC:** Cynthia Jackson-Glenn e-mail: Cynthia.jackson-glenn@rsc.ohio.gov, ph 513-504-8597.

Board Recruitment & Development Coordinator: Sheri Stanger e-mail: SheriMED@aol.com, ph: 914-478-7248.

International Coordinator: Clara Berg e-mail: ClaraB428@hotmail.com, ph: 718-428-1591; **EC:** Janette Peracchio e-mail: jbperacchio@gmail.com, ph: 860-558-7648.

Website Coordinator: Susan Green e-mail: mshrg2@aol.com, ph: 814-899-4239; Sheri Stanger email: SheriMED@aol.com, ph: 914-478-7248.

When sharing or copying information and articles from our newsletter, please credit:

News From Advocates for Deaf-Blind
as the source. **Thanks!**

LIVING HONOR GIFT, MEMORIAL OR CONTRIBUTION to The National Family Association For Deaf-Blind

Enclosed is \$_____ given as a contribution or as a gift in honor or memory of:

☐ Living Honor - A tribute to someone you wish to honor while they are present to enjoy your thoughtfulness.

☐ Memorial - A gift in honor of someone who has passed on. The notice of this thoughtfulness will be sent to whomever you specify.

☐ Mary Margaret O'Donnell Memorial Fund - An ongoing fund established in memory of our former president.

☐ Contribution to NFADB - to be used as needed.

All honors, memorials and contributions are tax deductible and are used to further the goals and activities of NFADB.

Please send a note about this gift to:

Name: _____

Address: _____

City: _____

State: _____ Zip: _____

GIVEN BY:

Address: _____

City: _____ State: _____ Zip: _____

Send this form with your donation to:

**NFADB,
141 Middle Neck Road
Sands Point, NY 11050**

Thank you!

SUPPORT THE NFADB! MEMBERSHIP CATEGORIES (*U.S. FUNDS ONLY)

REGULAR: any person who is deaf-blind, their parent, guardian or family member.

- ☐ **One Year:** \$15
- ☐ **Three Years:** \$35
- ☐ **Lifetime (Individual/family)** \$100

Regular members are eligible to serve on the NFADB Board of Directors. All members automatically receive our NFADB newsletter which is also available by request in BRAILLE, LARGE PRINT or electronically. Indicate preference on application.

ONLY REGULAR MEMBERS ARE ELIGIBLE FOR APPOINTMENT TO OFFICE

ALL MEMBERS AUTOMATICALLY RECEIVE OUR NFADB
MEMBERSHIP KIT AND OUR NEWSLETTER

CONTRIBUTING SPONSORS: those involved by reason of monetary or other gifts of value to the Association.

- ☐ **Contributing Sponsor** - \$_____

Name: _____

Name: _____

Address: _____

City: _____ State: _____ Zip: _____

Phone: (____) _____ FAX: (____) _____

E-mail: _____

Information about person who is deaf-blind

Name: _____

Birthdate: _____

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:
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