



*Supporting infants,
children, and youth with
combined vision and
hearing loss*

The Beacon



Newsletter of
The Wisconsin DeafBlind Technical Assistance Project
Volume I, Issue 3: September 2011



Our Parents Share.....

CHARGE Syndrome Conference

CHARGE syndrome is a recognizable (genetic) pattern of birth defects which occurs in about one in every 9-10,000 births worldwide. It is an extremely complex syndrome, involving extensive medical and physical difficulties that differ from child to child.

Margaret and Arlen, parents of Elizabeth, recently attended the 10th International CHARGE Syndrome Conference in Florida. Here is what Margaret had to say of the experience:

“We attended several sessions hosted by the Perkins School of the Blind staff. Our daughter will benefit from what we learned. We will be using the potty training technique that was taught and will be working with our school to implement social skills mentoring for Elizabeth. We also learned valuable information about pain management for those with CHARGE syndrome.”

Over 750 people attended this conference. Siblings had the chance to meet together with other siblings of children with CHARGE syndrome, grandparents and parents all were offered the opportunity to learn and share their experiences, while the kids like Elizabeth attended their own camp. Margaret says she met families from all over the United States as well as Australia.

For more information about CHARGE, go to www.chargesyndrome.org.

If you have recently been to a conference or have discovered resources that have helped you, please let us know. We will share your experience in a future newsletter.

National Deaf-Blind Child Count

Each year at about this time, WDBTAP gathers updated information on deaf-blind children in Wisconsin birth to age 21 and compiles it in a report to the National Consortium on Deaf-Blindness. When you receive your letter asking for updating information, please be sure to complete it and mail it back in the stamped envelope provided as soon as possible. This will help us continue our services to the deaf-blind children in our state. If you have any questions, please contact Becky Hovde at (608) 356-2023 or rebecca.hovde@wesp-dhh.wi.gov. Thank you for helping us reach out!

“Transitions” at Deaf-Blind Family Weekend

"Transition information is very helpful!"

"Parental personal experiences and advice is very beneficial"

Parents at DB Weekend ' 11

This year's Deaf-Blind Camp theme was “Transitions”. Families discussed the early transitions from birth to school age in a morning session, and in the afternoon, the presentation was on transitions from school age into adulthood, given by Ruth Silver, founder of the Center for Deaf-Blind Persons. A continuing theme across all presentations was not to wait until your child is in the midst of the transition to prepare for the next steps, **begin early!!** If you would like more information about the transition information from school age to adult presented at the DB Weekend, contact the Center for Deaf-Blind Persons in Milwaukee at (414) 481-7477 or www.deaf-blind.org.

Jolene Gruber
Grant Coordinator- WDBTAP



Feedback From Satisfied Customers of Our Lending Library

"Thank you so much for the use of the equipment for "A". It was really helpful!"

"J' loves the sunshine toy! I'd also like to try the Wiggly Giggly Rattle, vibrating pouch and fan-tastic. I could use anything that vibrates a lot and is easily operated."

We have added some new switches and other resources to our library recently. A new catalog will be on our website (www.wdbtap.wi.gov) in the near future!

If you would like to check out and "try before you buy" from our Lending Library, go to our website at www.wdbtap.wi.gov or contact Becky at rebecca.hovde@wesp-dhh.wi.gov or (608) 356-2023.

Winners of the Grand Prize Drawing at Deaf-Blind Family Weekend!

The "Movie Night" gift assortment was won by Julian O. and his family.

Have a great movie night in!

Link Lites

www.WonderBaby.org

Link Lites

WonderBaby.org, a project funded by Perkins School for the Blind, is dedicated to helping parents of young children with vision impairments, as well as children with multiple disabilities. Here you'll find a database of articles written by parents who want to share with others what they've learned about playing with and teaching a blind child, as well as links to meaningful resources and ways to connect with other families.

The website shares:

- ◇ Family activities that encourage bonding and development
- ◇ Find resources—WonderBaby collects ideas, interesting websites, and toy reviews all in one place so you can find information you need.
- ◇ Free newsletter, giveaway contests

From their website:

"WonderBaby is an online community where parents can find tips on raising a child who is blind, learn more about multiple disabilities, and enter giveaways for fun resources."

****If you find this website helpful, let us know by sending a brief review of your experience to Becky Hovde at rebecca.hovde@wesp-dhh.wi.gov.**



This year's Deaf-Blind Family Weekend theme was transitions. Families discussed the early transitions from birth to school age in a morning session, and in the afternoon, the presentation was on transitions from school age into adulthood .

The message across all presentations was to not wait until your child is in the midst of the transition to prepare for the next steps, **begin early!!**

Parents at DB Weekend 2011 said.....

"Transition information is very helpful!"

"Parental personal experiences and advice is very beneficial"

If you would like more information about the transition information from school age to adult presented at the DB Weekend, contact the Center for Deaf-Blind Persons

by phone at (414)481.7477 or www.deaf-blind.org

Deaf-Blind Family Weekend Recap



Calendar of Events

November 1, 2011—Census materials will be sent out to all families and service providers for updates/changes

November 15, 2011—All census materials due back in WDBTAP office

March 9-11, 2012— 10th Annual Statewide Family Conference “All Under One Umbrella”



What Types of Technical Assistance Does WDBTAP provide?

- Parent/Family trainings and assistance in connecting families with one another
- Statewide and regional workshops for service providers and families
- Observation, support and coaching in programming for children
- Intensive deafblind training series for paraprofessionals who work one on one with children and youth who are deafblind
- Assistance in identifying children and youth who are deafblind
- Referral to relevant local, regional, and national agencies
- Lending library with materials, equipment, and toys to benefit deafblind children/youth on the Registry

We are here for YOU!



You can now find us on Facebook!



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