



THE BEACON

Newsletter of the Wisconsin Deaf-Blind Technical Assistance Project

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Success In Small Steps

by Brian Vanderbloemen, father of Rachel

Our daughter, Rachel, was born 8 weeks early, and in critical medical condition. She required multiple surgeries, a three-month stay in the hospital and a solid amount of luck before she was healthy enough to come home. She was diagnosed with CHARGE Syndrome, a collection of genetic birth defects that affect the ‘mid line’ of her body (Eyes, Ears, Nose, and Throat). To say it was a challenging time would be a gross understatement.

“Today, Rachel has a sense of determination that few people possess.”

No parent goes into the process of becoming a parent thinking about every possible outcome. We all imagine a happy, healthy baby adding joy to the home. In Rachel’s case, our whole world was shifted in an instant. Every day, we still experience joy with Rachel (and her siblings), but it’s fair to say that with her challenges at birth, it was hard to imagine at the time.

We were fortunate to be in Dane County for Rachel’s birth and subsequent health needs. We had access to not only one of the finest Neonatal Intensive Care



Rachel Vanderbloemen,
LaFollette High School
Junior Prom Queen

Units (NICU) in the United States, a well-respected University Hospital - with its vast numbers of specialists and world-renowned experts, but also an early relationship with UCP of Greater of Dane County (UCP). It’s that early relationship that was the key to the future. Within days the staff of the NICU were helping us make contacts with UCP’s Birth to 3 Connections program, already making plans for Rachel’s needs after leaving the hospital. UCP’s Birth to 3 Connections helped us realize we were not alone.

Their professionalism and base of knowledge of kids and their development is invaluable.

Without their resources, experience, and the staff's ability to find and implement innovative ideas, surely we (and many, many others) would be left floundering; desperately searching for solutions to problems we didn't even understand. What a disservice this would be to children.

I'll never forget those early days, with various therapists and educators from the Birth to 3 Connections program visiting the house for sessions. Every week, the staff would show up with new and interesting ideas and techniques to use with Rachel to maximize her (at the time) limited abilities.

Success came in small steps.



Today, Rachel has a sense of determination that few people possess.

Fast forward 17 years, and Rachel is now a Junior in High School. She is a member of the High School Choir, the Key Club, and takes a 'typical' class load (Algebra/Trigonometry, ASL III, etc.). She was recently selected as prom queen by her peers.

Rachel didn't get rid of CHARGE, that's not possible, but through the skills and techniques we started learning within a few weeks of her birth, Rachel learned how to work with and around her disabilities. Today, she is a pleasant, funny, loving, caring individual who has a stake in her future. She's become a force in her own education, advocating for herself when needed. She has become a professional at using available technology to adapt to her skills and abilities.

It's sentimental to look back, and I'm sure in my own memories I'd call them the 'good old days.' I know in my head, though, that it was terrifying. Having UCP's Birth to 3 Connections there for support, education and the various therapies was the glue holding everything together. I don't know what we would have done without UCP.

We Wish You All A Joyous Holiday Season and Our Best Wishes for a Safe and Healthy New Year!

From the Staff At WDBTAP

Marcy Dicker, Project Director

Jolene Gruber, Grant Coordinator

Heidi Hollenberger, Deaf-Blind Consultant

Jodi Andersen, Family Specialist

Lynn Brekke, Office Assistant

Meet Our New & Improved Website

Take a look at our new and improved WDBTAP website, www.wdbtap.wi.gov. We still have some work to do on it but two areas we are especially proud of are the lending library page and the resource page. Parents and providers wishing to check out materials from the library can send the request directly from the webpage. The items are grouped in user friendly categories, such as, Toys, Resources for Parents, Interactive Equipment, etc.



The resource page is still under construction but what we hope to do is load the local resources map with resources from our families. Are you aware of a doctor or dentist who provides special attention to your child? Is there a local person who can sew special needs items or a group or agency that has been particularly helpful to you? If you are aware of anything that may help another family or teacher, please email us. We will check it out and get it posted on our webpage.

As mentioned we still have a few bugs, so if you contact us through the site and do not receive a response, please contact Lynn at 608-356-2023 or at lynn.brekke@wesp.dhh.wi.gov.

WDBTAP PARENT SUMMIT: Hope for the Future

By Jodi Anderson; WDBTAP Family Specialist

On August 15 and 16th, the staff of the Wisconsin Deafblind Technical Assistance Project (WDBTAP) hosted 17 families with children who have combined vision and hearing losses from around the state of Wisconsin in Warrens, WI at the Three Bears Lodge.

The purpose of this summit was to discuss the educational successes and challenges encountered in the school system and state programs and how WDBTAP can better support our families. Families were able to give firsthand feedback on the current resources most useful for their child and generate ideas on what programs they would like to see put in place to meet the needs of this unique population.

From this gathering the following issues were brought forth as priority areas for parents:

1. School Community
 - a. Trusted adults at school who could be a voice for the child
 - b. Inclusion of the child in the school community
 - c. Peers supporting the child/student
2. IEP/IFSP Process & Regulations
 - a. Having someone with knowledge of DB at the IEP/IFSP meeting
 - b. Training of both the school staff as well as advocacy training for family
 - c. Quarterly information, strategies- on going information
3. Professional and Family Knowledge
 - a. Importance of knowledge of communication techniques for children who are deaf-blind
 - b. Administrators having high expectations for staff working with children who are deaf-blind.
 - c. The current lack of acknowledgement of parents' expertise



4. Transition
 - a. Necessary for someone who knows child to continue on team
 - b. Understanding what is possible in adult services
 - c. Consistency of staff- Transition to new staff

5. Communication with Family and Team (s)
 - a. Knowing what child enjoyed/ did at school, examples not just daily routines
 - b. Daily communication with school and family
 - c. Trust of staff working with nonverbal students

6. Family Support
 - a. Programs and Resources available
 - b. Conferences and regional meetings
 - c. Sibling Support Groups



WDBTAP staff are currently working on creating goals based on these priorities and will be sharing them as new strategies and programs are created. We look forward to making Wisconsin a better place for our children with combined vision and hearing losses to learn, grow, and thrive. We ask for your suggestions, comments, and input as we move forward. Please feel free to contact me via email jodi.anderson@wesp-dhh.wi.gov, cell 262- 581-7433, or join us on our closed group on Facebook (see article on how to join).

CLOSED FACEBOOK GROUP!

By Jodi Anderson, WDBTAP Family Specialist



One of the requests we received from the recent Family Summit was for the creation of a closed Facebook group just for our Wisconsin families. A safe and secure place to network and be able to ask questions that pertain just to our unique kiddos. I am pleased to announce this is now a reality – the Wisconsin Deaf-Blind Families Support Group. It is a closed group, so only the members can see posts and only family will be accepted as members, no staff or professionals can see what is posted. I will be the moderator of this group, so none of my posts will reflect anything personal about my child (my husband can post on behalf of our family).

So, how do you join? First, log in or join Facebook and look up Wdbtap Anderson (that is my alias on Facebook as the administrator of this group) and ask to become my “friend”. Once we are “friends” I will invite you to the group and then you can start posting! It is that easy!

NEW IN OUR LENDING LIBRARY

LIGHTED CLIP FAN

Feel the breeze! This fabulous fan has soft foam fan blades making it user friendly. Built in LED lights allow the user to create 64 different exciting light show effects and patterns. Great for increasing visual attention. Fan has a separate on/off switch for the lights. Clip-on design allows mounting anywhere. Comes on a flexible gooseneck.



DISCOVERY TUNNEL

A fabulous multi-sensory experience! Slide your hand through the beaded curtain and experience auditory, visual and tactile stimulation. The white ball inside the tunnel lights up in many different soothing colors illuminating all the mirrors inside. At the same time you feel a slight vibration and hear one of six high quality mood-setting music pieces. The tunnel will provide hours of fun and relaxation. Also works with an external capability switch.



2014 Census

We have had a great response to our 2014 census. If you have not returned your census form, there is still plenty of time to do so. If for any reason you did not receive a census form, please contact me at lynn.brekke@wesp-dhh.wi.gov and I will get a form out to you!

What do we use this information for? WDBTAP compiles a variety of information on the students within the state who have combined vision and hearing loss and forwards it to the National Consortium on Deaf-Blindness (NCDB) for the federal deaf-blind registry.

The census information is vital to planning and implementing services for deaf-blind children and young adults, their families and educators.



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Project Officer, Louise Tripoli-Louise.Tripoli@ed.gov

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 deaf-blind training series for paraprofessionals who work one on one with children and youth who are deaf-blind
- Assistance in identifying children and youth who are deaf-blind
- Referral to relevant local, regional, and national agencies
- Lending library with materials, equipment, and toys to benefit deaf-blind children/youth on the Registry

Wisconsin Deaf-Blind Technical Assistance Project

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