



DB STAR

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Michigan Services for
Children & Young Adults
Who Are DeafBlind

Central Michigan University
105 Sloan Hall
Mount Pleasant, MI 48859

Phone: 989-774-2725 (V/TTY)
Toll Free: 888-758-0508 (V/TTY)
Fax: 989-774-1572

★ **Director**

Beth Kennedy

★ **Family Services Coordinator**

Samantha Wood

★ **Consultant**

Jill Gaus

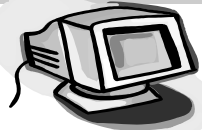
★ **Administrative Secretary**

Linda Kleinhans

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<i>Inside this Issue</i>	Staff Introductions	2-3
	Volunteers' Perspectives	6
	Having Fun	7
	Upcoming Events	8



From the Director's Desk

By Beth Kennedy

Happy New Year! It is with great pleasure that I inform you that DB Central is once again at full staff. Though Patti Nowak and Marianne McJames will be missed, I am excited about what the new staff bring to the project. Please refer to page 2, which has staff photos and brief descriptions. There are a variety of ways the DB Central staff can support you. Don't hesitate to contact us!

This issue of the DB Star is dedicated to Marilyn Park, who passed away on January 13, 2004, following a lengthy illness. Our thoughts and prayers are with her family.

In This Issue.....

By Laura Welch

Families from all across Michigan attended the Third Annual Family Retreat in Lansing, Michigan on September 19-21, 2003. With over 20 families in attendance, many volunteers, and several informative speakers, this retreat was a success. The weekend allowed families to create networks and share stories & experiences with other families who have children with a vision and hearing loss. Attendees were also able to further their knowledge on such topics as advocacy resources and services in the community that are available to them. Finally, and most importantly, the retreat gave families the opportunity to relax and have fun.

We would like to dedicate this current issue of DB STAR to the families in attendance at the retreat. Without the families, there would have been no retreat. Please enjoy the stories shared by fellow parents and retreat attendees who have written nearly all of the articles in this issue.



Staff Introductions

DB Central is full-staff once again! We at DB Central would like to thank everyone for their patience and understanding during the past months. After intensive searches, we have hired both a Family Services Coordinator and an Administrative Secretary. Now, we are pleased to introduce our staff to you:

We have hired a new Family Services Coordinator named Samantha Wood (to replace Patti Nowak), who began working on November 18th. Samantha recently moved to Michigan from New York State where she worked as a counselor in a public school. She comes to DB Central with grant experience on the state and federal level related to low incidence disabilities. Samantha is enthusiastic about picking up where Patti left off and looks forward to meeting and working with the families connected to DB Central.



After an intensive search for a new Secretary, DB Central was pleased to hire Linda Kleinhans. She started on November 17th and has already begun to catch up on the work that had been piling up. Linda most recently worked as a medical office manager for a hospital-owned family practice. She is excited about this career change and the new experiences it will bring, and looks forward to getting to know all of you.



Beth Kennedy is the Director and Educational Consultant. She has worked in the field of Deaf-Blindness for twelve years: seven at Perkins School for the Blind in the DeafBlind Department, two consulting on a Federal grant in Florida, and has been with DB Central for three years.



Laura Welch is DB Central's graduate assistant this year. After receiving her undergraduate degree at the University of Michigan—Ann Arbor, she came to Central Michigan University this year to work on a Specialist's Degree in School Psychology. Laura started working at DB Central in late August and has learned a lot about deafblindness. She is enthused about this opportunity to learn valuable information to help children & young adults, now and in her future endeavors.



Jill Gaus, shown here with her Leader Dog, Heidi, is a part-time consultant to DB Central. She is also President of the adult group called SHI-M=DB, Self Help For Independency in Michigan Equalizing the Deafblind. Jill is a nurse and teaches in colleges about deafblind and deafblind interpreting.



Tim Hartshorne, Ph.D., is the grant holder for DB Central. This means he is the CMU employee who is responsible for the grant. Tim is a professor of psychology, with a specialization in school psychology. Presently he is on a temporary administrative assignment as Assistant Vice Provost, working on projects like curricular proposals, accreditation of the University, and providing support to the academic deans and department chairs. Tim is author of numerous publications, most recently focused on behavior challenges in children with CHARGE syndrome. Tim's interest in CHARGE comes from his 14-year-old son who has the syndrome. Tim is married to Nancy, who wrote the grant that brought DB Central into existence.



Where Were You on the Weekend of September 19-21, 2003?

By Joe Jeney & Marilyn Park

If you happened to attend the DB Central Family Retreat at the Holiday Inn in Lansing, Michigan, you experienced, as we did, an opportunity to hear and speak with Marlyn Minkin from Seattle who helps families with children who have hearing and vision impairments identify and problem solve issues related to their family's needs. We also enjoyed comfortable camaraderie with other families, some of whom were familiar faces and others, much to our delight, who were new to our group. It was a chance to relax in an environment where we didn't have to be consumed with the everyday thoughts of arranging childcare, preparing meals, or cleaning up afterward.

Although we greatly miss Patti Nowak, who has been such a strong supporter of all families, it was very apparent that she had done much of the pre-planning for this event thereby greatly helping MADB members, along with remaining DB Central staff, continue final planning activities.

We especially appreciated hearing experiences and ideas related to educational advocacy, both from professionals and families. Many questions and comments from participants concerned issues of working within the system, strategies for team building and posi-

tive approaches to obstacles, challenges, and interpretation of the laws affecting our children. It was also encouraging to see extended family and IEP team members attending the retreat, highlighting the importance and necessity of supportive community involvement.

Sunday morning before we left the retreat, Marlyn encouraged us to think about balancing our lives, including the need for leisure time. So many of us rarely do much for ourselves because we are so busy caring for our daily family and work demands, as well as the additional complications of meeting the needs of our child with disabilities. She emphasized the need to commit to creating specific behavior changes in order to feed and nurture ourselves. *As parents of an older child, we realize the critical importance of reminding ourselves of this concept!*

Finally, we returned home feeling our souls had been nurtured. We are so thankful for the opportunity to connect with new and reconnect with deepening relationships among those who experience similar situations and help us to feel less alone in understanding and accepting the rewards and challenges associated with having a child with deafblindness.

“...Marlyn encouraged us to think about balancing our lives, including the need for leisure time.”

Excellent Time..... By Laura Welch & Marcia Smith

In a recent phone interview, I had the opportunity to talk with Marcia Smith, who is the grandmother of a child who is deafblind. When asked what she thought of the 2003 Retreat, she replied it was not what she was expecting, in a good way. It “flooded” her because it was the first time she had ever done anything like it. Her favorite part of the retreat was meeting all of the other families who have children with disabilities. Marcia said that before the retreat she had never realized that there were so many people who had children with problems. Although her grandson did not attend childcare, her niece did and really enjoyed the crafts. If Marcia was given the opportunity to talk to other families who were not able to attend the retreat, she would recommend that they go if given the chance.

Keeping My Promise To Myself

By Cheryl Kruger

We really enjoyed the DeafBlind family retreat at the Holiday Inn. We thought that the panel topic of advocating for your children's educational needs was especially pertinent for most families — either now or in the future (some of the kids were too young to attend school or had not yet encountered major difficulties).

One comment that left an impression on me was made by another parent at the conference who said that she was realizing that her child, who communicates using sign language, could only learn as much language as the child was presented with. In other words, unlike children who hear/speak English and are surrounded by people who also communicate using spoken English, the limiting factor was not the child's disabilities so much as the abilities of family, friends, teachers, aides, etc. to present the child with a rich sign language vocabulary. Since then, I have increased my efforts to convey fuller communication, explanations, descriptions, etc. to our son using sign language. We have continued to take sign language classes and have truly begun to appreciate how expressive this visual language can be. We now know how to sign children's books in order to make the experience fun while vividly communicating the words and pictures on the pages in ways not limited by spoken utterances.

On the last day, the primary speaker, Marlyn Minkin, asked us to write down and commit to doing something for ourselves because most of what we do as parents of deafblind children is for others. The thing that I decided to do for myself was to walk a circular route near our home. After I had walked about 1 mile of the course that I had selected, it started raining and the route turned out to be 6.5 miles long! Although this was not the vision that I had of a pleasant (and less lengthy) walk in the sunshine, I had a rain poncho in my jacket pocket and a grim determination to fulfill my commitment and finish the route, so I trudged on and it stopped raining shortly before I reached home. In the end, I felt great and was glad that I had stuck with it and completed the journey. My husband, John, also decided to take this hike and we have continued to take turns walking this route about every other week since. John (who believes there is no such thing as bad weather, only bad clothing), also had a rainy walk one day.



Volunteers' Perspectives

By Laura Welch

The parents were not the only ones having fun at the Family Retreat. There were also many volunteers who watched the children so that families could relax and attend sessions. Most of the childcare activities took place at the YMCA. Some activities were clean mud (grated bar soap, toilet paper and water), ping pong, a playroom with colorful mats and cushions to climb on, and several types of craft activities.



Here are some comments from some of the volunteers:

Sara Urlaub:

“A group of 3 children would sing and sign the YMCA song when we walked through the parking lot to the Y. Very cute. As an Interpreter Training Program student it was good for me to see the different levels of sign skill that the children had — real world experience. Thanks for the experience and the AWESOME food.”

Jon Decker:

“There are many things that I learned with this experience. The most poignant one that I learned is that when it comes to boys between the ages of 8-12, no matter how cool I think I am as a volunteer, if I am partnered with an attractive young woman with these children, I will be almost completely ignored and they will fall madly in love with that woman. I also learned that if I am ever going to help out with one of these things again, I really need to have, at the very least, a basic grasp of sign language.”



From an ITP Student Volunteer's Journal

By Amy Vezino

Today I was really excited to work with the deafblind community for the first time. I was also eager to work with kids again, since the job I had for 3 years before moving to Lansing this summer was with kids. I didn't thoroughly enjoy getting up early on a Sunday morning, but the ITP is all about sacrifice! Ms. Kennedy had split up kids and volunteers into groups. Two of the three kids in my group were siblings of deafblind and had no challenges of their own. The other little girl had severe vision and hearing losses. She was an adorable three-year-old with brown curly hair, but she was not able to communicate with me or even acknowledge that I was there. That was something I didn't expect and wasn't sure how to handle, but I kept talking and signing very close to her while trying to find textures she would enjoy touching. I finally got a smile from her as I brushed a feather across her cheek, my own little success in communication. Trying to give her a break from her wheelchair, I brought her out on the brightly colored mats, but with little balance and the inability to walk, I found another challenge. We all went to a central location so everyone was really helping each other out, and I was able to work with more kids. I spent quite a while playing ping pong with an older brother and making bead necklaces with two beautiful blonde girls. They wore me out and I even took a nap when I got home. I learned to expect the unexpected, and I now realize I will experience situations I never even imagined before! I'm a little more prepared in case some of the people I meet in the future do not have the language or communication skills I take for granted. It was definitely a worthwhile way to spend my Sunday!

Having Fun

By Laura Welch & Theresa Troupe

Recently, I had the opportunity to talk to a parent, Theresa Troupe, by phone, bombarding her with questions about the 2003 retreat:

Laura: What was your favorite part of the retreat?

Theresa: Meeting people and hanging out.

Laura: If you were given the chance, what would you tell families who were not able to attend the retreat?

Theresa: You really should try to make it. It was a lot of fun. There was good information and good networking.

Laura: How did you like the facilities?

Theresa: Nice.

Laura: Did your children enjoy the activities?

Theresa: Very much.

Laura: What was their favorite activity?

Theresa: They loved the gym.



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Central Michigan University
105 Sloan
Mount Pleasant, MI 48859

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UPCOMING EVENTS

February 6, 2004

2004 Michigan Early Hearing Intervention-ists/Parents Conference (*a conference to provide an opportunity for parents to learn about early intervention services; the ultimate purpose of the training is to improve hearing health care service delivery for the 0-3 year old population and their families*)

Sheraton Lansing Hotel
Lansing MI

517-335-8878

May 13-14, 2004

Annual Michigan WIC Conference

Radisson Plaza Hotel
Kalamazoo MI

517-335-8625

July 18-21, 2004

DeafBlind Transition Camp (DBTC)

East Lansing MI
Contact DB Central

The MSDB Adaptive Technology Workshops

January 16, 2004 Kalamazoo, K-RESA

March 19, 2004 Macomb ISD

April 29, 2004 Traverse City ISD

Pat Love-Sypho, Tech. Assist. Coord.

1-800-622-6730, ext. 1489

Email: lovep@michigan.gov

Just a reminder:

The 2003 Census information is due in our office by March 5, 2004. Feel free to contact our office if you have any questions.