Happy DeafBlind Awareness Week! This issue is packed with information about the demographic information collected for the December 1, 2009, child count. Of note, fifty-three new children/young adults were identified this year! We truly appreciate your assistance in reporting updated information and new kids! Because so many new parents and professionals will now have access to project services, we have also included an overview of services. More detailed information can be accessed via the website, or by calling the office to talk with a staff member. We would love to hear from you!

We continue to work with the Information Technology (IT) Department at CMU to move to an electronic data collection system. We thought that it would be ready for 2010, but the development process has taken longer than expected. With any luck, we will go electronic next year! Thank you for your patience.

Jennifer Bigelow-Stambaugh, our new Family Support Coordinator, has jumped right in, and has been very busy since starting with DB Central in April. So that you can get to know her a little better, she wrote an introduction (with photo!) for this issue. A number of families have already benefitted from her knowledge and expertise. We are lucky to have her!

Although I hate to end on a sad note, I have to mention that Deirdre McDonald, our Administrative Secretary, is leaving the project. She is in graduate school and has found a full-time position in her field. We wish her well! In her last few days with us, Deirdre is training a temp, Anne Miller, who will help to make sure that the office continues to run smoothly until the position is filled.
A message from the Helen Keller National Center

“In response to a need identified by members of the deaf-blind community, the 2010 Helen Keller Deaf-Blind Awareness Week focuses on the role of the Support Service Provider (SSP). SSPs are individuals specially trained to enable people who have combined vision and hearing losses to access their environments and make informed decisions. They share their sense of sight and/or sound to provide context for every day events such as a day of shopping, a night on the town or a 5K charity run.

At the present time, a young man who is deaf-blind is hiking the Appalachian Trail, while other individuals are attending social activities, exploring hobbies and managing errands—all with assistance from SSPs.”

For more info on SSPs, Deaf-Blind Awareness Week, and more, visit www.hknc.org.

We are very pleased to introduce our new Family Support Coordinator...

Jennifer Bigelow-Stambaugh

I would like to take this opportunity to introduce myself to you; my name is Jennifer Bigelow-Stambaugh, and I am the new Family Support Coordinator for DB Central. I reside in the central Michigan area and graduated from Central Michigan University with a Bachelor’s Degree in Psychology in 1996. I’m currently enrolled in the Master of Science in Administration program at Central Michigan University.

My first day at DB Central was on April 12, 2010. It has been a very exciting initiation. I’ve been able to be a part of the follow-up from the 2009 DeafBlind child count, participated in the Person Centered Planning Training Initiative, and participated in the final weekend of the 1st year Family Leadership Initiative. I have worked with individuals with disabilities for over 13 years in various capacities. I have worked as a case manager and developmental disabilities manager for the State of Michigan within the Department of Community Health. Prior to this, I provided community case management supports for individuals in South Bend, Indiana.

I look forward to working with the families of DB Central and believe working with you is a great opportunity which will allow me to draw from my experience, but will also foster growth in the complex nature of low incidence disabilities.

Please feel free to contact me by email at bigel1je@cmich.edu, 888.758.0508 (toll-free), or 989.774.2726 (VP) for assistance or just to introduce yourself. I am very excited to get to know you and your family and look forward to meeting you!
DB Central services are offered year-round, free of charge.

Following a request for service, DB Central staff will provide support in one (or more) of the following formats:

**Telephone/ email:** Contacts will be made with the family and/or schools, agencies and other service providers to provide information and resources, participate in meetings, and to consult as needed.

**Webcams:** Using Skype, project staff can participate in meetings, conduct classroom observations, and have face to face discussions. A limited number of webcams are available for loan from the project library.

**Information Sharing:** DB Central provides publications and media that reflect best practices in the field of DeafBlindness. Examples include access to a lending library, electronic project newsletters (3 times per year), mailing to target audiences (e.g. parents of transition-age students), online training modules (under construction), a website (www.dbcentral.org) and an e-mail distribution list to families.

**Referral to other agencies/organizations:** If you call the project with an issue that staff cannot address, every effort will be made to link you with a different resource.

**Parent Networking:** DB Central recognizes the value of parents as resources for one another and aims to connect parents of children who are DeafBlind. The project maintains a Family Directory and helps to organize family social events with the state parent group Michigan Association for DeafBlind (MADB).

**Onsite Consultation:** In some circumstances, DB Central staff will visit the home, school or community setting to work with families and service professionals who are impacted by DeafBlindness. Attempts to address and resolve issues via distance consultation (i.e. phone, email, webcam) will likely precede on-site visits.

**Trainings:** The project will offer a variety of regional and statewide trainings over the course of the grant. Information about trainings can be obtained by visiting the project website, www.dbcentral.org. Administrators can book professional development trainings for their staff by contacting the project. (See “Training Opportunities.”)

**Educational Technical Assistance:** Assistance specific to education or school will be discussed by staff and referred to the appropriate staff member.

*Please note: A signed “Family Consent for Services” form is required for services involving a specific child/children.
2009 DeafBlind Census Findings

Michigan Major Etiology Categories 2009

- Hereditary/Chromosomal Disorders: 71
- Prenatal Congenital: 49
- Postnatal Noncongenital: 41
- Complications of Prematurity: 68
- No Determination of Etiology: 159

Michigan Major Etiology Categories 2008

- Hereditary/Chromosomal Disorders: 53
- Prenatal Congenital: 44
- Postnatal Noncongenital: 43
- Complications of Prematurity: 60
- No Determination of Etiology: 143

Total students reported grew from 343 to 388, including 53 new students!
Top 10 Chromosomal Etiologies
1. Other (49)
2. CHARGE (43)
3. Usher I Syndrome (8)
4. Stickler Syndrome (7)
5. Cornelia de Lange (6)
6. Down Syndrome (6)
7. Dandy Walker Syndrome (4)*
8. Goldenhar Syndrome (4)
9. Wolf-Hirschhorn Syndrome (4)*
10. Pierre-Robin Syndrome (3)*

*new in Top 10 list

Top 5 Prenatal Etiologies
1. Microcephaly (18)
2. Other (16)
3. CMV (14)
4. Hydrocephaly (8)
5. Maternal Drug Use (6)

Top 5 Postnatal Etiologies
1. Other (12)
2. Severe Head Injury (7)
3. Meningitis (5)
4. Asphyxia (4)
5. Encephalitis/Stroke/Tumors (3 each)

Maternal Drug Use has replaced Fetal Alcohol Syndrome in our Top 5.

These rankings are the same as last year!
Current DB Central Census By County
Source: December 1, 2009 DeafBlind Census

Ages 0-21

**County Counts**

Allegan—3
Alpena—1
Baraga—2
Barry—1
Berrien—5
Branch—4
Calhoun—4
Cass—4
Cheboygan—1
Chippewa—3
Clare—1
Delta—1
Eaton—2
Genesee—31
Grand Traverse—2
Gratiot—6
Hillsdale—1
Huron—2
Ingham—18
Ionia—2
Isabella—7
Jackson—10
Kalamazoo—8
Kalkaska—1
Kent—28
Lapeer—4
Lenawee—1
Livingston—6
Mackinaw—3
Macomb—10
Manistee—1
Marquette—2
Mecosta—2
Menominee—1
Midland—2
Monroe—15
Montcalm—2
Muskegon—4
Newaygo—2
Oakland—34
Oceana—1
Ontonagon—1
Otsego—1
Ottawa—18
Roscommon—1
Saginaw—7
Sanilac—4
St. Clair—8
St. Joseph—3
Tuscola—3
VanBuren—6
Washtenaw—10
Wayne—44
Current DB Central Census By County
Source: December 1, 2009 DeafBlind Census
Ages 22-26

County Counts
Calhoun—1
Barry—1
Branch—1
Genesee—2
Ingham—1
Isabella—1
Jackson—3
Kalamazoo—1
Kent—5
Lapeer—1
Macomb—2
Mecosta—1
Muskegon—1
Oakland—1
Ottawa—4
St. Clair—1
Tuscola—1
VanBuren—1
Washtenaw—4
Wayne—3
Wexford—3
UPCOMING EVENTS

June 27—July 2, 2010
Art/Drama Week at Holley Family Village, DeSales
For information, contact HFV at 313.343.3165.

June 29, 2010
SAMHSA ADS Center Training Teleconference
Register by June 25 at http://promoteacceptance.samhsa.gov

June 30, 2010
“IEP/High School Transition” Parent Training Workshop, Detroit
Topics include Michigan Merit Curriculum, age of majority, diploma or certificate, EDP, and What is Your Vision. Register by June 28 by calling Celena Barnes at 313.935.0965.

July 4—9, 2010
Family Week I at Holley Family Village, DeSales
For information, contact HFV at 313.343.3165.

July 10, 2010
Lions Bear Lake Camp Open House, Lapeer
All families are invited to see the camp and get a feel for its programs. Includes activities for children, info sessions, and free lunch. Preregister at bearlakecamp.org.

July 11—16, 2010
Family Week II at Holley Family Village, DeSales
For information, contact HFV at 313.343.3165.

July 12—30, 2010
Summer Literacy Program (Ages 6—12), Redford
Daily activities include free lunch, computer skills, reading, field trips, and more. $25 registration, transportation $5/week. Contact Kathleen Mitchell at 313.592.3175 (V) or 313.681.5200 (VP).

July 16—18, 2010
CHARGE Syndrome/DeafBlindness Weekend for Families and Professionals, Kingsport, TN
David Brown and Tim Hartshorne will provide one-on-one consultation and presentations on learning and behavior in children with CHARGE/DeafBlindness/multisensory issues. Contact Jennifer Vick at jennifer.vick@vanderbilt.edu.

July 18—21, 2010
Lions Bear Lake Camp for First Timers, Lapeer
This introductory camp is for visually impaired children who have never been away from home. Visit bearlakecamp.org or email Stephanie Glashauser at sglashau@emich.edu.

July 18—23, 2010
Deaf Family Week at Holley Family Village, DeSales
For information, contact HFV at 313.343.3165.

July 18—30, 2010
23rd Annual Michigan A.G. Bell Summer Camp Program, Irish Hills
For oral deaf and hard-of-hearing students in grades 3-12. Campers will be totally mainstreamed. For more information, visit www.ymcastorercamps.org or call Mark Reeve at 313.331.2378.

July 18—31, 2010
Lions Bear Lake Camp for Lifers, Lapeer
Traditional camp program. For more information, visit bearlakecamp.org or email Stephanie Glashauser at sglashau@emich.edu.

July 21—25, 2010
AER International Conference 2010, Little Rock, AR
For information, visit www.aerbvi.org/2010conference or email conference@aerbvi.org.

July 30—August 1, 2010
8th Annual NODCC Conference, Santa Clara, CA
$210/person. Register by July 22. For more information, visit www.nodcc.org.

August 2—20, 2010
Summer Literacy Program (Ages 13-17), Redford
Daily activities include free lunch, computer skills, reading, field trips, and more. $25 registration, transportation $5/week. Contact Kathleen Mitchell at 313.592.3175 (V) or 313.681.5200 (VP).

August 11—15, 2010
Deaf/Blind Week at Holley Family Village, DeSales
For information, contact HFV at 313.343.3165.

August 13—14, 2010
Parent to Parent: A Conference on Visual Impairment, Minneapolis, MN
Sessions include IEPs/Legal Rights, education, O&M, medical, Braille, fitness, employment, technology & more. Contact info@MNAPVi.org.

For more details and upcoming events, visit our website at: www.dbcentral.org