From the Director’s Desk - By Beth Kennedy

I cannot believe that it is summer (not that we would know from the weather)! DeafBlind Awareness Week is upon us, once again. This issue is packed with information about resources for families and professionals who may need support as they strive to meet the needs of a child who is DeafBlind. We have included project information, as well as contacts on state, national, and international levels. We have also highlighted some “who’s who” in the field in honor of this week.

This year, we are piloting our new database. It allows for electronic update of census records via links and passwords sent out via e-mail. Many parents and professionals helped us to work the bugs out of our new system by letting us know about glitches they experienced while doing their updates. We continue to work with the Central Michigan University IT Department to make sure that next year’s census will be even more successful. If you did not receive an e-mail inviting you to update your child’s/student’s information electronically, it might be because we do not have your e-mail address on record. Please contact our office prior to the end of January 2012, when the initial e-mails will be sent. If you did assist us with piloting the new system this year, we welcome your feedback on how to make the process more efficient and user-friendly.

It is our hope that, at some point in the near future, the census will be conducted almost exclusively over the Internet. We know that this saves time, money, and trees — so help us make sure that we have current e-mail addresses! Many of the people registered on our census will have new teachers in the fall. Letting us know about new contacts will make data collection much easier. The results for this year are summarized in this issue. Our numbers are down slightly this year, but the data is more accurate.

The new database will also make tracking our activities much easier. We will have a wealth of information on demographics, consultation, training, and information dissemination linked to each of the students whose teams have accessed services at our fingertips! We anticipate that the new database will facilitate reporting and improve overall services.
It’s National DeafBlind Awareness Week!
June 26 - July 2, 2011

In 1984, in honor of Helen Keller's birthday, President Reagan proclaimed the last week of June as “Helen Keller Deaf-Blind Awareness Week.”

For more information, visit the Helen Keller National Center’s (HKNC) website at www.hknc.org.

In honor of the week, this edition of DB Star includes additional resources and information to promote awareness and understanding of DeafBlindness. In addition, we have featured the 2011 participants of the HKNC Deaf-Blind Young Adults in Action who emphasize the potential of individuals with DeafBlindness and the contributions they can make to our society.
In Michigan, who should be registered with DB Central?

Individuals with both vision and hearing losses represent a heterogeneous group and include:

- Individuals who have a cochlear implant and either a documented vision loss or demonstrate inconclusive responses during evaluations.
- Individuals who are both deaf and blind as demonstrated by accurate vision and hearing tests (including those with additional disabilities).
- Individuals who have hearing and visual impairments of a mild to severe degree (including those with additional disabilities).
- Individuals who may have been diagnosed as having a degenerative pathology or disease which will affect vision and/or hearing (including those with additional disabilities).
- Individuals with multiple disabilities who may demonstrate inconclusive responses during evaluations or in the natural environment to visual and auditory stimuli.

This is a functional definition of DeafBlindness. What this means is that, in Michigan, a person is considered DeafBlind for purposes of the census or receiving services from DB Central if they have both a documented vision and a documented hearing impairment ranging from mild to severe; OR, they function as if they have both a hearing and vision loss, based upon inconsistent responses to auditory and visual stimuli in the environment or inconclusive responses during hearing and vision evaluations. A conclusion that a child is functionally deaf-blind may be reached based upon educational evaluation for purposes of initially reporting that child to DB Central.

A student can be registered with DB Central regardless of their educational label.
Services Geared Toward Families

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.

To request family support services or for more information on services available through DB Central, please contact our Family Support Coordinator, Jennifer Bigelow-Stambaugh, at bigeltje@cmich.edu, 888.578.0508 (toll free) or 989.774.2726 (VP).
Services Geared Toward Professionals

DeafBlind 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:

Phone/VP contacts: Project staff members are available to address your questions and/or concerns via telephone or videophone. Call a staff member to learn more about services, locate resources, ask questions, discuss recommendation reports, arrange future activities, etc. Project staff can participate in meetings via conference call.

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.

Dissemination: DB Central disseminates publications and media that reflect best practices in the field of DeafBlindness through a lending library, newsletters, brochures, and a website (www.dbcentral.org).

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.

Video footage review: The team can collect video footage of the student who is DeafBlind and submit the clips for review by project staff. After viewing the footage, project staff will schedule a conference call with the team to discuss the activities. A written report of all recommendations will be sent to the team. The footage will only be viewed by project staff and tapes/DVD's will be returned to the school, or destroyed, once the recommendation report is complete. A limited number of flip video cameras are available for loan from the project library.

Onsite consultation: In some circumstances it may be possible for project staff members to arrange a visit to the school. If a visit is scheduled, it is helpful for the project staff to observe typical activities. A team meeting should be scheduled on the day of the visit, in order to discuss the observation and any recommendations project staff members may have. Attempts to address and resolve issues via distance consultation will likely precede onsite 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.”)

Family support: People who are DeafBlind flourish in environments that provide consistent services and supports. A full range of family support services are available to all relatives and guardians of a child on the project census. The services are intended to promote and foster consistency with educational efforts. (See “Services Geared Toward Families” on previous page.)

*Please note: A signed “Family Consent for Services” form is required for services involving a specific student(s).
Requesting Services from DB Central

Call the project or email a project staff member to discuss your question/concern.

Resources that will address your question/concern can be sent to you.

If additional support is necessary, project staff members decide how to address your needs.
* The target individual must be registered with the project.
* A signed “Family Consent for Services” form is required.

Ongoing phone, email, webcam, or videophone interactions can be made to address your concerns. Project staff members make recommendations.

If additional support is necessary, project staff members will decide how to address your needs.

An onsite visit for observation and a team meeting. Project staff members make recommendations.

Team training with coaching. An action plan is required.
Hello, my name is Corrina Veesart. I am 29-years-old and live in the small coastal community of Los Osos, which is on the Central Coast in California. I communicate using tactile ASL. I am deaf-blind from an undiagnosed congenital condition. I have been a member of and have attended the American Association for the Deaf-Blind (AADB) national conventions since I was 11-years-old. I graduated from community college with honors and an AA degree in General Studies. Currently, I am looking into volunteer opportunities to gain work experience. Because I really like physical activities, I want to apply that passion to helping people. I continue to take classes while I seek a job. I may pursue another AA degree in Health, Fitness, Nutrition, Recreation Administration, or Human Studies. I also may want to transfer to a four-year college. I’m not sure where my path is going to lead me, but I do know that I want to ensure that the deaf-blind have the right support available so that they can be productive participants in a wide range of activities. My quest is to fight for our equal inclusion in our communities, which will lead to physical and emotional wellness.

Haben Girma

Haben Girma currently attends Harvard Law School. Her work as an advocate for disability rights began when she served as a U.S. delegate for the U.S./Costa Rica Disability Rights and Leadership Exchange with Mobility International USA. In the summer of 2010, she joined DeafBlind Young Adults in Action in Washington, DC, to meet with Members of Congress and their staff to promote policies affecting deafblind persons. With DeafBlind Young Adults in Action and the Helen Keller National Center, Haben also attended the White House’s Celebration of the 20th Anniversary of the ADA, where she met President Obama. Girma attributes much of her success to the teachers for the blind in Oakland, California.

Mussie Gebre

My name is Mussie Gebre. I am deaf-blind and a member of DBYAA. I was born in Eritrea, a small northeastern African country, and I came to the U.S. in 1993. Currently, I live in the East Bay of Northern California. I am majoring in Anthropology and Psychology. In addition to my studies, I am an assistive technology (AT) consultant and train deaf-blind consumers how to use AT products that empower them to live independent and productive lives.
Virginia Jordan

Virginia Jordan was born and raised in Atlanta, Georgia. She is currently finishing up her Master’s at the University of Georgia in Teaching Additional Languages. Upon graduation this August, she plans to start her teaching career. As an advocate, Virginia is passionate about enhancing the educational experiences of students with disabilities. She began advocating for the Deafblind community as a senior in high school when she spoke at the Georgia Capitol. For the past three years, she has been a member of Deafblind Young Adults in Action (DBYAA). In October of 2009, Virginia attended the Helen Keller World Conference in Kampala, Uganda, which included visits to two Deaf schools with Deafblind programs. This opportunity inspired her to become more involved in implementing change for the deafblind community on an international level. Virginia hopes to have many more opportunities to visit other countries and touch the lives of deafblind children.

Sarah McMillen

Sarah McMillen resides in Rochester, NY. She graduated from The College at Brockport with Bachelor in Science in Health Science. Sarah is very enthusiastic about advocating for the Deaf-Blind (DB) and physical and recreational activities. She has a couple of accomplishments that she feels are noteworthy. Several other DB advocates in Monroe county and she received several county legislators' recognition of the vitality of the Support Service Providers (SSP) program and set up a first-time focus group about the SSP program with the county's Commissioner of Department of Human Services' office. As a DB advocate, she performs various duties with another advocate, who is also a DBYAA member, Heather Grizzle, such as some outreaching with various community's stakeholders, and overlook a collaborative committee to ensure the DB people are receiving quality services in Monroe county.

Heather Grizzle

I'm Heather Grizzle and I was born and raised in Atlanta, Georgia. I was diagnosed with Usher’s Syndrome Type I at 28. I am a second year Psychology major at Rochester Institute of Technology in addition to pursuing a second major in Professional and Technical Communications with minors in Writing Studies and Public Policy. I am also the Student Leader on NTID’s Low Vision Support Committee and involved with the Center for Disability Rights in Rochester, NY as a deafblind advocate. My ultimate end goal in life is to be a lawyer and be on the front lines when it comes to battling ignorance in America.
Jamie Taylor
My name is Jamie Taylor. I am deafblind and I am also an enthusiastic new member of DBYAA. I wear many hats. In my current position as the Technology and Transportation Specialist at the Commission of Deaf, DeafBlind and Hard of Hearing Minnesotans, you may find me diving deep into statewide accessible technology policy or co-teaching workshops on how accessibility interplays with Complete Street initiatives among many other things. I hold a Master's degree in Deaf Education from the University of Minnesota.

Justin Gaines
My name is Justin Gaines and I am Deaf-Blind, fully Deaf. I was born in Concord, California. My birthday is 4 April, 1990. My family moved to many states because my dad was working for the Navy. When I was 8 years of age, we moved to the country of Hungary. There, I lived for 2 years. I attended a school for the deaf and did learn Hungarian Sign Language. Then, my family moved back to California where I went to California School for the Deaf in Fremont. I finished my program there in 2008, and then moved to Colorado. I went to Colorado School for the Deaf and Blind (CSDB) and graduated with a High School Diploma in 2009. After I graduated, I stayed at CSDB for another program called Bridges To Life (BTL) to learn independent life skills. After that, I moved back to California. I am currently at HKNC (Helen Keller National Center) participating in a training program. My goal is to go to NTID/RIT to study Computer Science and Computer Systems.

Tyler Clarke Kennedy Samuel
Tyler is a sophomore attending the University of Evansville (IN) where she is pursuing a B.A. in Vocal Performance. This past year in college she participated in two opera productions: La Bohème and Suor Angelica. She was also a semi-finalist in the National Assoc. of Teachers of Singing Vocal Competition held at Berea College (KY) this past fall. Tyler was inducted into the prestigious Sigma Alpha Iota International Music Fraternity in Spring 2011. During her high school tenure she participated in the following activities: 2010 Mid-South Female Vocalist Winner for the Grady-Rayam Negro Spiritual Foundation Competition, Concert Chorale of Nashville Vocal Scholarship Winner, 2009 Princely Players Vocal Arts Fellow, TN Mid-State & All-State Choirs, Tennessee Governor’s School for the Arts, East Literature Rising Legacy Choir, The MET Singers Honor Choir and in the summer of 2009 toured Europe as a member of the Sound of America Honor Band and Chorus. Tyler has been an advocate for persons with visual impairments by participating as a delegate to several leadership forums sponsored by the National Federation of the Blind. She is a member of TN Students for the Blind and for 2007-2008 served as the student representative for the Mayor’s Advisory Council on Special Education. It is Tyler’s desire to go continue training for a career in opera after college.
Shannon Boelter

My name is Shannon Boelter and I am 21 years old from Eagan, Minnesota. I am fully Deaf and have CHARGE Syndrome, which also involves reduced vision. I have just completed my second year at St. Paul College and will attend Gallaudet University this fall, where I hope to major in Child Development. I have written and self-published a book for young teens and hope to become an author and teacher for young children in the Deaf community. My primary concern is that Deafblind individuals have the support services that are necessary to become self-sufficient citizens. I benefited from Intervener services, which helped me function independently in the community. This includes technology so that Deaf and Deafblind have full accessibility to information.

Eduardo Madera

My name is Eduardo Madera. I have been profoundly deaf since birth with night blindness. I grew up in an arid, small town of Bishop in California that commands a breathtaking view of the Sierra Nevada Mountains. In December 2005, due to financial struggles, my parents realized it was best to relocate to a rural area 25 miles west of Atlanta, Georgia in hopes of improving our future.

I attended a small school for the Deaf in Atlanta and adopted the subtle differences in Georgia’s American Sign Language. By the time I entered the high school, I noticed a drastic change in my visual field. I had difficulty understanding my teacher and peers fanning their hands around me. I felt overwhelmed. At the age of 14, I was diagnosed with Usher Syndrome. The discovery of my condition changed me forever; I resolved to go to a mainstream high school, which was a very challenging transition for me socially. This opportunity forced me to grow emotionally and intellectually. It also helped me thrive academically and has significantly enhanced my relationship with others because of better communication and understanding of my visual situations and needs. As a young advocate, I steadfastly believe I can influence the policy of various laws that needs to be resolved.

Anthony Garro

I’m Tony Garro from Chino, California. I was born three months premature and the second twin boy. I weighed 1lb. 14oz. Prematurity caused my Deaf-Blindness and other disabilities. I have mild CP and am learning disabled. I work for a super market chain called Vons Market, basically in southern California and Nevada. I’m a courtesy clerk and have been there five years. Being Deaf-Blind I have encountered many situations during my employment. I had to take responsibility to be my own advocate. Being Deaf-Blind I’ve needed specific accommodations in my work place. That’s hard for others to understand when they’ve never dealt with a disability. I attended California School for the Blind and graduated from Lugo High School in Chino. I also attended the Davidson Program at the Jr. Blind of America, which helped me a great deal, especially with independence and mobility. Through all the special needs and services I’ve received I’m able to use pubic transportation to and from work and to what ever appointment I need to get to. There’s no way I could be as independent as I am without the skills and training I’ve received. I enjoy dancing, sports, particularly, basketball. I also like to DJ.
Dr. Jan van Dijk at CMU!

By Val and Amanda

On March 15, 2011, DB Central brought leading authority on children with multiple disabilities, Dr. Jan van Dijk, to present at Central Michigan University.

Families, professionals, students, and more attended his presentation on individuals with DeafBlindness or participated through the webcast we were able to offer. He showed video footage of assessments conducted with local families and discussed his child-guided assessment techniques and general intervention strategies for behavioral state, orienting response, learning channels and sensory avenues, child likes and dislikes, memory, social interactions, communication, and problem-solving.

His presentation was a great learning experience for all involved, and offered a rare opportunity to learn from one of the experts in the field of DeafBlindness. The event was a huge success and we hope to sponsor Dr. Jan Dijk again in the future. Contact the project to learn how the recorded session can be viewed. For those of you who were able to attend, we thank you for helping to make the event a success and hope you enjoyed the presentation!
Thank you to everyone who participated in DB Central’s annual census of children and young adults with DeafBlindness in Michigan.

Introducing the 2010 DeafBlind Census Findings...

2010 Count by Age

Number of Individuals

Age

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21

Major Categories for Cause of DB

- Chromosomal: 43%
- Prenatal: 17%
- Postnatal: 10%
- Complications of Prematurity: 12%
- No Determination: 10%
- Information Not Provided: 17%
2010 Count by County for Ages 0-21

County Counts
Allegan: 3
Alpena: 1
Baraga: 3
Berrien: 4
Branch: 3
Calhoun: 5
Cass: 2
Cheboygan: 1
Chippewa: 2
Clare: 4
Dickinson: 1
Eaton: 1
Genesee: 32
Grand Traverse: 2
Gratiot: 6
Hillsdale: 1
Huron: 1
Ingham: 15
Ionia: 2
Isabella: 4
Jackson: 8
Kalamazoo: 7
Kalkaska: 1
Kent: 24
Lapeer: 5
Lenawee: 1
Livingston: 6
Macomb: 12
Manistee: 1
Marquette: 2
Mecosta: 2
Midland: 1
Monroe: 14
Montcalm: 1
Muskegon: 4
Newaygo: 1
Oakland: 27
Oceana: 1
Ontonagon: 1
 Otsego: 1
Ottawa: 15
Saginaw: 5
Sanilac: 3
St. Clair: 7
St. Joseph: 2
Tuscola: 3
Van Buren: 6
Washtenaw: 11
Wayne: 51
Total: 316
### 2009 Census Findings vs. 2010 Census Findings

**Top 10 Chromosomal Causes**

<table>
<thead>
<tr>
<th></th>
<th>2009</th>
<th>2010</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Other</td>
<td>Other</td>
</tr>
<tr>
<td>2</td>
<td>CHARGE Syndrome</td>
<td>CHARGE Syndrome</td>
</tr>
<tr>
<td>3</td>
<td>Usher I Syndrome</td>
<td>Usher I Syndrome</td>
</tr>
<tr>
<td>4</td>
<td>Stickler Syndrome</td>
<td>Stickler Syndrome</td>
</tr>
<tr>
<td>5</td>
<td>Cornelia de Lange</td>
<td>Cornelia de Lange</td>
</tr>
<tr>
<td>6</td>
<td><strong>Down Syndrome</strong></td>
<td><strong>Usher II Syndrome</strong></td>
</tr>
<tr>
<td>7</td>
<td>Dandy Walker Syndrome</td>
<td>Dandy Walker Syndrome</td>
</tr>
<tr>
<td>8</td>
<td>Goldenhar Syndrome</td>
<td>Wolf-Hirsschhorn Syndrome</td>
</tr>
<tr>
<td>9</td>
<td>Wolf-Hirschhorn Syndrome <strong>Trisomy 13 (Trisomy 13-15, Patau Syndrome)</strong></td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>Pierre-Robin Syndrome</td>
<td>Pierre-Robin Syndrome</td>
</tr>
</tbody>
</table>

**Top 5 Prenatal Causes**

<table>
<thead>
<tr>
<th></th>
<th>2009</th>
<th>2010</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Microcephaly</td>
<td>Other</td>
</tr>
<tr>
<td>2</td>
<td>Other</td>
<td>Microcephaly</td>
</tr>
<tr>
<td>3</td>
<td>Cytomegalovirus</td>
<td>Cytomegalovirus</td>
</tr>
<tr>
<td>4</td>
<td>Hydrocephaly</td>
<td>Hydrocephaly</td>
</tr>
<tr>
<td>5</td>
<td>Maternal drug Use</td>
<td>Maternal drug Use</td>
</tr>
</tbody>
</table>

**Top 5 Postnatal Causes**

<table>
<thead>
<tr>
<th></th>
<th>2009</th>
<th>2010</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Other</td>
<td>Asphyxia</td>
</tr>
<tr>
<td>2</td>
<td>Severe head injury</td>
<td><strong>Hydrocephalus/Brain stem deterioration</strong></td>
</tr>
<tr>
<td>3</td>
<td>Meningitis</td>
<td>Severe head injury</td>
</tr>
<tr>
<td>4</td>
<td>Asphyxia</td>
<td>Meningitis</td>
</tr>
<tr>
<td>5</td>
<td>Encephalitis/Stroke/Tumors</td>
<td>Encephalitis</td>
</tr>
</tbody>
</table>

**Which counties changed over the last year?**

- Baraga +1
- Barry -1
- Berrien -1
- Branch -1
- Calhoun +1
- Cass -2
- Chippewa -1
- Clare +3
- Delta -1
- Dickinson +1
- Eaton -1
- Genesee +1
- Huron -1
- Ingham -3
- Isabella -3
- Jackson -2
- Kalamazoo -1
- Kent -4
- Lapeer +1
- Mackinaw -3
- Macomb +2
- Menominee -1
- Midland -1
- Monroe -1
- Montcalm -1
- Newaygo -1
- Oakland -7
- Ottawa -3
- Roscommon -1
- Saginaw -2
- Sanilac -1
- St. Clair -1
- St. Joseph -1
- Washtenaw +1
- Wayne +7
Upcoming Events

June 24–July 1, 2011
Leader Dogs for the Blind GPS Youth Camp
For more information, visit: http://www.leaderdog.org/programs/youth/index.php

July 14–15, 2011
Picture Exchange Communication System (PECS) Advanced Training
Detroit, MI

July 21–22, 2011
Picture Exchange Communication System (PECS) Basic Training
Traverse City, MI

July 29–31, 2011
CHARGE Syndrome Foundation Conference
Orlando, FL

September 17, 2011
5th Deaf Arts Festival
Holley Family Village campus, Brooklyn, MI

September 27–October 1, 2011
XV World Deafblind International Conference
Where: Sao Pablo, Brazil
For more information, visit: www.dbi2011.com.br

October 26–28, 2011
Showcasing Exemplary Practices: The 5th National Symposium on Dispute Resolution in Special Education
Valley River Inn, Eugene, Oregon

November 30–December 3, 2011
2011 TASH Conference
Atlanta, Georgia
For more information, visit: www.tash.org/2011TASH
Check it Out

Take a look at the following webcasts from Perkins School for the Blind!

**Reflections on Deafblindness: Hands & Touch**
http://support.perkins.org/site/PageServer?pagename=Webcasts_Reflections_on_Deafblindness
By Barbara Miles
In this webcast, Barbara Miles, a well-known author and lecturer, discusses the unique function hands serve for individuals who are deafblind. For people with vision and hearing impairments, hands become eyes, ears, and a voice. Barbara's realization that hands have so many critical roles changed the way she interacts with the hands of children who are deafblind.

**Good Sleep Strategies**
www.perkins.org/goodsleepstrategies
By Veronika Bernstein, Ph.D
In this webcast, Veronika Bernstein, Ph.D. describes the challenges faced by children with visual impairments and their families in developing good sleep habits. Dr. Bernstein provides a variety of strategies that may be used to address this challenge.

**Parents as Ambassadors**
www.perkins.org/parentsasambassadors
By Robbie Blaha
Author/Expert Robbie Blaha has worked with students who are deafblind for more than thirty years. In the fall of 2008, she was the keynote speaker at the Discover Conference, held on Perkins School for the Blind's Watertown, MA campus, where she shared her wisdom, insights and humor with parents and educators.

**Smart Boards**
http://support.perkins.org/site/PageServer?pagename=Webcasts_smartboards
By Wendy Buckley
Wendy Buckley is a computer teacher/specialist within the Deafblind Program at Perkins. She is also adjunct faculty at UMass Boston where she co-teaches braille courses for both the TVI and O&M Programs. In this presentation Wendy discusses Smart Boards. Smart Boards, interactive white boards, are a presentation system consisting of a whiteboard, computer, projector and tools. This presentation offers an overview of various tools that can be used with a Smart Board. These include free web resources, commercially available software and alternative access devices for both a keyboard and a mouse. Extensive resource lists are included.
Highlights from our Lending Library

**Understanding Deafblindness: Issues, Perspectives, and Strategies**
Edited by Linda Alsop

This book represents an outstanding overview of all major issues related to deafblindness. The easy-to-use format includes plenty of illustrations, diagrams, and "points to remember" sidebars. The two-volume binder set is divided into the following chapters: psychosocial aspects; concept development; intervention; vision; hearing; touch; sensory integration; neurological issues; health; communication basics; early communication; communication and interactive relationships; calendar systems; the van Dyke perspective; family issues; self-determination; behavior; gross motor; fine motor and play; O&M for infants and young children; O&M for adolescents and young adults; daily care and self help; IFSP/IEP; physical activity, PE, sport and recreation; social/sex education; transition; and community support.

**Communication and Congenital Deafblindness**
Authored by Inge Mogensen, Inger Rodbroe, Inger Simonsen, Airi Ahonen

Four booklets on Communication and Congenital Deafblindness, each with their own focus, target parents and professionals who are in contact with individuals with congenital deafblindness. These books have been written to support and inspire the networks around each person with deafblindness. Video examples are collected on a DVD to illustrate the concepts of each booklet. The booklets are written in English and based on the work of Deafblind International's Communication Network.

Titles include:
1. Congenital deafblindness and the principles of intervention
2. Contact and social interaction
3. Meaning making
4. Transition to the cultural language

**Beyond Pegboards: A Guide for Teaching Adolescent Students with Multiple Disabilities**
Authored by Cynthia O'Connell

This practical, 250 page guide uses a theme-based approach to help teachers create meaningful learning opportunities for students with multiple disabilities. It is filled with very easy to replicate activities that can become a springboard for more activities and ideas. All activities are referenced in a critical skills chart that ties them to the skills and concepts that they address. Examples of how activities relate theme-based teaching to the educational standards are also included.

**Deafblindness: Educational Service Guidelines**
Edited by Marianne Riggo and Barbara McLetchie

Developed in cooperation with the Hilton/Perkins Program and the National Association of State Directors of Special Education, this 126 page publication is a best practice guide that educational administrators at the state, local and program levels can use to understand the implications of combined vision and hearing losses on learning; to recognize the need for specialized assessment, program planning and service delivery.
Highlights from our Lending Library

**CHARGE Syndrome**

Authored by Timothy S. Harthshorne, Margaret A. Hefner, Sandra Davenport, James Thelin

CHARGE syndrome affects approximately 1:10,000 births worldwide, is extremely complex, and has varied medical and physical manifestations. It was first described in 1979, named in 1981, and only as recently as 2004 was a gene for CHARGE found. In addition to a host of other conditions, most individuals have communication-related problems, including breathing, swallowing, hearing and balance, and speech.

Each of the editors is an established expert on CHARGE and has received the highest award bestowed by the CHARGE Syndrome Foundation, the Star in CHARGE, and represent four different disciplines: sensory genetics and neurodevelopment, genetic counseling, audiology, and psychology. They have concluded that studies have advanced to the degree that a single source of information is necessary. This, the first known book on the subject, describes the sensory, physical, and behavioral findings in CHARGE, indicates what kinds of studies need to be done to confirm the findings, and describes how these findings affect the function and development of the individual with CHARGE.

**Remarkable Conversations**

Edited by Barbara Miles and Marianne Riggio

This book addresses the needs of children of all abilities, from those who use nonlinguistic forms of communication such as objects or body movements to those who use linguistic forms such as sign language or writing. It is invaluable to aspiring teachers, to teachers in special and regular education settings, to families, to clinicians, and to all who advocate for quality programs for the deafblind.

**Tactile Strategies for Children Who Have Visual Impairments and Multiple Disabilities: Promoting Communication and Learning Skills**

Authored by Deborah Chen and June Downing

In order to promote their growth, development, and ability to communicate, young children who are visually impaired and have additional disabilities need to learn to use their sense of touch effectively and develop skills that are not necessarily based on the use of vision. Highlighting critical information for families as well as for communication experts, this user-friendly new manual provides you with both essential information about alternative communication and countless practical strategies and insights to create effective solutions for working with children. Teachers, early interventionists, and parents looking for valuable techniques will find them here, on topics ranging from how to assess a child’s tactile skills to how to interact effectively with children and plan interventions. The suggestions and insights in *Tactile Strategies* will be welcome additions to your teaching plans.
Highlights from our Lending Library

Child-guided Strategies: The van Dijk Approach to Assessment

Authored by Catherine Nelson, Jan van Dijk, Teresa Oster, Andrea McDonnell

This product offers an easy-to-use guidebook with an accompanying DVD that follows the assessment of a baby, a young child, and a teenager. The van Dijk assessment is unique as it follows the lead of the individual learner. Critical to the process is the recognition that assessment and intervention must always occur hand-in-glove and that meaningful assessment guides intervention. This product contains the guiding principles and guidelines to conduct an assessment that follows the van Dijk approach. Topics include: Behavioral State, Orienting Response, Learning Channels, Approach-Withdrawal, Memory, Social Interactions, Communication, and Problem Solving.

Calendars: for Students with Multiple Impairments Including Deafblindness

Authored by Robbie Blaha

This book is written for students who need help structuring and organizing their time and activities. It includes information about:

- The benefits of calendar systems
- Calendar programming based on individual students' needs and skills
- The continuum of calendars available for expanding students' skills
- Communication and time
- Benefits of anticipation calendars, daily calendars, and expanded calendars
- Parents and calendars

Cortical Visual Impairment: An Approach to Assessment and Intervention

Authored by Christine Roman-Lantzy

The current leading cause of visual impairment among children is not a disease or condition of the eyes, but cortical visual impairment (CVI)—also known as cerebral visual impairment—in which visual dysfunction is caused by damage or injury to the brain. The definition, nature, and treatment of CVI are the focus of great concern and widespread debate, and this complex condition poses challenges to professionals and families seeking to support the growth and development of visually impaired children. On the basis of more than 30 years' experience in working with hundreds of children of all ages with CVI, Christine Roman-Lantzy has developed a set of unique assessment tools and systematic, targeted principles whose use has helped children learn to use their vision more effectively. This one-of-a-kind resource provides readers with both a conceptual framework with which to understand working with CVI and concrete strategies to apply directly in their work.
<table>
<thead>
<tr>
<th><strong>DeafBlind Resources</strong></th>
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<tbody>
<tr>
<td><strong>DeafBlind Central: Michigan’s Training and Resource Project</strong></td>
</tr>
<tr>
<td><strong>Project Director:</strong> Beth Kennedy</td>
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<tr>
<td><strong>Family Support Coordinator:</strong> Jennifer Bigelow-Stambaugh</td>
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<td><strong>Administrative Secretary:</strong> Amanda Patterson</td>
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<td><strong>Graduate Assistant:</strong> Valerie Weber</td>
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<th><strong>DeafBlind Central</strong></th>
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<tbody>
<tr>
<td>Central Michigan University</td>
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<tr>
<td>Sloan 105</td>
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<tr>
<td>Mount Pleasant, MI 48859</td>
</tr>
<tr>
<td><strong>Phone:</strong> (989) 774.2725 (V/TTY)</td>
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<tr>
<td><strong>Toll-Free:</strong> (888) 758.0508 (V/TTY)</td>
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<tr>
<td><strong>VP:</strong> (989) 774.2726</td>
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<tr>
<td><strong>Fax:</strong> (989) 774.1572</td>
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<tr>
<td><strong>Email:</strong> <a href="mailto:dbcen@cmich.edu">dbcen@cmich.edu</a></td>
</tr>
<tr>
<td><strong>Website:</strong> <a href="http://www.dbcentral.org">www.dbcentral.org</a></td>
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<tr>
<th><strong>Michigan Families for Hands and Voices</strong></th>
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<tr>
<td><strong>P.O. Box 10038</strong></td>
</tr>
<tr>
<td>Lansing, MI 48913</td>
</tr>
<tr>
<td><strong>Phone:</strong> (517) 241.7066</td>
</tr>
<tr>
<td><strong>Email:</strong> <a href="mailto:info@mihandsandvoices.org">info@mihandsandvoices.org</a></td>
</tr>
<tr>
<td><strong>Website:</strong> <a href="http://www.handsandvoices.org">www.handsandvoices.org</a></td>
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<th><strong>Michigan Commission for the Blind: DeafBlind Services</strong></th>
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<tr>
<td><strong>Michigan Commission for the Blind</strong></td>
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<tr>
<td>Michigan Department of Licensing and Regulatory Affairs</td>
</tr>
<tr>
<td>201 N. Washington Square, 2nd Floor</td>
</tr>
<tr>
<td>P.O. Box 30652</td>
</tr>
<tr>
<td>Lansing, MI 48909</td>
</tr>
<tr>
<td><strong>Phone:</strong> (517) 373.2062 (V), (517) 373.4025 (TTY)</td>
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<tr>
<td><strong>Toll-Free:</strong> 1.800.292.4200 (V), 1.888.864.1212 (TTY)</td>
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<tr>
<td><strong>Email:</strong> <a href="mailto:DeafBlind@michigan.gov">DeafBlind@michigan.gov</a></td>
</tr>
<tr>
<td><strong>Website:</strong> <a href="http://www.michigan.gov/mcb">www.michigan.gov/mcb</a></td>
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<tr>
<th><strong>Michigan Department of Education: Low Incidence Outreach</strong></th>
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<tbody>
<tr>
<td><strong>1505 W. Court Street, Suite 227</strong></td>
</tr>
<tr>
<td>Flint, MI 48503</td>
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<tr>
<td><strong>Phone:</strong> (810) 760.2206</td>
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<tr>
<td><strong>Toll-Free:</strong> 1.888.760.2206</td>
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<tr>
<td><strong>Fax:</strong> (810) 760.6949</td>
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<tr>
<td><strong>Email:</strong> <a href="mailto:msdb-outreach@michigan.gov">msdb-outreach@michigan.gov</a></td>
</tr>
<tr>
<td><strong>Website:</strong> <a href="http://mde-lio.cenmi.org">http://mde-lio.cenmi.org</a></td>
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<th><strong>Michigan Parents of Visually Impaired</strong></th>
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<tbody>
<tr>
<td><strong>Phone:</strong> (989) 855.2430</td>
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<tr>
<td><strong>Email:</strong> <a href="mailto:MPVI@intergate.com">MPVI@intergate.com</a></td>
</tr>
<tr>
<td><strong>Website:</strong> <a href="http://www.mpvi.org">www.mpvi.org</a></td>
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<tr>
<th><strong>Michigan Association for DeafBlind</strong></th>
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<tr>
<td><strong>Website:</strong> <a href="http://dir.groups.yahoo.com/group/MichiganAssociationDeafBlind/">http://dir.groups.yahoo.com/group/MichiganAssociationDeafBlind/</a></td>
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<th><strong>Self Help for Independency in Michigan</strong></th>
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<tr>
<td><strong>Equalizing the DeafBlind</strong> (SHI-M=DB)</td>
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<tr>
<td><strong>Jill Gaus</strong></td>
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<tr>
<td>3123 Catalpa Drive</td>
</tr>
<tr>
<td>Jackson, MI 49203</td>
</tr>
<tr>
<td><strong>Phone:</strong> (517) 764.6178</td>
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<tr>
<td><strong>Email:</strong> <a href="mailto:jgaus@sbcglobal.net">jgaus@sbcglobal.net</a></td>
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<tr>
<td><strong>Website:</strong> <a href="http://www.shimdb.org">www.shimdb.org</a></td>
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<tr>
<td>DeafBlind Resources</td>
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| **Helen Keller National Center for Deaf-Blind Youths and Adults** | **Helen Keller National Center**  
141 Middle Neck Road  
Sands Point, NY 11050  
**Phone:** (516) 944.8900, ext. 253 (TTY)  
(720) 457.3676 (VP)  
**Email:** janet.gilmore@hknc.org  
**Website:** www.hknc.org  |
| **American Association of the DeafBlind** | **American Association of the Deaf-Blind**  
8630 Fenton Street, Suite 121  
Silver Spring, Maryland 20910-3802  
**Phone:** (301) 495.4402 (TTY)  
(301) 495.4403 (V)  
**Fax:** (301) 495.4404  
**Email:** aadb-info@aadb.org  
**Website:** www.aadb.org  |
| **National Consortium on DeafBlindness** | **National Consortium on Deafblindness**  
The Teaching Research Institute  
345 N. Monmouth Ave  
Monmouth, OR 97361  
**Phone:** (800) 438.9376 (V)  
( 800) 854.7013 (TTY)  
**Fax:** (503) 838.8150  
**Email:** info@nationaldb.org  
**Website:** www.nationaldb.org  |
| **National Family Association for DeafBlind** | **National Family Association for Deafblind**  
141 Middle Neck Road  
Sands Point, NY 11050  
**Phone:** (800) 255.0411  
**Fax:** (516) 883.9060  
**Email:** nfadb@aol.com  
**Website:** www.nfadb.org  |
| **Perkins School for the Blind: DeafBlind Program** | **Perkins School for the Blind**  
175 North Beacon Street  
Watertown, MA 02472  
**Phone:** (617) 924.7502  
**Fax:** (617) 926.2027  
**Email:** Barbara.mason@perkins.org  
**Website:** http://www.perkins.org/inside-perkins/deafblind-program/  |
| **DeafBlind International** | **DeafBlind International**  
**Website:** www.deafblindinternational.org  |
| **The CHARGE Syndrome Foundation** | **CHARGE Syndrome Foundation, Inc.**  
141 Middle Neck Rd.  
Sands Point, NY 11050  
**Phone:** (516) 684.4720  
**Toll-Free:** (800) 442.7604  
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