“From the Director’s Desk” By: Beth Kennedy

It is difficult to believe that Year 1 of the grant cycle is already drawing to an end! We have accomplished a great deal, paving the way for even more to get done in Year 2.

In this issue, we have submissions by family members, great information on adult services and guardianship, a recap of our Puberty and Sexuality training, important information about the new interpreter law and testing procedure, and Upcoming Events.

As you read through this issue, please keep in mind that DB Central staff members are here to assist you as you plan for your child/student’s future. Nicole and I can discuss your concerns via phone and/or e-mail and address them by offering information, distance consultation, and/or an onsite visit.

Please be sure to watch for upcoming trainings, listed in this newsletter, as well as advertized on our website and via postal and electronic mailings. We will be offering regional trainings throughout the grant year.

If you have not joined our professional or family e-mail lists, please contact our office to let us know of your interest. We continue to try to streamline our services and utilize environmentally friendly methods for accomplishing our work. Please be sure that we have your e-mail so that you can receive the newsletter electronically.

Have a great school year!
We had a great time at the (CHARGE) conference---we haven't been to one in 8 years so it was really good to be surrounded by so many professionals and families—it always inspires me and reassures me that all the hard work is worth it and to keep pushing forward.

My favorite session on Friday was the very first one by Bryan D Hall, "How CHARGE Association was identified..." I thought I knew the history, but this was a great story about how one person's interest and hard work can make such a huge difference for so many. His observations and studies helped to document the recurring patterns he found in children with choanal atresia, which then helped to identify CHARGE Association. I learned something new about how this Syndrome was first discovered and can't help but be thankful for him and the others who helped discover this Syndrome. The case studies he presented just amazed me, since some were back in the 70's and we have come so far in medical care and knowledge since then.

My favorite session on Saturday was by Diane Haynes, "Constructing meaningful conversations." I thought Diane Haynes was terrific! She had great examples of different ways to communicate, and how to interact with others. She explained proprioception in a way that everyone could understand and appreciate. It was a great reminder of why our kids crave movement and how it helps them to process all of the input they receive. I also liked her advice to reduce “verbage” and to use other senses—I need to remind myself of that when I start to lecture and Cody tunes me out!

On Sunday, after breakfast we took a trip into Chicago—wow! Every part of the trip was an adventure, from the van ride to the train station, to riding on our 1st train to Union Station. We packed as much as we could into our trip, we rode in our first taxi—(very expensive), our first city bus—(you needed exact change & had to learn the bus route), our first water taxi—(this was so fun) and walked and walked. Cody did better walking and adapting to the crowds than Vic did! We had a great time and made some great memories. Cody thought he was a pro on the way home and wanted to stand during the bus ride and hold onto the strap like in the movies, and he learned how to read the train schedule and counted down the stops to ours. I found the train station to be huge, noisy and somewhat overwhelming but Cody loved it!
Signing Time!

For the Troupe family, one of the highlights of this year's CHARGE conference was getting to meet Rachel from Signing Time (Matthew's favorite thing to watch). When she started signing the theme song to him, he got so excited that he nearly jumped into her arms!

Of the experience, Matthew's mom says, “It was awesome to see him so excited. [Rachel] is a rock star in our house. So, of course, I had to have her hold 1 week old Sarah Anne as well, because I am sure that it will be one of her favorite shows as well (she won't have much choice in our house).”

Already, Matthew and Sarah Anne enjoy watching Signing Time together. Matthew's mom told us, “We try to give Matthew daily opportunities to interact with the baby. Sometimes he’s open to it and sometimes not.”

A video of Matthew meeting his sister for the first time can be viewed at http://www.youtube.com/watch?v=LIUCmmtB6ql.

Matthew with Rachel from Signing Time

Matthew enjoying his favorite pastime—sitting in his recliner watching Signing Time—with new sister Sarah Anne.

Two Higher Education Scholarships Available to Individuals with CHARGE Syndrome

The Bella Cavallo Foundation Scholarship Program is offering two scholarships to individuals with CHARGE syndrome who are seeking to further their education beyond high school. The program will award one grand-prize scholarship in the amount of $1,000, and one runner-up scholarship in the amount of $500. To be eligible, applicants must have been diagnosed with CHARGE syndrome, be a high school graduate OR have the equivalent of a high school degree OR plan to graduate before August 31, 2010, and have maintained a cumulative GPA of 2.8 or higher throughout high school and/or college. Applications must be submitted by December 31, 2009. For more information and application materials, visit: http://thebellacavallofoundation.org/scholarship.pdf.
Sexuality Education for Students Who Have Multiple Disabilities Proves to be Sought-After Topic

By Nicole Bruce

Over 150 family members, teachers, consultants, social workers and other professionals attended Addressing Puberty & Sexuality Concerns for Students Who Have Multiple Disabilities at Oakland Schools on August 10. Presenter Robbie Blaha, from Texas School for the Blind and Visually Impaired, spent the day discussing the complex nature of teaching sexuality education to individuals with multiple disabilities, including DeafBlindness. Pat Love-Sypho, a consultant for Michigan Department of Education Low-Incidence Outreach (MDE-LIO), also shared information on the materials, models and services available from MDE-LIO to help teach this topic to individuals who have a vision loss, are DeafBlind or have other disabilities. As evidenced by the large audience and the group’s active participation, the topic of puberty and sexuality is of major concern for people living and working with individuals with multiple and low-incidence disabilities across the state.

Of the evaluations received (126/154), nearly 80% of respondents felt that they had either no, or only some, knowledge base about the topic. Over 85% of respondents felt that the training provided them with new knowledge. Additionally, all respondents felt confident that they would share the information they received with others.

A small group of professionals convened on August 11, following the training, to discuss the importance of continuing training efforts focused on this topic. The group, Michigan Collaborative on Accessible Sexuality Education for Students with Multiple Disabilities (MiCASE), worked to brainstorm the resources necessary to continue training efforts, as well as those needed to develop training materials and a system for offering statewide consultation and coaching related to sexuality education.

The training, a collaborative effort between DeafBlind Central, MDE-LIO and Oakland Schools, was offered free-of-charge. State board continuing education units as well as social work continuing education credits were offered through MDE.

MDE– Low Incidence Outreach Provides Technical Assistance for Sexuality Education

MDE-LIO has been available to provide technical assistance to teachers, parents, and general educators that work with students with visual impairments. Assistance may be in the following manner:

- Loan of gender models (List of Human Reproductive Models and Contraceptives-Word Doc) available from MDE-LIO
- Consultation about appropriate resource materials
- Loan of resource materials

For more information contact: msdb-outreach@michigan.gov or call 888.760.2206
Are You Eligible for Vocational Rehabilitation Services?

Vocational rehabilitation provides services to help eligible persons with disabilities gain and maintain competitive employment. Michigan has two state Vocational Rehabilitation agencies: Michigan Rehabilitation Services (MRS) and Michigan Commission for the Blind (MCB). You are eligible for Vocational Rehabilitation (VR) services from these agencies if you...

**Michigan Rehabilitation Services:**
- Have an existing physical or mental impairment
- Have vocational or work-related barriers due to a disability
- Require VR assistance to obtain and maintain employment
- Have the ability to benefit from VR services that may lead to employment

In order to apply for VR through Michigan Rehabilitation Services, you must complete an MRS application form which will help determine whether or not you are eligible for services. You also will be required to attend an orientation/intake interview for an overview of MRS and to ask any questions you may have. For more information on employment-related services from MRS, visit www.michigan.gov/mrs.

**Michigan Commission for the Blind:**
- Have a visual impairment which constitutes or results in a substantial impediment to employment and/or independent living
- Can benefit in terms of employment and independent living outcome
- Require services to prepare for work and maintain employment

Michigan Commission for the Blind limits services to those who are blind or have visual impairments. For more information on employment-related services from the Michigan Commission for the Blind, call toll-free: 1-800-292-4200 (voice), 1-888-864-1212 (TTY), or visit www.michigan.gov/mcb.

*If you have been determined to have a disability by the Social Security Administration and receive either Social Security Disability Insurance (SSDI) or Social Security Income (SSI), you will be considered eligible for services from both agencies.

**New Program Seeks to Make Alternative Textbooks for Visually Impaired Students Available Faster**

AccessText, a new service released in beta version this August, is an online database that makes it simpler for disability-student services at colleges to track down alternative forms of course materials from book publishers. When electronic versions do not already exist, the college may get permission to scan the pages of a book so a student can make the font larger or use other text-to-speech or refreshable Braille reading devices. In addition, colleges will be able to share materials with other approved institutions, so book-scanning efforts need not be repeated at multiple institutions. When AccessText goes live in July 2010, members will pay between $375 and $500 for the program on a sliding scale based on the size of the institution.
As the parent of a child with special needs, it is important that you understand what guardianship is, as well as how it may affect you or your loved ones. As a parent, you have probably been very involved in making decisions for your child regarding medical care, education, housing, financial matters, and more; in essence, you have acted as your child’s guardian. Once your child turns 18, you will no longer have the right to make decisions for him or her, unless you apply to a court for guardianship rights. It is important to be familiar with guardianship options so that you and your child/family can make the choice that best suits your adult child.

A guardian is a court-appointed person who makes decisions on behalf of your adult child. For individuals with developmental disabilities that began before the age of 22, there are two types of guardians: plenary guardians, who make almost all decisions (such as where to live, consent for medical treatment, etc.), and partial guardians, who have the right only to make decisions on specific issues designated by the court when the adult with disabilities is deemed to lack the capacity or legal competence to make those decisions for him or herself.

To institute guardianship procedures, a Petition for Appointment of Guardian must be filed with the Probate Court in the county in which you live. The petition involves areas such as the nature of the “incapacity”, the reason for guardianship, names of the proposed guardians, and information regarding the individual’s property. Once the petition has been filed, the court may appoint a temporary guardian (Ad Litem) to determine whether there is a need for guardianship and if proposed guardian is appropriate. A hearing will be scheduled, which your child will be required to attend.

An adult with disabilities does have the right to forego a court appointed guardian if he/she can manage his/her own life, even if help is required, to do so. The court should not assign a guardian if the individual can take care of him/herself and make informed decisions, with or without help from others. In order to prove that a guardian is not needed, the court will need to see/hear information that explains how the individual’s needs could be met without a guardian. This can be accomplished a number of ways. Some examples are to show that the individual can understand and give permission for medical treatments (even if other people help him or her to understand); understand and release information about him/herself; make a home for him/herself or live in a place where his/her needs are met; take care of personal items and buy food, clothing, and other needs (or can make sure someone else does it for him/her); arrange for education; and handle money or arrange for someone to handle it for him/her.

Witnesses, such as friends, family, co-workers, etc., can come to court and testify on the individual’s behalf. An Independent Evaluation can also be done by a physician or mental health professional to describe the individual’s skills (the court will pay for this if the individual is not able). Additionally, lawyers familiar with guardianship options can be contacted for more support and information (if the individual does not have a lawyer, the court will appoint one) prior to your hearing.

Several resources are available to learn more about guardianship and guardianship rights. Visit the National Guardianship Association’s website at http://www.guardianship.org for more information and resources, or call the Michigan Protection and Advocacy Service at 800.288.5923.
New Michigan Interpreting Test

In lieu of the QA interpreting examination previously used by the state of Michigan, the Division on Deaf and Hard of Hearing has announced the acquisition of a new interpreting test—the Michigan Board for Evaluators of Interpreters (MI BEI).

On August 27, 2009, the Department of Energy, Labor & Economic Growth signed the contract of acquisition of the MI BEI. The test, which involves both a written English portion and a performance test, has been successfully administered in Texas since 2006. As an added bonus, interpreting reciprocity will be established with the state of Texas so that BEI certification, whether obtained in Michigan or in Texas, will be recognized in both states.

The performance test will include: Expressive Interpreting, Expressive Transliterating, Receptive Interpreting, Receptive Transliterating, and Sight Transliteration. Examinees will be required to pass the written English portion of the MI BEI test before moving on to the performance portion.

The Division estimates that testing will begin in late October. In the meantime, start preparing! The Division urges individuals to review a sample of the written English test, which can be found at http://www.dars.state.tx.us/dhhs/samptest.shtml, to get an idea of what to expect and how to prepare to pass the written portion of the examination. A word of caution! Michigan’s standards and rules regarding the test will be different from those of Texas, so do not assume that all information on the Texas website will apply to Michigan.

Visit www.mcdc-dodhh.org for updates and information regarding the new interpreting test.

Research Participation Opportunity for Adolescents and Adults with CHARGE Syndrome

Adolescents and adults 13-years and older who have CHARGE syndrome (as well as their parents/guardians) are invited to participate in a research study being conducted by Dr. Kim Blake, MD, and Dr. Nancy Salem-Hartshorne, PhD, to evaluate quality of life growing up with CHARGE syndrome.

The study asks questions about participants’ past and present lives with CHARGE syndrome, and consists of a 30-45 minute questionnaire concerning their “quality of life” (i.e., the good and not so good things in their lives).

Volunteers will be sent a packet which includes consent forms and the questionnaire, which must be mailed back to the researchers.

If you wish to participate in this study, contact Nancy Hartshorne at harts1ns@cmich.edu or (989) 774-6469, or Dr. Kim Blake at kblake@dal.ca or (902) 470-6499 (Atlantic Standard Time).
**Michigan Association for the Deaf Blind Now on GoodSearch!**

If you haven’t heard of GoodSearch, you’re not alone. GoodSearch is an internet search engine powered by Yahoo! Search which works like any other search engine—you can search the internet for web pages, videos, images, shopping, and more. So what’s the catch? GoodSearch will donate the advertising proceeds for any search you submit to the charity of your choice. You can even see how much your charity has raised.

Michigan Association for the Deaf Blind (MADB) is now a participating charity on GoodSearch. If you would like to help out MADB while surfing the web, go to [www.goodsearch.com](http://www.goodsearch.com), select Michigan Association for the Deaf Blind from the list of participating charities, and start searching. You can also make GoodSearch your home page!

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**Low-Cost and Free Braille Books from Seedlings Braille Books for Children**

**Low-Cost Braille Books**

Seedlings Braille Books for Children now has 1,000 Braille books available, ranging from Print-Braille-&-Picture Books for toddlers and preschoolers (like *Clifford's Animal Sounds* and *Curious George at the Zoo*) to 2-volume novels for teens and tweens. Books are sold for a fraction of their production cost to keep the prices affordable for you. For a full list of available titles, visit [http://www.seedlings.org/whatsnew.php](http://www.seedlings.org/whatsnew.php).

**Free Braille Books**

Through Seedlings’ Book Angel Program, visually-impaired children in the US can receive two free books from Seedlings per year. You send a list of four Seedlings' books that you would like to have and Seedlings will send two of them to you free of charge! This program is almost over for 2009, so don't delay. Register today at [http://www.seedlings.org/bkangel2009.php](http://www.seedlings.org/bkangel2009.php).

**ABCs for VIPs**

In September 2009, Seedlings will launch a new program in concert with the Michigan Department of Education’s Low Incidence Outreach Division called ABCs for VIPs (Visually Impaired Preschoolers).

ABCs for VIPs will make 1,000 braille books available for loan to teachers, schools, libraries, and individuals throughout the state of Michigan. With access to this large pool of Print-&-Braille books, teachers will have the materials needed to encourage early braille reading, libraries will have books available for ALL children, and parents will be able to nurture the love of reading at home.

If you are interested in borrowing Print-&-Braille Books when the ABCs for VIPs Program begins in September, go to the [Michigan Department of Education--Low Incidence Outreach website](http://www|michigan.gov) or call 888-760-2206.
National Federation of the Blind Testifies Before Congress for Support of the Google Books Project Settlement

By Deirdre McDonald

In case you have not heard of the Google Books project, here is a brief rundown. The Google Book Search (or Google Books Project) was started in 2004 in an effort to digitize millions of books and make them available to the public via the internet (for a cost, of course). In 2005, a class action lawsuit was filed against Google by the Authors Guild and several publishers, who claimed the digitizing process infringed their copyrights on a massive scale. A settlement was reached in October 2008: Google agreed to pay $125 million for the right to legally digitize millions of books still under copyright, and then to split the proceeds from selling those books with publishers and authors. The agreement would allow online readers to search for and buy books in total or page-by-page, and provide U.S. libraries with free access to the database, effectively making literature and information more accessible than ever before.

Many organizations are opposed to the settlement because, as a class action lawsuit, the settlement will affect thousands of authors who may have their rights signed away by organizations who do not represent their interests. In addition, some claim the settlement provides Google an effective monopoly in the scanning and exploitation of millions of works whose copyright holders cannot be located or choose not to involve themselves in the class action.

The settlement is currently pending Congressional approval. On September 10, 2009, The National Federation of the Blind testified before the House Judiciary Committee to advocate for approval of the proposed settlement. The Federation also urged the United States Department of Justice, which is reviewing the terms of the settlement, to support the agreement.

Dr. Marc Maurer, President of the National Federation of the Blind, told the House Judiciary Committee: "The Google Books settlement is a major step forward in advancing the civil rights of blind Americans and others who cannot read print because it substantially increases our opportunities for education and employment." He went on to say that the Justice Department should respect the agreement of the parties to the settlement and allow its access provisions to be fully implemented. In doing so, he said, “the government will send a strong message that it values the participation of the blind in society and believes that we should have access to all of the information to which our sighted friends and colleagues have access."

The outcome and effects of the proposed settlement are yet to be determined. Of course, if the settlement is approved and the Google Books Project moves forth, it will be a huge benefit to the visually impaired community. We will continue to monitor the progress of this story and keep you updated.

Family and Professional Needs Survey Results Are In!

A big thank you to all the families and professionals who took the time to complete our Family and Professional Needs Surveys! We have compiled the responses and received a lot of valuable feedback.

Both our families and professionals agreed that the most important training topics are Communication Strategies, Real-Life Learning/Functional Learning/Teaching Strategies, and Assistive Technology.

In response to your request for more training in these areas, we plan to schedule regional trainings throughout the state on each of these topics during our next grant year.

If you have not sent in your Family Needs Survey or Professional Needs Survey, please feel free to complete it and send it back to us. Your input is very valuable to us!!!
# UPCOMING EVENTS

**September 20 - 25, 2009**  
**Expanding the Curriculum for Travelers Who Are Deaf-Blind**  
Where: Helen Keller National Center for Deaf-Blind Youths and Adults, Sands Point, NY  
Participants will acquire the tools, strategies, and resources needed to teach a comprehensive O&M program to non-cognitively delayed DeafBlind adults. Participants must be members of one of the following categories and currently teaching or supervising in their field: COMS, NOMC, agency-trained mobility instructors with 5 yrs exp and previous supervision under a certified specialist, or dog guide trainers.

**October 12, 2009**  
**Spread the Word to End the Word**  
Where: Central Michigan University, Plachta Auditorium  
Our language frames how we think about others. Join Special Olympics Michigan in helping to eliminate the use of the “R” word. Will feature a presentation and athlete panel. Free and open to the public. 7:00—8:00 pm.

**October 17, 2009**  
**Central Michigan University Disability Awareness Fair**  
Where: Central Michigan University, Finch Field House  
Fun family event promoting services and products. Free and open to the public. 10 a.m. to 3 p.m.

**October 24, 2009**  
**2009 Discover Conference**  
Where: Watertown, MA  
The 2009 Discover Conference is designed for families of school age children who are blind, visually impaired and deafblind including those with additional disabilities. It will be held on Saturday, October 24 at Perkins’ Watertown, MA campus. Online registration will be active in early September 2009. For updates, visit www.Perkins.org/Discover.

**November 12 - 15, 2009**  
**Getting In Touch With Literacy Conference**  
Where: Costa Mesa, CA  
GITWL ’09 will focus on all forms of literacy, including print, braille, auditory, tactile graphics comprehension and the use of assistive technology. Mark your calendars now and plan to attend this international event focusing on literacy for individuals with visual impairments of all ages and developmental levels. For more information and to register, visit www.gettingintouchwithliteracy.com.

**November 13 - 15, 2009**  
**2009 AER Regional Conference**  
Where: Cleveland, Ohio  
Registration is now open for the 2009 AER Regional Conference, featuring COMA’s O&M Conference Within a Conference. For more information or to register, please visit http://www.aerbvi.org/regionalconf/.

**November 18 - 21, 2009**  
**TASH 2009**  
Where: Pittsburgh, PA  
This year’s theme is “If not us, who? If not now, when?” The conference will focus on how WE can act NOW to disseminate information, facilitate change, and empower those with significant disabilities to be active participants and create lives of their own. For more information, visit http://www.tash.org/2009tash/.

**December 7 - 9, 2009**  
**2009 OSEP National Early Childhood Conference**  
Where: Arlington, VA  
For more information, visit http://www.nectac.org/~meetings/national2009/splash.html.

**January 16, 2010**  
**Challenge Mountain**  
Where: Petoskey, MI  
Save the date!

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