From the Director’s Desk - By Beth Kennedy

Is it just me, or is time passing more quickly than ever? On October 1, we begin the final year of this five year grant cycle. While we have achieved a great deal, it hardly seems like it should be time to start wrapping up all that we set out to do in our grant proposal! Please watch your mail and email for updates and possible requests for support as we await decisions within the United States Department of Education regarding continued funding.

We decided to print this issue and mail it via post, due to the number of new family members and professionals we have found in the process of collecting census information. We hope that it will prompt those of you who are new to us to learn more, either online or by contacting someone in the office. Having an issue in hand may also entice those of you who are familiar with the project to access other issues online, and remind you of our services. We will return to our promise to “go green” after this issue, so make sure that we have your email address on file. For those of you who cannot access the newsletter online, please be sure to let us know—we will be happy to print and mail each issue to you.

In addition to project updates and useful resources, this issue has articles written by people who have received scholarship monies from DB Central in order to pursue leadership activities and/or trainings. Through the generosity of families who establish memorial funds through the project, we are able to provide support to people beyond the scope of what our grant funds would allow. If you would like to learn more about these monies, please contact me, or Jennifer.
Challenge Mountain is a fully adaptive ski hill between Boyne City and Petoskey, Michigan dedicated to providing therapeutic recreation to youth with disabilities.

The nonprofit program is one of very few in the Midwest!

Challenge Mountain has offered to create a ski experience for you and your family. Necessary adaptive equipment and trained volunteers will be available to offer a fun day in the snow and a safe, but thrilling opportunity to ski—regardless of ability!

Ski equipment, instruction, and lunch expenses will be paid by DB Central. Parents and siblings may ski free of charge as well. Information and registration forms will be mailed to families in November. For more information, contact Jennifer by phone: (989)774.7888, VP: (989)546.4626, toll-free: (888)758.0508, or email: bigelje@cmich.edu.

In July 2012, Dr. Barbara McLetchie received the Anne Sullivan Award, acknowledging a lifetime of service and dedication to the field of deafblindness.

Dr. McLetchie ran the teacher training program at Boston College for many years. She continues educating people around the world through her work as an international consultant for Hilton/Perkins.

Congratulations on a well-deserved achievement!
4th Annual disABILITY Awareness Expo

A valuable one-stop event with resources that are both informational and entertaining.

10 a.m. to 2 p.m.
Saturday, Oct. 13, 2012
Education and Human Services Building
on the CMU campus in Mount Pleasant

You’re invited
As an individual, a family member, or a caregiver of a person living with a disability, you’re invited to discover the many area resources available to help enhance and improve quality of life at the CMU disABILITY Awareness Expo.

This family focused event will highlight the university’s monthlong effort to increase disability awareness this October. In addition to information tables and vendors, the event will include:

- Interactive demonstrations
- Engaging activities for children
- Therapy dogs
- Refreshments

As Oct. 13 draws closer, check out the website – cmich.edu, keywords Disability Expo – for details about the disABILITY event.

For more information about the disABILITY Awareness Expo:
Contact Beth Kennedy, DeafBlind Central director, at 989-774-2726
or kenne1bm@cmich.edu

CMU is an AA/EO Institution (see cmich.edu, keyword: AAEO).

Individuals with disabilities requiring an accommodation to attend the Disability Awareness Fair are asked to call 989-774-2726 at least two weeks before the event.
Hi, my names Ashley Medes, I was recently in a pageant called National American Miss, in Dearborn, this past July. I thought it would be an amazing opportunity for me to learn face to face interview skills, exposure to using a microphone and talking in front of a large group of people. I learned lots of good leadership skills that I hope will come in handy when I become an advocacy lawyer. I also learned that if you set your mind to something, and work hard at it, you can do anything. Without your help sponsoring me, I wouldn’t have had these amazing experiences that I’ll remember forever. Thank you DB Central!

 Ashley’s talent for the pageant was signing to the song “What Makes You Beautiful”.

A Conference on Wolf-Hirschhorn Syndrome

By: Jacqueline J. Leich

I recently attended the 20th Annual 4p- Support Group Conference in Indianapolis, Indiana. What is 4p-? To make it easier to understand 4p- (pronounced four “p” minus) is a condition that affects the fourth chromosome. This condition can be known as simply 4p- or it can also be known as “Wolf-Hirschhorn Syndrome.” What determines which name it is? The amount of the deletion is what determines the name of the syndrome. If your deletion is found to be in the region where it is called the “critical region” it becomes Wolf-Hirschhorn Syndrome or WHS for short. My daughter, Anna McCann has WHS.

The degree that this syndrome affects the child varies greatly. The range of abilities our kids have is very encouraging. Some of our kids have taken their first steps at age 2, while some of our kids have taken their first steps at age 20. My daughter is ten years old and is not taking steps yet. We have been very excited and overjoyed that she recently began sitting on her own without support. Our family has been attending the bi-annual conferences for the past ten years. This year we were able to put Anna on the floor for the group picture and she was able to sit alone for the shot. I have been fascinated by her ability to surprise me with her new found strengths.

Speaking of strength Anna and our kids are great suppliers of it. When we get together at these gatherings we can be compared to a mini-reunion. We get to see how much our children have grown. We see new abilities and new struggles that we can help each other with. The hotel is full of all families with children of all different ages. These children share so much uniqueness the five days we share are completely rewarding. Just going to the elevator is exciting as you meet families and get to look at how cute and special and the “same” they are to yours. When their child performs the same mannerisms as yours the feeling of not being alone in this syndrome is great. Talking with others who just plain “get it” is beyond words.

My daughter has brought me so much knowledge. She has given me trips to places I would not have gone to if I was not her mother. I am proud to be able to attend her gatherings and keep up with the families I look to for support.
FCC LAUNCHES NATIONAL DEAF-BLIND EQUIPMENT DISTRIBUTION PROGRAM

The FCC has announced the launch of the National Deaf-Blind Equipment Distribution Program (NDBEDP), effective July 1, 2012. The FCC also has announced the selection of 53 entities certified to distribute equipment and provide related services under the NDBEDP in each of the 50 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands.

The NDBEDP is mandated by the Twenty-First Century Communications and Video Accessibility Act (CVAA), which provides funding of up to $10 million annually for the distribution of communications equipment to low-income individuals who are deaf-blind. The FCC will administer the NDBEDP as a pilot program for two to three years.

National Deaf-Blind Equipment Distribution Program

Background

The Twenty-First Century Communications and Video Accessibility Act of 2010 (CVAA) authorizes the Federal Communications Commission (FCC) to provide funding for local programs to distribute equipment to low-income individuals who are deaf-blind (who have hearing loss and vision loss). The FCC may use up to $10 million annually from the interstate Telecommunications Relay Service fund for this purpose.

Pilot Program

In 2011, the FCC established the National Deaf-Blind Equipment Distribution Program (NDBEDP) as a pilot program. The pilot program will run for two years, beginning July 1, 2012. The FCC may extend the program for a third year. The pilot program will provide valuable information that the FCC will use to help develop and implement an effective and efficient permanent deaf-blind equipment distribution program.

How does the pilot program operate?

For the pilot program, the FCC selected and certified one entity in each of the 50 states, plus the District of Columbia, Puerto Rico, and the Virgin Islands, to receive FCC support to distribute equipment to low-income individuals who are deaf-blind. The FCC allocated a minimum of $50,000 to each of the 53 certified programs, plus additional funding based on the size of each state’s population. As a result, states with large populations were allocated larger amounts of funding than states with small populations.

The FCC also set aside $500,000 each year for the Perkins School for the Blind to coordinate outreach to promote this new equipment distribution program nationwide.

Who is eligible to receive equipment?

Under the CVAA, only low-income individuals who are deaf-blind are eligible to receive equipment. Applicants must provide verification of their status as low-income and deaf-blind.

For this program, the CVAA requires that the term "deaf-blind" has the same meaning given in the Helen Keller National Center Act. In general, the individual must have a certain vision loss and a hearing loss that, combined, cause extreme difficulty in attaining independence in daily life activities, achieving psychosocial adjustment, or obtaining a vocation (working).

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The FCC defines "low income" to mean not more than 400% of the Federal Poverty Guidelines, as indicated in the following chart:

### 2012 Federal Poverty Guidelines

<table>
<thead>
<tr>
<th>Number of persons in family/household</th>
<th>400% for everywhere, except Alaska and Hawaii</th>
<th>400% for Alaska</th>
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<tr>
<td>1</td>
<td>$44,680</td>
<td>$55,880</td>
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<td>2</td>
<td>$60,520</td>
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</tr>
<tr>
<td>8</td>
<td>$155,560</td>
<td>$194,480</td>
<td>$178,840</td>
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For each additional person, add $15,840

Source: U.S. Department of Health and Human Services

**What kind of equipment can be distributed?**

The equipment distributed must be designed to make telecommunications (such as wireline and wireless telephone communication), advanced communications (such as Internet-based voice communication, e-mail, instant messaging, and interoperable video conferencing services), and access to the Internet (including information services) accessible. The equipment distributed may be hardware, software, or applications, separate or in combination, mainstream or specialized. The equipment must meet the needs of the deaf-blind individual to achieve access. Certified programs may also provide equipment warranties, maintenance, and repairs for such equipment, depending on available funding.

**Besides distributing equipment, what will the NDBEDP certified programs do?**

Certified programs will inform their communities about this new program to distribute equipment to low-income residents in their states who are deaf-blind. They will verify that applicants are eligible to receive equipment. They will assess each applicant’s communications equipment needs to select appropriate equipment to meet those needs. They also may help install and provide training for the equipment distributed.

**How do I find the certified program that serves my state?**

Information about how to find the NDBEDP certified program in your state will become available during the summer of 2012 on the FCC website, by calling 1-888-CALL-FCC (1-888-225-5322) voice or 1-888-TELL-FCC (1-888-835-5322) TTY, or by sending an email to dro@fcc.gov.
The National Family Association for Deaf-Blind (NFADB), originally started by and for families of individuals who are deaf-blind, now extended to all persons and organizations that wish to support individuals and families who are deaf-blind, held its first National Symposium July 13-15, 2012 at the Texas School for the Blind and Visually Impaired in Austin, Texas.

Fifty-one family leaders and four self-advocates from 24 states, Washington, DC and Puerto Rico attended the 2012 NFADB Symposium, “Preparing Leaders for Today and Tomorrow: Family Leadership in the 21st Century.” The overarching goal of the Symposium was to give family leaders the understanding and knowledge needed to be effective in advocating for individualized communication supports. These supports are necessary to allow individuals with deaf-blindness equal access to auditory, visual and environmental information that is often not accessible to them.

The leaders were given information on three crucial individualized supports for those with deaf-blindness: Interveners, Interpreters and SSP’s (Support Service Providers) and how when properly trained, these supports can dramatically enhance life for someone with deaf-blindness. At the end of the Symposium, the family leaders were asked to identify their vision for individual supports for a person with deaf-blindness. They addressed not only their personal vision, but also what they would like to see happen at the local, state and national levels. The theme of collaboration and leading other parents in advocating for individualized supports became universal at the NFADB 2012 Symposium.

The National Family Association for Deaf-Blind is a nonprofit 501(c)3 organization which exists to empower the voices of families of individuals who are deaf-blind and advocate for their unique needs. If you would like more information regarding NFADB, or are interested in membership, please contact NFADB at 800.255.0411, NFADB@aol.com

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Comments from Individuals in Michigan that attended the National Symposium

Michigan had three individuals attend the Symposium; Jennifer Bigelow-Stambaugh, DB Central Family Support Coordinator; Roxann Davis, Michigan Association for DeafBlind President and Family Leader, and Gay Corey; Family Leader. All three felt the experience was both educational and inspirational.

Jennifer commented, “As Family Support Coordinator for DB Central, I was pleased that Michigan had two Family Leaders that were able to participate in the Symposium. It was a great opportunity to have Family Leaders from various states share time together and learn more about individualized communication supports. The information shared will be helpful to family leaders in their advocacy efforts.”

Roxann noted, “It helped me to see that there are so many opportunities that are out there when individuals are fully supported by interveners, interpreters, and support service providers.” She felt, “It was great to hear the personal stories which influenced how I have advocated for my daughter this current school year.”

Gay enjoyed the experience and noted that, “Participating in the symposium gave me greater insight into the roles that interveners, interpreters and SSP’s provide. There are individuals who are deaf-blind that could truly benefit from a properly trained communication support specialist. The 1st challenge is to identify persons whose lives could be significantly enhanced with the support of an individualized intervener, interpreter or SSP. The next challenge is to find/train interveners, interpreters and SSP’s. The biggest challenge is to make it work through advocacy.”
Upcoming Events

**September 27, 2012**
Can You Hear Me Now? Telephones and Cell Phones for People with Hearing Loss
WEBINAR
Information: http://www.formdesk.com/michigandisabilityrightscoalit/Canyouhearme

**October 8, 2012**
Everything My Child Needs to Know About Sexuality But, I Was Afraid to Tell!
Workshop ($10—scholarships available)
Where: Charlotte, MI
For More Information: 800.359.3722

**October 13, 2012**
4th Annual Disability Awareness Expo
Where: Education and Human Services Building—CMU
For More Information: cmich.edu, keywords Disability Expo or 989.774.2726

**October 20, 2012**
Independent Skills Living Workshop: It’s Laundry Day!
Where: C.O.O.R. ISD, Roscommon, MI
When: October 20, 2012
For More Information: 517.241.5144 or patrickc2@michigan.gov

**November 8, 2012**
Wrightslaw - Special Education & Advocacy Training Program
Time: 8:00 a.m.-4:30 p.m.
Location: Laurel Manor, Livonia, MI
DeafBlind Resources

DeafBlind Central: Michigan’s Training and Resource Project

Project Director: Beth Kennedy
Family Support Coordinator: Jennifer gelow-Stambaugh
Administrative Secretary: Amanda Patterson
Graduate Assistant: Katie Tennant

DeafBlind Central
Central Michigan University
Sloan 105
Mount Pleasant, MI 48859
Phone: (989) 774.2725
Toll-Free: (888) 758.0508
VP: (989) 546.4626
Fax: (989) 774.1572
Email: dbcen@cmich.edu
Website: www.dbcentral.org

Michigan Families for Hands and Voices

“Hands & Voices”
“What Works for your Child is what makes the Choice right”

Michigan Hands and Voices
P.O. Box 10038
Lansing, MI, 48913
Phone: (517) 241.7066
Email: info@mihandsandvoices.org
Website: www.handsandvoices.org

Michigan Commission for the Blind: DeafBlind Services

Michigan Commission for the Blind
Michigan Department of Licensing and Regulatory Affairs
201 N. Washington Square, 2nd Floor
P.O. Box 30652
Lansing, MI 48909
Phone: (517) 373.2062 (V), (517) 373.4025 (TTY)
Toll-Free: 1.800.292.4200 (V), 1.888.864.1212 (TTY)
Email: DeafBlind@michigan.gov
Website: www.michigan.gov/mcb

Michigan Department of Education: Low Incidence Outreach

Low Incidence Outreach
1505 W. Court Street, Suite 227
Flint, MI 48503
Phone: (810) 760.2206
Toll-Free: 1.888.760.2206
Fax: (810) 760.6949
Email: msdb-outreach@michigan.gov
Website: http://mde-lio.cenmi.org

Michigan Parents of Visually Impaired

Phone: (989) 855.2430
Email: MPVI@intergate.com
Website: www.mpvi.org

Michigan Association for DeafBlind

Website: http://dir.groups.yahoo.com/group/MichiganAssociationDeafBlind/

Self Help for Independency in Michigan Equalizing the DeafBlind

SHI-M=DB

Jill Gaus
3123 Catalpa Drive
Jackson, MI 49203
Phone: (517) 764.6178
Email: jagaus@sbcglobal.net
Website: www.shimdb.org
### DeafBlind Resources

<table>
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<tr>
<th>Helen Keller National Center for Deaf-Blind Youths and Adults</th>
<th>American Association of the Deaf-Blind</th>
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<td>Helen Keller National Center 141 Middle Neck Road Sands Point, NY 11050 Phone: (516) 944.8900, ext. 253 (TTY) (720) 457.3676 (VP) Email: <a href="mailto:janet.gilmore@hknc.org">janet.gilmore@hknc.org</a> Website: <a href="http://www.hknc.org">www.hknc.org</a></td>
<td>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: <a href="mailto:aadb-info@aadb.org">aadb-info@aadb.org</a> Website: <a href="http://www.aadb.org">www.aadb.org</a></td>
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<td>National Consortium on DeafBlindness The Teaching Research Institute 345 N. Monmouth Ave Monmouth, OR 97361 Phone: (800) 438.9376 (V) (800) 1854.7013 (TTY) Fax: (503) 838.8150 Email: <a href="mailto:info@nationaldb.org">info@nationaldb.org</a> Website: <a href="http://www.nationaldb.org">www.nationaldb.org</a></td>
<td>National Family Association for Deafblind 141 Middle Neck Road Sands Point, NY 11050 Phone: (800) 255.0411 Fax: (516) 883.9060 Email: <a href="mailto:nfadb@aol.com">nfadb@aol.com</a> Website: <a href="http://www.nfadb.org">www.nfadb.org</a></td>
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<tr>
<td>Perkins School for the Blind 175 North Beacon Street Watertown, MA 02472 Phone: (617) 924.7502 Fax: (617) 926.2027 Email: <a href="mailto:Barbara.mason@perkins.org">Barbara.mason@perkins.org</a> Website: <a href="http://www.perkins.org/inside-perkins/deafblind-program/">http://www.perkins.org/inside-perkins/deafblind-program/</a></td>
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<td>DeafBlind International Website: <a href="http://www.deafblindinternational.org">www.deafblindinternational.org</a></td>
<td>CHARGE Syndrome Foundation, Inc. 141 Middle Neck Rd. Sands Point, NY 11050 Phone: (516) 684.4720 Toll-Free: (800) 442.7604 Fax: (516) 883.9060 Email: <a href="mailto:info@chargesyndrome.org">info@chargesyndrome.org</a> Website: <a href="http://www.chargesyndrome.org">www.chargesyndrome.org</a></td>
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Don't forget the latest issue of the DB Central Newsletter, DB Star, can always be found online: www.dbcentral.org