

Region 4 PTAC Meeting
August 19, 2015
Learners who experience Deaf-Blindness



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& Family Engagement

National Center on Deaf-Blindness

- As a national technical assistance center funded by the federal Department of Education, NCDB works to improve the quality of life for children who are deaf-blind and their families.
- I am the Initiative Lead for Early Identification/ Referral and Family Engagement and am based in the KS office of NCDB.



What I want to accomplish:

Increase your understanding of:

- The diversity within the population
- The major etiologies of Deaf-Blindness nationally and in your state
- National and state resources related to Deaf-Blindness

& Brainstorm possible ways in which Parent Centers and State DB Projects can enhance collaboration.

National Definition of Deaf-Blindness

Federal definition of deaf-blindness written in the regulations for the Individuals with Disabilities Education Act (IDEA) of 2004:

*Deaf-blindness means concomitant [simultaneous] hearing and visual impairments, the **combination** of which causes such severe communication and other developmental and educational needs that they cannot be accommodated in special education programs solely for children with deafness or children with blindness.*

Definition (cont.)

An important part of the federal definition is that two sensory losses (vision and hearing) combine to create a disability that is very different from either hearing or vision loss alone.

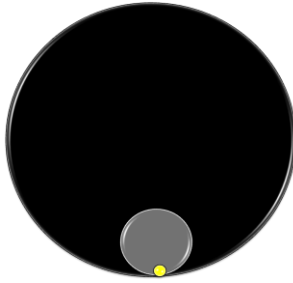


National Child Count

- Each state conducts a census of children and youth who are deaf-blind (birth through age 21).
- Information from all states is compiled and reported in the annual *National Child Count of Children and Youth who are Deaf-Blind*.



Population of Children With Deaf-Blindness



Black circle: All children age 3-21 in the U.S. (~76,600,000)

Grey circle: Children age 3-21 receiving special education (6,535,838)

Yellow circle: Children age 3-21 with deaf-blindness (8,686)

Population of Children With Deaf-Blindness (cont.)

Because deaf-blindness is so rare, school districts often have limited experience working with children who are deaf-blind. They may not have personnel with specialized training in deaf-blindness.



Population of Children With Deaf-Blindness (cont.)

What this means is that families are often responsible for educating schools and other service providers about deaf-blindness. This can be very stressful for families.

Diversity in Deaf-Blindness

- Individuals with deaf-blindness have different combinations of vision and hearing loss or impairment.
- Some have no vision and hearing.



Diversity in Deaf-Blindness (cont.)

- Some individuals have other disabilities in addition to vision and hearing loss.
- There are a wide variety of causes of deaf-blindness and many are associated with additional challenges such as physical disabilities, cognitive disabilities, or health problems.



Key Questions:

Two key questions to ask, when assessing whether a learner has DB:

1. Does she have enough vision to compensate for her lack of hearing?
2. Does she have enough hearing to compensate for her lack of vision?

(John McInnes)

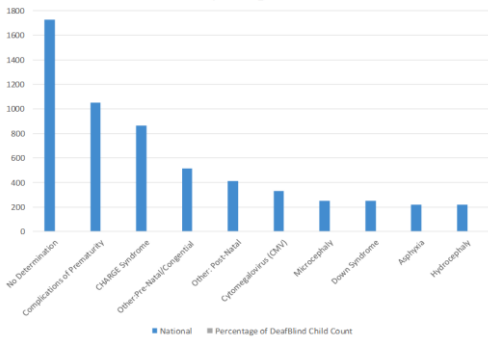
Deaf-Blindness is a Disability

- about INFORMATION GATHERING
- which LIMITS ACCESS



National Prevalence:

2013 Top Etiologies-National



Region 4 Stats

State	Age Group							Total
	0-2	3-5	6-11	12-17	18-21	21+	Unknown/ Missing	
Illinois	13	47	118	139	84	1	0	402
Indiana	4	27	49	84	25	0	0	189
Iowa	3	6	27	26	10	0	0	72
Michigan	10	31	105	101	62	23	0	332
Minnesota	29	45	108	118	34	0	0	334
Missouri	29	19	46	75	21	0	0	190
Ohio	10	27	110	147	49	0	0	343
Wisconsin	7	16	51	55	19	0	3	151
Total	105	218	614	745	304	24	3	1713

Simulation

When you take a break today try the following...
Cover your eyes and try to walk to the bathroom
and wash your hands and then at your lunch.

- How did you feel?

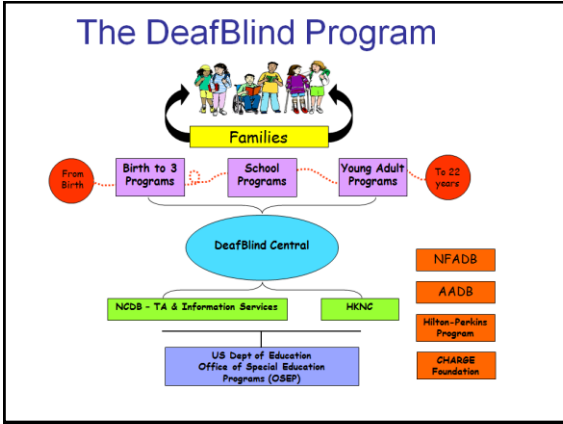
- What was missing for you to feel confident in completing the tasks?

Contacts in your Region:

State	DB Project Contact	Family Specialist
Michigan- DeafBlind Central	Beth Kennedy Beth.Kennedy@cmich.edu (989) 774-2726	Jennifer Bigelow-Stambaugh bigel1je@cmich.edu (989) 774-7888
Illinois- Project Reach: Illinois Deaf-Blind Services	Michelle Clyne mclyne@shillrockcenter.org (630) 790-2474	Maria McCarrick mariamccar@comcast.net (309) 839-0892
Indiana- Indiana Deafblind Services Project	Lisa Poff Lisa.Poff@indstate.edu (812) 237-7679	same
Iowa- Iowa's Deafblind Services Project	Kelly van Dyk kvandyk@iowa-braille.k12.ia.us (319) 472-5221, Ext. 1002	Phyllis McGowan pmcgowan@iowa-braille.k12.ia.us (319) 472-5221, ext 1028

Contacts in your region (cont):

State	DB Project Contact	Family Specialist
Minnesota- Minnesota Deafblind Technical Assistance Project	Deanna Rothbauer deanna.rothbauer@metroccsu.org (612) 638-1531	same
Missouri- Missouri Project for Deafblind Services	Jennie Mascheck jennie.mascheck@msb.dese.mo.gov (314) 776-4320 ext 1250	Ginny Williams (573) 295-4808
Ohio- Ohio Center for Deafblind Education	Deborah Telfer dtelfer1@udayton.edu (614) 785-1163	Leanne Parnell lparnell@ohiodeafblind.org 614-785-1163 x106
Wisconsin- Wisconsin Deafblind Technical Assistance Project	Marcy Dicker marcy.dicker@wesp-dhh.wi.gov (262) 787-9540	Jodi Anderson jodi.anderson@wesp-dhh.wi.gov 262-581-7433.



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 Western Oregon University
 345 Monmouth Ave, OR 97361

Phone: (503) 838.8754
Fax: (503) 838.8150
Email: info@nationaldb.org
Website: www.nationalbd.org

National Family Association for Deaf-Blind (NFADB)

Address:
 141 Middle Neck Road
 Sands Point, NY 11050

Phone: 800-255-0411
Email: NFADB@aol.com
Website: www.NFADB.org

Helen Keller National Center (HKNC)

Address:
141 Middle Neck Road
Sands Point, NY 11050

Phone: (516) 944-8900
Email: hkncinfo@hknc.org
Website: www.hknc.org

**American Association of the Deaf-
Blind**

Address:
PO Box 8064
Silver Spring, MD 20907-8064

Phone: 301-563-9064 Videophone
Email: aadb-info@aadb.org
Website: www.aadb.org

CHARGE Syndrome Foundation

Address:
318 Half Day Rd #305
Buffalo Grove, IL 60089

Phone: (516) 684-4720
Toll Free: (800) 442-7604
Fax: 1-888-317-4735
Email: info@chargesyndrome.org
Website: www.chargesyndrome.org

Families Lead Website



Family Leadership Project

<http://familieslead.org/>

OHOA Deaf-Blind Intervener Learning Modules

A national resource designed to increase awareness, knowledge, and skills related to the process of intervention for students who are deaf-blind. Developed by National Center on Deaf-Blindness.

For a list of partners and contributors visit:
nationaldb.org/ohoamoodle/contributors.html

For more information:
Go to nationaldb.org/ohoamoodle/ or
contact Amy Parker, Ed.D, parkera@wou.edu



National Center on Deaf-Blindness Initiative Groups

The Initiative Groups are:

- Intervener Services
- Early Identification/ Referral
- Technology Solutions
- Family Engagement
- National Child Count
- Literacy
- Transition

www.nationaldb.org

Directions to create a profile can be found here:

<https://nationaldb.org/help/guides/profile>

Once your profile is created, **please join the Family Engagement Initiative** to stay on top of what's happening nationally related to trainings, etc.

State Deaf-Blind Projects and Parent Centers Working Together: Highlighting Collaboration

- Back in the Fall of 2014 OSEP sent letters to all SDBP's and Parent Centers asking for increased collaboration amongst both agencies.
- As a result, a technical work group (TWG) was formed to begin to discuss what could be done to help move the collaborations forward. The TWG is comprised of individuals from SDBP's, NCDB, NFADB and Regional Parent Centers.
- It was determined that the first step was to get an understanding of where states were with their collaborative efforts and then build support to increase collaboration.
- So, in June 2015 the Highlighting Collaboration form was disseminated
- From June until now (August 2015) completed forms have been submitted
- Thus far, 20 states have turned in their forms!!! We would love to get more!
- Now we need your help/ suggestions for sharing the ideas & work going on in the individual states.
- WHY? Because when we share, we are better and more families can be served.
- And also because it's a request to us from OSEP.

I need your ideas & suggestions:

- Have you contacted your SDBP to complete the "Highlighting Collaboration" form?
- How would you like the information that the TWG has collected shared with you all?
- In what ways can NCDB best support increased collaborative efforts amongst the network?
- What information is missing that would assist you in connecting families with needed resources?

Remember Deaf-Blindness is...

- about INFORMATION GATHERING
- LIMITS ACCESS
- EXPONENTIALLY MORE than a hearing loss plus a vision loss

As a result, parents need access to support, training, and resources to promote positive outcomes.

Thank you for your time today!

Please don't hesitate to contact me...

megan.cote@hknc.org

(913) 707-3280 (cell)
