

**ILLINOIS ADVISORY BOARD FOR SERVICES FOR
PERSONS WHO ARE DEAF-BLIND**

**Thursday, March 10, 2011
James R. Thompson Center
100 W. Randolph Street, Room 9-031
Chicago, IL 60601
10:00 a.m. to 2:00 p.m. (lunch break included)**

MINUTES

Members in attendance: Catherine Klein, Jody Wolfe, Bob Griffith, Faith Young, Laura Frankiewicz

Regular Attendees Present: Michelle Clyne, Elizabeth Klein

Members by Phone: Rose Slaght, Gail Olson, Faye Manaster

Regular Attendees by Phone: John Miller

Guest Present: Shelle Hamer

The meeting started at 10:24. Shelle Hamer joined the meeting to see if she's interested in joining our Board as Laura is considering stepping down as of our June 2011 meeting. Shelle has her Master's working with students with vision impairments. In AZ, she worked at the school for deaf-blind. She currently works as NSSEO where she coordinates services. She also chairs the IL Vision Leadership Council (IVLC).

I. Minutes of the December 2, 2010 meeting – Gail Olson moves to approve the minutes. Faith Young seconds the motion.

II. Old Business

1. **HKDB Awareness Week** – Faith Young e-mailed us a link to a video. Wally from Engage Creative suggests that we use this filmmaker and style of the video. We should consider using this type of style for our campaign using Jerrie Lawthorn as our profile. Take a look at the video and give Faith feedback asap. Faith said she spoke to RFBD about Jerrie's book and will do a joint release. Wally has spoken to the filmmaker and he has agreed to do it for us. Shooting the video doesn't take long, but the editing will take a while. Jerrie is aware and is willing to be involved with this. We would still do a video and do a profile which would include information about her book. For our campaign, we would probably only send the e-mail out one day. Faith thinks that there was a timeline summary of Jerrie's bio/accomplishments. Michelle will contact Tina to see if she knows where it is and will look for it. Faith will also contact Charita to see if she has it. Faith wants to get her book on bookshare.org too.
2. **Discussion of deaf-blindness definition** – Our goal was to look at definitions of deaf-blindness from different agencies to see if we can agree on a definition. We can then encourage these different agencies to adopt. Laura Frankiewicz said that the population of deaf-blindness is underreported because on the PUNS and the definition of deaf-blindness doesn't exist on the PUNS. This would give us more accurate information of

the amount of people who are deaf-blindness. Laura and Gail agree that we have to really look in detail and make some comparisons. Faith would be interested in knowing about other states and how they have come up with their definition. Is there any consistency among other states? Gail asked if there are any states that are leaders in the area of deaf-blindness? Michelle recommended Texas and Washington. No matter what we decide what the definition is, Project Reach has to use the federal definition. These aren't easily changed or modified. Bob said that we need to get this changed legislatively because then it will be changed across the board. Laura said that we need to get an "in" with a legislator to see if they are willing to take this on. We need to reach out to a rep/legislator. Would it cost the state more money? Faith said that we can start on this now, but won't be ready to present this information to a legislator in about a year. Faith suggests that we get 2 different legislators at the same time to push for this at the same time. Michelle can look at Washington and Texas to see if there is a unified definition. We are going to discuss this again at our April meeting once we get more information. Bob asked if John Miller's commission ever took on this type of project. John said no and he doesn't think it's the right time to bring it to the legislature since there are so many important topics.

3. **Ethics Training Update** – Michelle will send out updates to us which are somewhat irrelevant because we don't control money. Michelle will contact us individually if we still have to sign the ethics statement.

III. New Business

1. **Project Reach Stakeholder Survey** – Michelle has sent us an e-mail and has asked for feedback on the survey. She is getting feedback from different groups. They are sending the survey out primarily electronically after they receive all of the feedback. They will send it out to the families, administrators and service providers. They will collect the information and turn it into a report and try to make changes based on the results of the survey. Michelle is required to capture a lot of information, but is going to adjust it so that it is more at a lower reading level and not as lengthy.
2. **Office of Attorney General Audit** - Laura has to organize it still but has received the minutes. Jody will bring Laura a CD with all of the minutes on it. Laura needs to talk to agency people about their in-kind costs. Sarah Sebert was able to get the interpreter and coffee costs. Bob thinks it's just the extra costs involved for our meeting, not the salaries. Laura took it to mean salary and benefits. Laura needs to provide them with the past few years of annual reports. Laura said we've never been audited before, but they are auditing all boards and commissions.
3. **Jerrie's replacement on the board** – Laura e-mailed Ryan Crock from the Governor's office. The process is that you have to apply on-line for her replacement. If we have someone to nominate, we can have them apply on-line and send Ryan an e-mail asking. Faith met someone who is a LeCobda member, Cindy Cologne Wilkerson, who is a rehab counselor. Faith will find out how to contact her through RFBD. Alan Sugar is a deaf-blind consumer who is active at the Lighthouse and he thinks he's the Treasurer of

IIADB. Catherine knows Alan and thinks he'd be very good. Catherine will get his contact information through Joann Rushing.

4. **Chicago Lighthouse deaf-blind program** – Per Laura's discussion with Joann Rushing, Title 20 funds have been cut as of last year to the Chicago Lighthouse. They extended the use of the funds through October 2010. At that point, the Lighthouse was "carrying" Mindy Jo Mayer and Joann because their salaries are funded by title 20 funds. The grant money is now used to find deaf-blind employment. That is why the funding has been withdrawn. Joann can still do supports for persons who are deaf-blind, but Mindy has been moved into another position at the Lighthouse. The Lighthouse deaf-blind program won't close, but the services are drastically decreased. Joann cannot continue to attend our board meetings anymore. Mindy's responsibilities were peer counseling, deaf-blind awareness day, interpreter training, and advocacy. Mindy asked if we could send a letter to Secretary Saddler with copying Robert Kilbury. Laura wrote a letter asking that they consider a replacement funding source. The Lighthouse is the only agency which provides support to the adult deaf-blind population.

Faye wants to know if other title 20 funding has been cut. Part of title 20 is a Social Security Act. Laura can call Secretary Saddler's office to ask who is in charge of title 20 funding. Rose said that we are going to have to know how many people this is affecting. As a start, Laura is going to send out the letter. We can certainly follow it up with more information as needed. Michelle suggests that we contact IL Association of the deaf-blind to ask them to contact their individual legislators.

IV. Standing Reports

1. LeCOBDA

Le Cobda's December meeting was a holiday party which was graciously sponsored by the Chicago Club Of the Deaf. The CCD provided a delicious holiday lunch and a visit with Santa and Mrs. Claus, with gifts of candy for le COBDA members.

At the February meeting le COBDA honored club volunteers with a special thank you and gift card. Joanne Rushing, head of the Deaf-Blind program at the Chicago Lighthouse, informed club members that the department had lost its Title 20 Funding, forcing the department to cut office staff. This took effect in June, 2010, but was extended for three months. Joanne is currently working with the Lighthouse Development Staff to obtain grants for the Deaf-Blind program. She encouraged members and volunteers to submit e mails and letters of support to aid this effort. At the Lighthouse Annual Benefit, the Deaf-Blind Program will be featured in a short video to increase awareness.

Submitted by Catherine Klein

2. **SSP Task Force** – Per Karyn Campbell, The ILADB is not yet fully formed. They have been concentrating on this effort. For that reason, the SSP Task Force has not moved ahead.

3. **IDHHC** – Per John Miller, Laura Thomas and Anil Phadke were appointed as new members of the commission. Faith asked for an update on the hearing aid bill. John said that this bill needs to be reintroduced. He hasn't heard anything new.

V. Agency Reports

1. Hearing and Vision Connections –

I am sad to announce that Hearing and Vision Connections will close by the end of March, 2011. With the closure of Hearing and Vision Connections (HVC), there is a desire to continue some of the services of HVC through expansion of the Illinois School for the Deaf (ISD) and the Illinois School for the Visually Impaired (ISVI) Outreach departments to include early intervention. ISD was the fiscal agent for Hearing and Vision Connections, a statewide training and technical assistance program for infants with vision and/or hearing loss in operation since July 1999. Outreach expansion to include Early Intervention would ensure that training and technical assistance previously provided by HVC continues statewide. EI Outreach will oversee the birth to three direct service programs at both schools, increasing the number of providers to cover unserved or underserved areas of the state. The Hearing Screening for Newborns Act mandated that infants be screened for hearing loss at birthing hospitals. As a result, children are identified and referred to Early Intervention far earlier than ever before. Infants with vision loss need intervention as early as possible. We want to ensure there are service providers and supports for families in place to serve them once they are identified. Provider support will continue through professional preconferences, web meetings and summer DTH and DTV events. Parent support will be in the forms of education and resources including Parent Infant Institutes at both schools, statewide parent conferences, newsletters, networking opportunities and new parent resource packets on hearing loss and communication options. Many of the services will be very similar to what is currently provided by Hearing and Vision Connections.

There is much to be worked out regarding this conversion, and although it is personally sad to say good bye to this program, it is also exciting that some of the services will carry on through the two state schools. We will keep you posted as things develop. In the meantime, please continue to contact us as usual. Additional information will be posted on our website and Facebook pages as it is available.

As we all know in Early Intervention, we are nothing if not flexible and adaptable to change. And I am so very grateful to all of our friends and colleagues out there who have supported us throughout the years and helped to ensure statewide services to infants and toddlers with vision and/or hearing loss.

Please see our Winter Newsletter at

http://www.morgan.k12.il.us/isd/hvc/resources/2010_Winter.pdf and our Facebook page at <http://www.facebook.com/pages/Hearing-and-Vision-Connections/128802893816523>

for information on numerous upcoming parent conferences, events and trainings with which Hearing and Vision Connections is involved.

Gail hopes that they hope that they will be back with a new name with a new program in a few months. Bob asked if there were any teachers retiring at ISVI and ISD. Gail said that they aren't the only people waiting for jobs.

Submitted by Gail Olson

2. ISBE – no report at this time

3. Philip Rock Center/Project Reach Agency Report

Project Reach Report February 2011

Project Reach staff are working to update the statewide Child Count for children and youth who are deaf-blind. This process is completed by phone and face-to-face visits with families and schools. We anticipate a slight increase in the child count this year. Information about Illinois 2009 child count numbers is available at <http://www.nationaldb.org/documents/products/2009-Census-Tables.pdf>

Illinois reported 425 students, as did New York. Two states had higher numbers than Illinois and New York: California and Texas.

Project Reach has been notified of dates and deadlines for the Annual Report. Data will be collected for the period of March 18, 2010 through February 28, 2011. The report is due April 15, 2011. The completed report will be available after it is submitted by ISBE to OSEP.

Work is being finished on a mid-project Stakeholder's Survey. Surveys for Families, Administrators, and Direct Service Providers were drafted with assistance from Loyola University's Center for School Evaluation, Intervention & Training. The drafts will be vetted before distribution to check for clarity of questions, readability for families with various reading skills, redundancy, and other issues that might affect reliable completion and data. Organizations that are helping to vet the documents include Illinois Statewide Technical Assistance center, Illinois Advisory Board for Services for Persons who are Deaf-Blind, Illinois Advocates for the Deaf-Blind, The Illinois Chapter of AER, Illinois Teachers of Deaf and HOH Individuals, and the Illinois Association of the Deaf-Blind. Surveys will be distributed electronically throughout March and April, and the final report will be completed in November 2011.

IADB will have their annual meeting at the Parent Meeting toward the end of March. Project Reach is in the process of their funding report. It has to be done online, which the feds have closed down until March 15. NCDB is looking to give training on using distance technology as another option. Reach has used Go to Meeting, Skype, screen casting, caption video and has saved them money.

The Fall has been a very busy and productive time at PRC. Two new teachers, a class leader, and three new students started in the Fall. I can say that everyone seems to have transitioned successfully and are now part of the PRC family. **Please take note of the change in Recommended Spring Home Visit - it is now March 30th @ 3 pm thru April 3rd.**

THANK YOU: A heartfelt thank you to the families who brought treats and gifts for the staff during the holiday season. Your thoughtfulness and generosity were greatly appreciated. PRC is also thankful to the many community groups and organizations that provided parties, gifts, and special events for our students. Thank you to the Borrego family and friends for bringing a gift for each of the PRC students in celebration of Rose's birthday. A fun time was had by all.

Budget Concerns

PRC's voucher payments continue to come in few and far between. We received a payment in November 2010 and we received another in January 2011. As of this date, the State is \$1.2 million behind in payments to PRC. We are afloat only because of some FY09 and FR10 obligations that remain unpaid. The situation is precarious, but manageable for now. There is also some good news. In January, ISBE posted their suggested budget on their website. PRC is included in the proposed budget at flat funding. To be included with no cuts is a blessing. Now the budget has to make it through the General Assembly and the Governor's Office. Many thanks to Laura Frankiewicz, IABDB chairperson, and Stacey Borrego, PRC parent for testifying on PRC's half at the DeKalb budget hearing in December with Michelle Clyne and myself. The budget hearings give constituents and consumers an opportunity to speak directly to the ISBE's budget committee. Thanks again, ladies for your valuable testimony.

Facility Safety Upgrade

As of February, all entrances at PRC will be locked during daytime business hours in addition to evenings and weekends. The staff will have access cards that will allow them to enter the building. Parents and visitors will have to ring the doorbell for access.

PRC Program News

Now that the holidays are behind us, staff and students are busy working on IEP and PRC Annual Goals. The annual goals as listed on our School Improvement Plan include:

- To increase effective practices in the instructional program for deaf-blind children
- To increase student literacy and numeracy across environments
- To improve the competencies of the staff to better meet the needs of the children
- To improve the use of technology as a method to encourage and document student performances
- To improve communication with all constituents
- To increase PRC student opportunities for experiences in the general education program
- To increase practice and service related to transition to adulthood

Art Therapy Intern

PRC is delighted to welcome art therapy intern Ms. Emily MacArthur. Emily will offer individual and small group art therapy experiences for all PRC students from February through the end of April. Emily is a student at the Art Institute of Chicago and will be at PRC on Monday, Wednesday and Thursday evenings. Welcome!

A Special Note

An abstract design submitted by Mr. David Csicsko, a Krueger family friend, has been selected for our cafeteria mural. More to come.

In addition., information about individual students, programs, and classrooms was provided in the full versions of the INKLINGS newsletter.

4. **DRS** – Per Bob Griffith, in March and May of this year HKNC, Sister Bernie, is doing training for rehab instructors on how to serve deaf-blind adults. The training is taking place in Champaign and in Chicago. This is a closed training for DRS employees.
5. **DCFS** – no report at this time.

Faith Young moves to adjourn our meeting at 12:14. Bob Griffith seconds the motion.