

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

**Thursday, October 7, 2010
James R. Thompson Center
100 W. Randolph Street, 9th Floor
Chicago, IL 60601
10:00 a.m. to 2:00 p.m. (lunch break included)**

MINUTES

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

Regular Attendees Present: Michelle Clyne, Sarah Sebert, Elizabeth Klein

Members by Phone: Rose Slaughter, Faye Manaster, Gail Olson, Maria Roeters

Regular Attendees by Phone: John Miller

I. Minutes of the June 3, 2010 meeting

Laura Frankiewicz asked if we could make more of an attempt to attend our meetings in person. It makes it difficult to run the meeting with so many people on the phone as well phone distractions.

Gail Olson makes a motion to accept the minutes. Maria Roeters seconds the minutes.

Sarah Sebert needs us to update a contact list to report to State Board of Education.

II. Old Business

1. HKDB Awareness Week – The week of June 27, 2010, Engage Creative sent out five DBAW profile emails with links to the redesigned IABDB website (www.bemyvoice.com) and the IABDB DBAW video also hosted on youtube.com. To date, 288 people have viewed the video at youtube.com. The profiles were sent to more than 1100 people each day of the campaign. Open and click results varied by day, but when reviewed as a total for the week, sheer numbers exceeded results from last year. As a total, 5957 emails were sent, of which 732 or 12.6 percent were opened. That compares with 2022 emails sent last year (a one-day event) of which 218 or 16.7 percent were opened. This year 96 or 13.1 percent of emails resulted in a click-through to the website or youtube. Last year 57 or 26.1 percent of emails resulted in a click-through. Detailed numbers regarding the campaign are included in the table provided with this report.

While absolute numbers increased due to the repetitive nature of this year's campaign, our percentage yield was lower. The exceptions to this statement are in the number of persons opting out of our mailing list and those reporting our campaign as spam. Both those numbers increased this year. Additionally, we had people use the forward feature of the profile for the first time this year. We also had someone from the Chicago Public School system contact us via our website contact form and ask to be added to our mailing list. This is the first time someone other than marketing companies has completed this form.

As stated at the beginning of the report, Engage Creative redesigned the website with direction from the DBAW subcommittee. Along with the redesign came changes in the way we maintain and host the website. Engage Creative has staff that will update the website as needed. This results in a reduced cost to host the website (design software and support is no longer necessary) so the website is now paid for until March 25, 2013. Only the domains need to be paid for on an annual basis and those are very inexpensive. Laura Frankiewicz sent Engage Creative a letter of appreciation on behalf of the Board for their work on the 2010 DBAW Campaign.

2010 DBAW Campaign Statistics

Email	Date	# Sent	# Bounced	Spam Rpts	Opt-Outs	Opens	Clicks	Forwards
Catherine	6/28/2010	1311	9.2% (120)	3	0.6% (8)	16.2% (193)	15.5% (30)	0
Dylan	6/29/2010	1181	0.2% (2)	3	1.0% (12)	13.7% (161)	13.0% (21)	0.6% (1)
Tamara	6/30/2010	1171	0.3% (3)	2	0.9% (11)	12.1% (141)	9.2% (13)	0.7% (1)
McKenna	07/01/2010	1158	0.4% (5)	2	1.3% (15)	10.2% (118)	10.2% (12)	0.8% (1)
General	07/02/2010	1136	0.4% (5)	0	1.2% (14)	10.5% (119)	16.8% (20)	0.8% (1)
Overall		5957	2.3% (135)	10	1.0% (60)	12.6% (732)	13.1% (96)	0.5% (4)
2009	6/22/2009	2022	35.5 % (718)	3	0.3% (7)	16.7% (218)	26.1% (57)	0
Educ & Serv			5.9%			18.6%	15.1%	
Marketing/PR			6.4%			13.5%	13.5%	
Non-Profit			5.9%			20.0%	12.3%	

For next year, Faith Young suggests that if we want to forward the e-mails, don't forward it from our own e-mail address, but use the forward feature within the e-mail. It still gives you the ability to put your name in there so the people you are forwarding it to know that it's from you.

Jody Wolfe asked if we got any feedback from anyone whether they liked the everyday profiles this year vs. one e-mail that we did last year. Faith Young said that they haven't gotten any feedback. Jody Wolfe asked whether we could poll those who we sent the profiles to see what they thought of the campaign.

John Miller thinks it is worth doing a survey. Catherine Klein wants to know if we had any response to the call of action items. Faith Young said that yes, there are statistics on this information, but only for the last day of the campaign. There were inconsistencies on how Engage set up these click through. Catherine Klein suggests that the call of action items could be a question on the survey.

Rose Slaght said that it never hurts to ask people. Jody Wolfe asked what our timeframe would be to start the next campaign. Faith Young said that we started our meetings last year in January. We have to give Engage flexibility in their timeline. Laura Frankiewicz said that the subcommittee worked well and that Engage did a great job. Rose Slaght said that the fact that Wally and staff were able to come to the SSP conference was a great experience.

Michelle Clyne said that PRC/Project Reach have a survey monkey account. She will check to see if we can use their account. The person who handles this at PRC is not available to help with this project until November either. Faith Young said that this timeframe sounds fine.

Michelle Clyne suggests that the people who developed the campaign are the people who should develop the survey.

2. **PRC Status** - Michelle Cline distributed the annual report for PRC. The school has lost two teachers and were able to hire very qualified teachers so they are fully staffed. The school just added three new students into the younger class. PRC received payment for everything owed to us for FY 10. It sounds great, but they are not supposed to be used for FY 11. Their vouchers are being approved for FY 11, but not being paid. They are financially stable now into November. They finished negotiations with the school and contracts are being signed. They know that there will continue to be challenges. There has been "talk" from other political figures and from the State Board of Education to somewhat restructure how the school is funded so this doesn't happen in the future. There continues to be a need for a residential alternatives for most of these students. They are open to look at ideas on how to transition to a different long term solution for funding sources.

Laura Frankiewicz said that because PRC is in the school code if any changes were made to the school, it would have to be changed by law. Laura Frankiewicz heard some ideas at the director's conference. One idea is that they would move PRC to a private facility and that the districts would pay for a day or residential rate. For some districts, it is financially more advantageous to do this. For students who are residentially placed, the districts can receive 100% of room and board costs. Michelle Clyne said that they have looked into Helen Keller school and that how Perkins is funded. Both of those programs are multi funded system. Michelle Clyne's concern is the bridge from getting here to there. It is Michelle's impression that the state needs a facility who can serve kids who could benefit from low incidence specialty services. Faith Young suggests looking at Oakwood in Hartford, CT. They have transitioned their services. Sarah Sebert asked who makes the placement at PRC. Michelle Clyne said that the parent initiates the placement and that then they get the district involved. The district is still responsible for evaluations and transportation, but doesn't pay for tuition.

Faith Young thinks that the Texas school for the Blind has a program which deaf blind kids go for extended study that the school districts can't provide. She thought that that was an interesting option.

Sarah Sebert said that the state board of education is looking at educational environment. What % of the day is spent with regular education kids? Sarah Sebert said that the thought is why couldn't the kids get their education in another environment.

Michelle Clyne said that these kids attend their residential program because the education continues into the evening and because of life skills services that they provide. Gail Olson wants to know if the extended day is reflected in the IEP. Michelle Clyne said that yes, this is documented in their IEP.

Jody Wolfe asked if there was a timeframe. Michelle Clyne said that no one has given them a timeframe. They have a legislator who said that they would be willing to facilitate a meeting, but they have no information on that. Michelle Clyne asked for specific suggestions on possible solutions (ie: agencies, models of schools). **Please send any ideas you have to either Michelle and/or Peggy Whitlow.** And in the meanwhile, they probably will be at a zero balance again and those who have publicized it again, they may contact the media again.

Faye Manaster said that there PUNS continues to not have any question on whether the child is deaf-blind. Faye Manaster asked these questions: How many deaf-blind kids are there in the state that will need services? and are any of the 200 kids on the residential waiver deaf-blind? Laura Frankiewicz said that we need to have better data to justify these services. Michelle Clyne said that the current definition by the state is very confusing. The state think we have less than 100 students who are deaf-blind. Faith Young said that if we adapt a new definition of deaf-blind, is that going to require legislative action? Michelle Clyne said she thinks it would be a legislative issue. Faith Young asked if we have enough friends in the legislature to accomplish this? We have 1 or 2 in the Chicagoland area, but don't have any in downstate. Gail Olson said that they have a senator in the Jacksonville area who would probably support us in this. Michelle Clyne thinks that at the National level, they are looking to make some changes to the definition of deaf-blindness. They are trying to take out some of the placement type language and keep the medical side of it. Michelle Clyne will follow up with us on that.

3. Other:

Laura Frankiewicz heard at the Illinois Alliance Special Ed meeting that they are creating a task force to look at streamlining services. Laura's personal opinion is that is very concerning. Sarah Sebert said that the task force will make a report to someone, but isn't a guarantee that anything will happen with what they suggest. Laura agrees with Sarah, but said that the fact that this concept is out on the table brings some up some concern.

III. New Business

1. **Review Current Goals** – Our annual report that went out in June was for '08-'09. We did rework some of those goals from our previous report and you should have received them by e-mail. Laura Frankiewicz said that maybe for next year, there should be a follow up to the call to action goal. Maybe we will get that information if we get that survey. Laura reviewed all goals and felt that if we worked on the HKAW, work on the

definition of deaf-blindness and work on getting deaf-blind on the PUNS questionnaire, that would be plenty of work. Gail Olson agrees that the priority should be goals #1 and #2. We should limit our focus to these as they will be a lot of work. Bob Griffith asked whether we wanted to approach DHS/DD to bring back their deaf-blind specialist. Gail said that maybe we could initiate the conversation with that agency. Laura Frankiewicz said that the position has been gone so long and wonders why after all long, it needs to be filled now? Gail Olson said we have to justify what the need is for this position. Michelle Clyne said that maybe if we had an agreed upon definition, we need to do that first before we advocate for a person.

Faith Young moves to make some minor changes and updates to our goals with the understanding that our working items are goals #1 and #2 and the other goals are ongoing. Gail Olson will second the motion.

2. **Ethics Training** – Michelle Clyne sent it out by e-mail. Her understanding is that everyone has no questions. Those who are members of agencies, please fax her a copy of the acknowledgement. Michelle Clyne will send those who are not here a copy and ask that you return it to her. This is only for people who are appointed members.

3. **Other –**

Deaf-blindness definition: We need IDEA definitions of deaf-blindness. We could have a subcommittee to review this information by phone. Bob Griffith said that he's sure that every state has their definition of deaf-blindness. Laura Frankiewicz asked whether we could contact NCDB and HKNC. Laura Frankiewicz can contact Laura Thomas to ask for her input.

IV. Standing Reports

1. **LeCOBDA**

In June, several Le Cobda members attended the conference in Jacksonville, Illinois. Also, a new camp was started for deaf-blind campers in Minnesota this year. I did not attend those activities and hope Joann Rushing and Mindy Joy Mayer will report on those events.

In July, Le Cobda members and volunteers were given a special tour at the field museum. Assisted by the museum's tour guide and our ssp's, we visited the Pawnee Earth Lodge to experience the life style of western native Americans. Then we had choices of eating places in the museum. After lunch, we met upstairs in the Evolving Planet exhibition to examine Dinosaurs. The day was both enjoyable and informative.

Dance specialist, Ellen Wade, one of our SSP's taught us Salsa dancing at the August meeting. Ellen demonstrated the Salsa dance steps to Salsa music and we

all joined in! Our next meeting is October 9th.

Angela C. Orlando of AADB is deaf-blind and writes for the periodical "clerc scar. She wants to establish an exclusive book-share program of books written by and-or about deaf-blind people. In case you have ideas to offer, I am attaching Angie's message:

"I asked the book share director about building a collection of books about DB and deaf-blindness. She agreed! And gave it to me to choose. BKS is paying attention to us now that we are becoming a known minority. There are some books in BKS but it's an odd group. I want your input. There are many, many books about blindness. Let's do the same for deaf-blindness. We do have Dona Sauerburger's and Theresa Smith's books. Jack Gannon's classic "Deaf Heritage" has been discussed but it's almost half graphics, and the staff aren't sure it can be done. So what would YOU suggest? Any ages, but especially for high school and college classes as there are special money for those. I'm thinking about "Not For Hearing People Only", made from columns in old Deaf Life magazine, some of Carol Padden and Jack Humphries stuff on sign language and culture. NO books of signs dictionaries. Can't be done. But a couple books about the art and skill of interpreting would be good. I only know old stuff. I will look through stuff published by NAD, Gallaudet Press, Dawn Sign Press, RID, see what Harris Communications has, but I'd really like ideas from you if you have any! Titles or authors. The list will mean more to director if I say ideas come from the DB Techies group, not just me. I have about a month before list is due, but sooner is best. I have to look up publishers and ISBN numbers and short summary why each book should be included. Right now they said maybe 25, depending on cost. But if I give longer list, they will keep going and there are a few people who might make donations for this group. I hope you'll have ideas. If you can't remember full title, that's fine. Tell me what you remember and I'll find it. Oh, and the books can be out of print, that's fine. If you reply with the names of book titles, I will forward them on to the right person.
Angela, dotbug3@sbcglobal.net

2. **SSP Task Force** – no report submitted
3. **IDHHC** – John Miller said that they are facing financial problems. They are changing how they do outreach. They cannot go into the community as much as before. In June, he was involved in a deaf-blind retreat which helped provide CEU credits for interpreters. The next committee meeting is Nov 4 at 1 pm, live on the web. They are trying to recruit a person to serve on a commission. People can apply on line to be a governor's appointee. They are looking for a deaf-blind appointee.

V. Agency Reports

1. Hearing and Vision Connections

FY 10 End of Year Report

I. Introductory Information

Mission Statement: All children in Illinois who are deaf, hard of hearing or visually impaired will have appropriate Early Intervention services.

Background: Hearing and Vision Connections (HVC), a training and technical assistance program for infants and toddlers who are deaf, hard of hearing, or visually impaired, is concluding its 11th year of operation. Funding began for this program July 1, 1999. The program is located at The Illinois School for the Deaf (ISD) in Jacksonville Illinois.

Nancy Scott, the programs hearing specialist, retired 6/30/10. She continues to work for us very part time on voucher, then hopefully on contract. All other staff are part time to varying degrees, are currently contractual, and may be converting to state staff positions January 1, 2011. The HVC budget from Department of Human Services, Bureau of Early Intervention has been approved at 50%, through December 30, 2010.

II. Statistical Information

Trainings/Presentations	75
Webinars	4
Participants Trained	2175
Exhibits	11
Data base: Electronic (newsletter)	1353
Data base: Hard Copy (newsletter)	285

Trainings by region:

Northern		Central		Southern	
Bloomingtondale	1	Macomb	2	Mt. Vernon	2
West Chicago	2	Champaign	4	East St. Louis	2
Chicago	7	Jacksonville	21	Carterville	2
Rockford	3	Normal	3		
Lombard	1	Peoria	4		
Arlington Hgts	4	Springfield	8		
Rock Falls	1	Bloomington	2		
Joliet	5				
Lisle	1				
Total	25		44		6

Exhibits by region:

Northern		Central	
Lombard	3	Chicago	2
Springfield	4	Peoria	2
	7		4

Technical Assistance

1 st Quarter	121
2 nd Quarter	104
3 rd Quarter	123
4 th Quarter	92
	44

III. Major Accomplishments

- Created a Q and A document (drafted by HVC and approved by the Bureau of EI) Based on the FY 09 Designated Service Coordination trainings and distributed to 25 Child and Family Connections offices.
- Conducted multiple Functional Vision and Hearing Screening trainings statewide
- Conducted 3 conferences for parents of children with hearing loss and 3 for parents of children with vision loss
- Participated in the planning of the Sharing and Vision Conference and exhibited.
- Collaborated on the 4th annual Illinois Family Leader Conference; Resources and Inspirations for Care Givers of Children with Disabilities.
- Brought Dr. Christine Roman to Illinois for a 2-day training on Cortical Visual Impairments in collaboration with ISVI, STARnet, IAER and ISU.
- Participated in the 2010 National Early Hearing Detection and Intervention Program in Chicago.
- Staff became trained on the use of Webex Webinar service and conducted 4 webinars and a 5 minute webinar orientation.
- Launched Facebook and DTV WIKI page.
- Quarterly newsletters were developed and distributed.
- Participated in Parent Infant Institutes at both Illinois School for the Deaf and Illinois School for the Visually Impaired.
- Collaborated with Illinois State University for Bridges, a two day training for DTH's in Bloomington.
- Conducted two day summer mini camp for DTV's in Champaign.
- Collaborated with the DHS Bureau of Early Intervention on the provision of webinar training to Designated Service Coordinators on Authorizations for Audiological Evaluations and Assistive Technology for Hearing Aids/Accessories.

IV. FY 11 Goals

Technical Assistance: Continue to provide technical assistance upon request and through the dissemination of information about Hearing and Vision Connections.

Training: Provide statewide training regarding infants and toddlers who are deaf, hard of hearing or visually impaired.

Provider Recruitment: Conduct recruitment activities for DTH's, DTV's, Deaf Mentors and interpreters through presentations at conferences, distribution of flyers, website provider information and presentations to students and colleges and universities.

2. **ISBE** – The federal government is coming in November to look at transition and educational environment.

3. Philip Rock Center/Project Reach Agency Report

Project Coordinator Michelle Clyne attended the required Deaf-Blind Project Directors' Meeting (PDM) Professional Development Day July 18 as well as the 2010 OSEP Project Director's Meeting July 19-21 in Washington, DC. The Professional Development Day focused on distance technology equipment, services, and processes. Participants received an overview of networking options, computer screen and presentation capture software and devices, and other distance technology information. Some of this information was shared with Project staff on August 20, including Jing, Snagit, and Camtasia. These tools will be evaluated for possibility of use for Project Reach TA so that purchasing decisions can be made.

Project Reach will be designing and distributing a survey among constituents regarding the availability of technology to those participants to participate in distance technical assistance. Project Reach is seeking assistance in the design of the survey from other national deaf-blind projects and other entities that use similar technology.

On August 19, Mark Campano from the Delaware Deaf-Blind Project provided an overview of a new data collection and aggregation system that he developed using File-Maker Pro. Staff viewed his demonstration through Go-To-Meeting and more questions have been developed. On September 17, Peggy Pausche and Michelle Clyne attended a distance meeting with the developers of the new data system, IT Solutions. This demonstration indicated that this new program would allow for more integration of student-specific and systems-change data, as well as a more effective means of tracking project effort and linked to outcomes. Once a quote is received a final decision will be made.

On September 4, 2010, The National Consortium on Deaf-Blindness and Project Reach hosted a follow-up face-to-face meeting with five of the six previously trained family leaders. Topics included the sharing of activities they have already completed as well as follow-up for goal setting. Some of the accomplished self-chosen goals included: educating health-care workers on how to communicate with a specific child who is deaf-blind, educating the public and officials about Philip Rock Center, writing a newsletter article, holding 2 parent trainings, joining and taking a leadership position on an advocacy association, and others. A long-term "what to do

next” plan was developed for ongoing distance support among the family leaders and well as exploring new learning opportunities.

Project Reach is working with Loyola University’s Center for School Evaluation, Intervention and Training (CSEIT) to prepare for a Stakeholder’s survey to be completed by November 2011. CSEIT is assisting with developing procedures, timelines, and the actual survey formats. Project Reach will be requesting collaboration from the Illinois Advisory Board for Services for Persons who are Deaf-Blind (IABDB), Illinois Advocates for the Deaf-Blind (IADB), Illinois Association of the Deaf-Blind (IAODB), and the Illinois Statewide Technical Assistance Center (IS-TAC).

Project Reach is moving forward on planned activities despite the uncertain future of our in-kind partner, the Philip Rock Center. If significant changes to PRC occur, regular project activities may need to be suspended until all major issues are resolved.

4. DRS

In May 2010, training was provided to the staff and Illinois Community Rehabilitation and Education-Wood (ICRE-Wood) from Helen Keller National Center (HKNC). ICRE-Wood is a rehabilitation center which provides services to individuals who are blind or severely visually impaired. These services include a full-time comprehensive rehabilitation training program. Training in identified skill areas (e.g., computer skills, activities of daily living, job retention skills) is also provided to meet the specific rehabilitation needs of each customer. Over the past two years, 10 people who are deaf-blind enrolled at ICRE-Wood.

The ICRE-Wood audience, approximately 20 people, was made up of Rehabilitation Teachers, Orientation and Mobility Teachers, nurses, administrators and office support staff. Sister Bernie and Laura Thomas from HKNC conducted a four day training session on the following topics: Etiology; Service Planning, Communication Tips, Techniques, Strategies and Methods; Orientation and Mobility Techniques; Effective use of Interpreters and Impact of Dual Sensory Loss.

Sr. Bernie and Laura will return to ICRE-Wood in September to provide session two (out of two) training to the same participants. This session will include a review of the homework assignments the staff received in May.

Bob Griffith said that DRS has sufficient VR money to pay for customer services. They got additional money from Rehabilitation Services Administration (OSERS). These services are separate from Veteran’s services. The Rehab program is mostly federally funded.

5. DCFS

Marsha Northrup passed out information. DCFS got 10 million to improve outcomes for youth in foster care. The Vermont Center for Deaf and Hard of Hearing is starting deaf-autistic program. DCFS is going through differential response pathways to have alternate means of responding to neglect to assist families at risk. They will have a separate set of investigators that determine

placement in program. Laura Frankiewicz said this seems similar to the education Response to Intervention system. Marsha will forward handouts electronically.

Per Marsha Northrup, the Deaf awareness day no longer in this building. It is at Columbia College next Wednesday from 10 a.m. to 3 p.m.

Meeting adjourned at 2:05 by Laura Frankiewicz. Our next meeting will be held back on the 9th floor.