

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

**December 3, 2009
James R. Thompson Center
100 W. Randolph Street, 9th Floor, Room 9-039
Chicago, IL 60601
10:00 a.m. to 2:00 p.m. (lunch break included)**

MINUTES

Members in attendance: Laura Frankiewitz, Roseann Slaght, Gail Olson, Mike Parvis

Regular Attendees Present: Sarah Sebert; Catherine Klein, Michelle Clyne; Jerrie Lawhorn; Jody Wolfe; Maria Roeters; Faye Manaster, Marsha Northrup

Regular Attendees by Phone: Faith Young

Guests: Elizabeth Klein, Ingrid Halvorsen

Minutes of October 1, 2009 Meeting –minutes approved by Roseann Slaght, second by Gail Olson. Corrections to October minutes: Faye Manaster needs to be added as a regular attendee by phone; Change Joann Rushing, Sarah Sebert, and Michelle Clyne, Jody Wolfe, Catherine Klein, Marsha Northrup to regular attendees present; Change Maria Roeters to regular attendee by phone.

Mike Parvis suggests amending the minutes to remove the word “dreadful” on page 2. Faye Manaster suggests changing the word to “inadequate and inappropriate”. There was discussion about whether this word should be removed or changed from the minutes. After a discussion among the group, Mike Parvis has withdrawn his change to the minutes. The decision was to keep the minutes as written originally in regards to the word “dreadful”.

Per Faith Young, under I Minutes of June 4, 2009 meeting – change to IABDB.

II. Old Business:

1.IABDB Annual Report

Introduction – We will make it more generational. Faye Manaster suggests adding something about war veterans who are deaf-blind. Faye Manaster suggests contacting the Dept of Veterans Affairs to let them know about who we are. Mike Parvis said that there is a program at the VA Hospital, maybe Hines, who has a unit working with the veterans and dealing with those who have hearing and vision losses. Michelle Clyne said that Marybeth Harrison is the

contact person at Hines. Laura Frankiewitz said that it logically flows into a goal that we seek out this department to let them know of our services. Gail Olson offered to contact the Department of VA Affairs.

Sarah Sebert said that the introduction of the annual report is very student specific. Faye Manaster will write something that will address more of our adult deaf blind persons. Gail Olson and Faye Manaster will work together on the introduction and send out a draft.

General Recommendations – We all agreed that less is more. Laura Frankiewitz wants to know why we took out some of the recommendations from year's past. Faith Young said that this is just a starting point and we need to add to this. We discussed whether we should take out recommendation #2 about SSP's. Laura Frankiewitz wants to make sure that the Task Force is a viable group and will talk to Joann Rushing about this. She will work on getting statistics about SSP's which support that it is more cost effective to have SSP's in the home rather than institutionalizing. Faith Young said that if Joann doesn't have statistics about SSP's, maybe she should contact AADB (American Association of Deaf-Blind) to get statistics about SSP's. Rose Slaght suggests moving #3 about officially appointing members to #1. Laura Frankiewitz will add something about the current interpreter law.

Summary of Major Activities – Maybe we should elaborate on #3 about plans for SSP's. Gail Olson said we need to spell out what SSP's are for our readers who don't know.

Goals and Objectives -

Goal #1

Gail Olson wants to know what benefit we get in getting a Governor's Proclamation. We decided to remove this objective.

Faith Young said that Wally from Engage Creative wants to see a call to action that would have 5 things people could do to help the cause of deaf-blindness. One idea is that we should have a link to bring up your legislatures to write to about deaf-blindness. Another example Faith Young has seen is through the Americans for the Art has a campaign right now for 10 ways to get involved in the arts. Faith Young agreed to add a call to action to our campaign.

Gail Olson suggests adding an objective to keep the website up to date. Faye Manaster wants to keep track of hits to our website. Faith Young says that the "hit" counter is not a very accurate count of how frequently our site is used. Faith Young said that we have to pay extra to get that information. Faith Young is paying for the domain and website every year. Rose Slaght suggests contacting IADB about having them help fund the website.

We will add as one of our objectives to goal #1 to start tracking our outreach efforts such as going to do presentations, awareness days, e-mail presentations to include in our future reports. Faye Manaster has a form that we can fill out and she will e-mail it to us. Faye Manaster and Rose Slaght will send out a simplified version of the form.

Goal #2

It was suggested by Mike Parvis to put establishing relationship with Office of Veteran's Affairs under Goal #2.

2nd objective is to work collaboratively with IDHHC (Illinois Deaf and Hard of Hearing Commission).

Faye Manaster suggests that we should establish a relationship with Healthcare and Family Services.

Goal #3

Faith Young suggests changing objective #3 to Maintain a dialogue to consumers and service providers who support consumers about opportunities to provide input regarding issues affecting their lives.

We agreed to add under Objective #2 to Work with Illinois Advocates for Persons who are Deaf-Blind to identify areas for collaboration and coordination of activities.

Add another objective to participate in Chicago Lighthouse Awareness Event.

Goal #4

Gail Olson brought up the point whether we will really monitor bills is really a lofty goal. Faye Manaster said that maybe we should encourage members to collectively monitor bills through our individual contacts and professional responsibilities and report back to the board at our meetings.

We agreed to take out Objective #2 under Goal #4 to meet with IL Legislatures.

Faith Young asked if we want to pursue interagency coordination between DHS Advisory Council as a DB representative (p. 6 of Dec '08 minutes). Faye Manaster will look into this more to see if we can have any interface.

Closing Comments – Faith Young thought we needed some new ideas from last year. Laura Frankiewitz thought that much of the information from last year is still very relevant. Faith Young will help with the closing comments once we finish the rest of the report.

Chart – needs to be updated. Michelle Clynee suggests separating out the initial appt date/date board member began attending meetings column. Or have separate groups for those appointed and those waiting appointments.

We want to finalize the annual report for our February meeting.

2. Ethics Training - the new ethics materials dated September 2009 were distributed by Michelle Clyne.

3. HK DB Awareness Week Campaign –Faith Young said we were supposed to come up with an idea for our DB campaign. We can't wait until the last minute so that Wally can start working on it. Can February's meeting be the annual campaign? This does not provide enough time for opportunity for filming. Need to have product in hand by April. Maybe we can have a separate sub-committee to work on the campaign.

4. HELEN KELLER DEAF-BLIND AWARENESS DAY

The Deaf-Blind program hosted their annual deaf-blind awareness day celebration at The Chicago Lighthouse on October 29, 2009. The event was titled, "Deaf-Blind Leaders Can Make a Difference". A panel of four deaf-blind individuals and one individual from the Illinois Deaf-Blind Advisory Board presented information about their advocacy efforts and how to seek information and resources to make a difference in the lives of deaf-blindness. Some of the vendors that participated were from the Chicago Police Department Domestic Abuse Department, the program manager for deaf and deaf-blind with Department of Rehabilitation Services, Helen Keller National Center, Hadley School for the Blind, Equip for Equality, Illinois Deaf Hard of Hearing Commission, and a representative with Metra.

A writer even caught the news of our event and wrote an article that appeared on the examiner.com website to promote our event. One comment from a participant said it was an excellent means of networking. Two young students who are deaf-blind were fascinated with Geraldine's presentation on how she participates in activities and teaches Braille and poetry regardless of her 90 plus years. Over 100 people from schools, businesses, organizations, medical personnel, and the community attended the celebration.

Submitted by Joann Rushing
Chicago Lighthouse Program Manager of Deaf-Blind Outreach

5. Other-

Board Appointments –Laura Frankiewitz has sent a letter to the new Secretary, Saddler, to ask about appointing Maria Roeters and Jody Wolfe.

III. New Business:

1. IABDB website –

Faith Young discussed the possibility of new website. Domain IABDB.org is available. Gail Olson said that Be My Voice doesn't have much name recognition yet so this would be a good time to switch.

We can do it for free if it's small enough, but our current website is over 5 pages. Laura Frankiewitz suggested we look for reduced or no cost host. The current website is not that expensive, but the feeling is that this is not the time to ask for funds for a website. Estimated cost is over \$150 a year. Gail Olson said that the annual cost for this board \$5,000 so could we use some of that money to pay for the website? But Sarah Sebert feels ISBE will not approve moving funds to website. If it goes to ISBE, we would not control content. Laura Frankiewitz feels we cannot decide today, but it on next meeting. Marsha Northrup asked if can we get funding from the IADB parent group? Rose Slaght will discuss this with Faith Young offline. Constant contact costs \$70 for annual campaign mailing.

2. Other –

Mike Parvis has taken a new position as a Rehab Services Advisor with the Department of Human Services. His responsibilities will be to monitor the ARA (American Reinvestment Recovery Act) grants. He will be resigning from the IABDB. His new position will be effective January 1, 2010. Mike Parvis will submit an official letter of resignation. Laura Frankiewitz wants to know whether Mike's position will be posted. Ingrid Halvorsen, Mike's current supervisor, would love to have his position posted and filled. Ingrid Halvorsen will be attending our meetings as a guest going forward and will work with us to get someone else appointed.

Medicaid Eligibility Brochure –

Faye Manaster passed out new Medicaid eligibility brochure. It will be available in alternative formats soon. It explains Medicaid eligibility. Faye Manaster passed one out during the meeting. On Tuesday, the Dept of Healthcare and Family Services talked about mandatory Medicaid managed care requiring people with disabilities to participate. This is all new, sending out RFP in January. It will be bid on by corporations. They are looking at starting in July 2010. Current SSI children are exempt from this case management, but then nobody would be exempt. In the past, this has failed. They want this to replace waivers. Do not have a special tract for people with disabilities. In other states, there is an adult division similar to DSCC. Faye Manaster's concern is that this is starting too massively and quickly and will disrupt established connections for medical needs.

IV. Standing Reports

1. Le COBDA

For our October meeting Joann Rushing obtained a large shipment of pumpkins from a farm. Each member was given a pumpkin to decorate, and we proved to be quite artistic. Some members wore Halloween costumes.

We also had a bazaar, and sold many handmade items and baked goods. The bazaar was held again in November.

November gave us the occasion to express our gratitude. After our Thanksgiving feast, individual members gave testimonies. We are thankful for wonderful friends. We acknowledged progress in services, education, employment, and all sorts of electronic devices. Technology has made a real difference in the lives of persons who are vision and hearing impaired. We hope the digital books that the National Library for the Blind (NLS) is going to distribute can be read with devices that are both audio and tactile braille.

Telebraille was an important solution for isolation. Now, two deaf-blind people in Illinois are working with the new Deaf-blind Communicator (DBC), which enables us to use the telephone as well as communicate with hearing people face-to-face. It is hard to believe that just a few years ago deaf-blind people could not use a telephone. We thank all of you.

Respectfully submitted,
Jerrie Lawhorn, Consumer

2. **SSP taskforce** – no representatives present to report.

3. **IDHHC** – no representatives present to report.

V. Agency Reports

1. Hearing & Vision Connections (HVC)

November Trainings:

- Nov 6, Illinois State University, Vision students (Part II: Screening, EI Overview and Recruitment, and Family Perspective. Part I was held 9/25: Impact of Vision on Development)
- Nov 10, Finding a Different Way to See, St. Johns Hospital
- Nov 14, South of Eighty Conference for Parents of Children with Hearing Loss
- Nov 19, Northern Illinois University, Vision students
- Nov 19, Functional Vision and Hearing Screening Training, Chicago

Newsletter:

The fall newsletter was distributed and can be found at <http://www.morgan.k12.il.us/isd/hvc/resources/newsletters.aspx>. The Winter newsletter is complete and will go to DHS for comment this week. Distribution is anticipated mid December.

Technology:

In an effort to more technology savvy, we are working with ISD Technology staff to initiate Webinar trainings. We are comparing Webinar programs in terms of accessibility, ease of use, cost, etc. We are "test driving" Webex on November 23rd. As much as possible, we are attending meetings by phone or satellite.

COMING UP

- Dec 2, Glasses Don't Fix Everything & Learning with a Vision Impairment, STARNET II, Arlington Heights
- Dec 3, Impact of Hearing Loss on Language and Life, and Understanding Amplification and Technology, STARNET II, Arlington Heights
- Dec 9 and 10, Deaf Mentor training
- Dec 15, HVC Advisory Council meeting, postponed until Spring 2010
- February 17, IAER Preconference: Working with Infants and Toddlers with Vision Loss (for Early Intervention Developmental Therapists/Vision and Developmental Therapists Orientation and Mobility)
- February 23, April 20 and Nov 16, Functional Vision and Hearing Screening trainings in Chicago area (Hearing Screening only being held February 11 and 12 in Carterville.
- March 4, ITHI Preconference (for Early Intervention Developmental Therapists Hearing and Deaf Mentors)

Other Announcements:

The Illinois School for the Deaf and The Illinois School for the Visually Impaired are actively exploring the possibility of new governance. They would possibly move from governance by the Department of Human Services to the Illinois State Board of Education or the Board of Higher Education.

Parent Conferences for parents of children who have visual impairments will be held Spring 2010 in the Rockford and Bloomington areas and March 27 in Mt Vernon. Topics include parent perspective, technology, transition and bullying. For more information, visit www.morgan.k12.il.us/isd/hvc

Parent Conferences for parents of children who have hearing loss will be held Feb 20 in Rock Falls and March 20 in Mt. Vernon. A parent conference was already held November 14 in Jacksonville. For more information visit http://morgan.k12.il.usd/isd/outreach_events.html

Institute for Parents of Preschool Children Who are Deaf or Hard of Hearing will be held June 13 – 18, 2010 in Jacksonville. Families can begin applying through DSCC beginning February 2010. For more information visit <http://www.uic.edu/hsc/dscc/>

Opening Doors, (formally the Parent Infant Institute at the Illinois School for the Visually Impaired) will be held June 4 and 5, 2010. For additional information , contact Jan McGovern at ISVI at 217-479-4437.

Dreaming New Dreams: Using the Home-Based Support Services Programs for Success is being held by Webinar January 6,7,8,9. You must attend Parts I and II can but pick the dates and times that work best for you. Visit www.thearcofil.org

Mom's Night Inn sponsored by Illinois Hands and Voices will be held Feb 20 and 21 at Holiday Inn Select, Naperville. For more information, contact ilhandsandvoices@gmail.com

National Early Hearing Detection and Intervention Program (EHDI) National Conference being held March 1-2 in Chicago. Visit www.ihdiconference.org

Fourth Annual Illinois Family Leaders Conference, Resources and Inspirations for Adult Family Members and Caregivers of children with Disabilities, May 1, 2010, Villa Maria, Lake Springfield, Springfield. Contact Mary Smith at mk-smith@wiu.edu

Submitted by Gail Olson, Coordinator, Hearing and Vision Connections

2. ISBE –

Todd Williams will be employed on Feb. 1st as a principal consultant (Deaf/Hard of Hearing position) in the special education division. It is expected that Todd will attend Advisory Board meetings, probably beginning in April.

Next fall (Sept. or Oct) OSEP (The Office of Special Education Programs) will be conducting a compliance visit for Illinois . They will be checking on all special education programs required by IDEA. The OSEP team will consist of three to four members. Areas of compliance will include general supervision, data collection systems, and fiscal systems. A report will be generated identifying any areas that Illinois ' is not in compliance with, and will highlight areas of compliance.

3. PRC/Project Reach

PRC School Programs –

This has been a very challenging year for PRC and indeed for most Illinois families, schools and service providers, as we face the reality of the state of our State. As of today the State Comptroller is holding 3 unpaid vouchers for PRC totaling 1.6 million. Peggy Whitlow, chief administrator, has had ongoing dialogue with people in the comptroller's office, so they are aware of our plight. Fortunately we were able to delay payments of some obligated funds to get us through December, however, 2010 continues to look grim. We are very thankful for the letters and calls to the legislators and representatives made by staff (on their own time) and families served by the center and school. The Thanksgiving home visit was successful, and everything went smoothly with the closing and reopening. We are planning to close again at Christmas, as we continue to make efforts to save money without sacrificing the educational program. The dates will be Dec. 23 @ 3 PM and we will reopen Dec. 27 @ 3 PM. Some staff may be available to help with respite for families during this period. December is a very busy month here at PRC. Elmhurst college sponsors a "Someone Special Holiday Party" - complete with photos, treats and Santa. This year the "Someone Special" event will be Wednesday, Dec. 2, at 6:30 pm. On Dec. 12 the children will travel to Winfield for the Knights of Columbus party. This is another event that has become a tradition. Families are welcome to join us for these upcoming events. We will also be participating in Gov. Quinn's initiative to make holiday cards for our servicemen. We also thank all of the families who helped prepare the shoeboxes for Operation Shoebox children. The project was very successful - we sent 20 shoeboxes full of gifts that will make an underprivileged child very happy. The DuPage County Health Department came to PRC on November 19, 2009 to administer the H1N1 vaccine to students for whom consent was received and for staff. Things went well and we have been fortunate to be flu free so far.

The Fall Open House was on Sunday, October 25. Many thanks to Maria McCarrick for sharing her feedback and reflections from the Family Leadership Training she participated in last year. It was touching to hear how the training had inspired her to implement a personal action plan. Well done!! PRC primary teacher Nick Pagani did a presentation on technology and I'm happy to report that all students are provided with a weekly experience with the touch screen computer. Michelle Clyne updated parents and staff on the progress of the Literacy portion of the curriculum. We distributed a copy of the updated Parent Handbook. In November parent progress notes were completed. These reports, prepared by the teachers, leaders and therapists provide feedback regarding child progress on their IEP goals. The format is a checklist with comments.

We are in the process of changing how our speech and language therapy

services are provided. Rachel Howe from Easter Seals of DuPage will continue to provide direct service and consultation to the students at Green Brook and Spring Wood Middle, but we will discontinue the Easter Seal based therapy on Wednesday afternoons. Instead PRC will hire a part time speech/language therapist and a speech therapy assistant who will provide services onsite at PRC. These changes will take place January 1, 2010.

Project Reach –

On November 25, 2009, Project Reach submitted to the Illinois State Board of Education the report "Project Reach: Illinois Deaf-blind Services Contributions to Illinois SPP". Copies of this 22 page report are available upon request. In brief, Project Reach activities during year one of the five-year project cycle supported the state's activities related to Indicators 1, 2, 3B, 5, 6, 7B, 8, 9, 10, 13, and 14. Evaluations from on-site trainings and on-site technical assistance were compiled. While the report offers much more detail, a brief overview follows:

There were 923 contacts with professionals (service providers), 407 contacts with families, and 81 contacts with paraprofessionals. Over 100 Technical Assistance Plans were initiated. Some were designed for overall project activities (such as screening for Usher Syndrome), and others for targeted and intensive activities with specific children. Service providers reported a gain in knowledge or skills to a level of 4.60 on a 5.0 scale. Families reported a gain in knowledge or skills to a level of 4.32 on a 5.0 scale. Families and service providers together reported an increase in student skills to a level of 3.7 on a 5.0 scale. It is anticipated that the child achievement score will increase, as many activities that were initiated in the beginning 2009-2010 school year (August and September 2009) have not yet been evaluated. Technical assistance recipients reported an overall satisfaction with services to a level of 4.93 on a 5.0 scale.

4. **DHS/DRS** – no report at this time
 5. **DHS/OMH/ODD** – no report at this time
 6. **DCFS** – no report at this time
- VI. Other** -All meetings for 2009-2010 are scheduled for Room 9-039. The meeting was adjourned.

Recorded by Jody Wolfe