

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

**Thursday, June 2, 2011
James R. Thompson Center
100 W. Randolph Street, Room 9-034
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, Roseann Slaght, Bob Griffith, Jerrie Lawthorn

Members by Phone: Gail Olson, Maria Roeters

Regular Attendees Present: Shelle Hamer, Elizabeth Klein, Joann Rushing, Michelle Clyne

Guest Present: Tina Lechnick

I. Minutes of the April 7, 2011 meeting – Gail Olson approves the minutes, Bob Griffith seconds the motion.

II. Old Business

1. **HKDB Awareness Week** – Wally will have a script for the video next week. Due to Laura's diligence, she was able to get footage from Harry Porterfield from the show "Someone you should know". Laura had to sign an agreement that we would only use the clip for this purposes, that they would get credit, and that we wouldn't make any money on it. There is a short segment which doesn't have Harry's voice on it and will try to extract a short piece. Wally shot video of Jerrie at her award's ceremony. The filmmaker has been traveling a lot so we can't get any additional footage of Jerrie. The plan is to create a video from what we have. Joann said that someone came to shoot a video of Jerrie at the Lighthouse that was used at the Gala Annual Event. Joann said that maybe we could use that video as well. Faith will ask Wally about using additional footage from the Lighthouse. The Sun Times will be interviewing Jerrie on June 23rd.
2. **Discussion of deaf-blindness definition** – Rose asked Tony Paulauski about the PUNS and a better time to suggest this is when the waiver application is due to the Federal Government. We will need to find out when that is going to happen and draft a letter from the board. We need to talk about the actual definition that we would recommend. We should have a subcommittee to discuss this issue. Bob thinks he can find out who will oversee the PUNS document and wants to meet with that person. Bob asked if Gail and Todd Williams would be interested in helping him with this since location wise it makes sense to be close to Springfield. The goal would be to meet in July to start a dialogue to change the PUNS to include deaf-blindness and report back to the board in October. Michelle said that Texas has a Medicaid Waiver and their eligibility is: must be 18 years or older, meet the financial criteria, and have a condition that meets the definition of deaf-blindness with at least one additional disability. Laura suggested that we meet with the people in Springfield first and then have a committee to

come up with a definition. Rose can send Bob some names of states that include deaf-blindness in their waiver. Bob wants to pursue an executive order with the Governor's office to propose a consistent definition of deaf-blindness. Bob makes a motion that the board explores having the Governor issue an executive order rather than going through the IL general assembly. Laura seconds the motion. Rose would want the Governor to adopt our recommendation rather than coming up with one on his own. Michelle said that the definitions are significantly different depending on the age of the deaf-blind individual. We should get deaf-blind definitions from all of our state agencies. Faith asked what agencies we need to go to? Rose said that it would be good to know who doesn't have a definition. Rose will help Bob gather the deaf-blind definitions from the agencies.

3. **Jerrie's & Laura's replacement on the board** – Shelle Hamer is interested in being on the board. She went on line and applied. Laura sent a letter to Chris Koch and haven't heard anything. Laura e-mailed Todd Williams and as you know, Todd is our ISBE liason who will help get Shelle appointed. For Jerrie's replacement, Laura has been in touch with Ryan Croke, who is our contact from the Governor's office. Alan Suger who was recommended by Catherine is too busy to join the board. Cindy Cologne Wilkerson who was recommended by Faith, but she's a DRS person and can't act as a consumer and she doesn't see herself as a consumer. We received 2 names online: James Dunnington who lives in Bloomington. James is visually disabled and uses a guide dog and has a hearing loss. He is retired and wants to use his time to help others. John June sits on a committee that Bob convenes. John is a retired teacher and is hard of hearing and lives in Minooka. John has served the deaf and hard of hearing community for over 40 years. Michelle asked if the consumer has to be deaf-blind? Per the code, we need one parent of a deaf-blind individual, a senior citizen and a deaf-blind individual. Gail said that all of John's experience is on the hearing side. James' 3rd choice of boards/committees was deaf-blind. Rose suggested that we should invite both to our meeting to see if they are really interested. John's 2nd choice was our board. Bob makes a motion to select John June to our board. Jody seconds the motion. Laura will ask Ryan Croke if Catherine can switch to the deaf-blind consumer role and John can fill the senior citizen role. Laura will send the recommendation of John June to the Governor's office. Faith is abstaining as she showed up to the meeting after we started this discussion.
4. **Meeting Location** - Jody reported that based on feedback, although it is not ideal for everyone, we will remain at this location (Thompson Center) for next year. Laura brought up the fact that Sarah will be retiring as of next March. Bob will follow up on the state board to have a go between person to help us with the room/phone.
5. **Annual Report** - Laura suggests adding to our recommendations to support the IL Blueprint for System Redesign. We will probably remove #1 since it is the same as the Blueprint. Laura needs help to add/finish our summary of major activities. Per Laura, the goal would be to submit the report by our October meeting. Jody offered to go back to input the missing pieces in the summary of major activities. Laura has a separate document of objectives that she will send to Jody. Laura will continue to work with Jody to finish the annual report. Bob suggests that we put in our objectives to have a full time deaf-blind specialist hired under DHS/DD.

6. **Other** - Jody reminded everyone that the CHARGE Conference will be held July 29-31 in Orlando, FL. Currently, we have about 650 families/professionals attending. We expect that number to be slightly higher. Professional Day will be held on Thursday, July 28th. Anyone who is interested in attending can go to the CHARGE Foundation website www.chargesyndrome.org to register.

III. New Business

1. **Board Elections** - Our candidates for next year are Bob Griffith for chair, Gail Olson for vice-chair and Jody Wolfe as Secretary. Rose makes a motion to approve the slate. Catherine seconds the motion.
2. **Review Goals for the summer** - Bob thinks that one of our goals should be that our board should be heard. We should have major agencies come to talk to us about what they are doing for the deaf-blind population. And then we could give them some feedback. Faith said that it would be a good opportunity to have some consumers here at our meeting so that they can tell the agencies what their needs are. Joann and Laura Thomas has been talking to Bill Gorman, director of state wide independent living center, about a way that the Centers do their intake form. On the intake form, there are categories of deafness and blindness and multiple disabilities, but not one category for deaf-blindness. They are trying to get the Centers to start using the word deaf-blindness on their intake forms. Laura said that we've had people in the past come to talk to our board and then they don't show up. If we have someone from the agency, we need to have questions ahead of time for them. Michelle suggests that we time their visits when we don't have too much on our agenda. When we invite a consumer, they will have to pay for themselves to get to the meeting. Tina said that we have to be cautious when inviting guests that to make sure we invite the right person that knows about deaf-blindness. Bob suggested that maybe we have a special meeting for agency visits. Michelle would need to look into the travel budget for parents and consumers to see if there is money for an extra meeting.

Bob is going to visit Kreider in the Dixon, IL. We are going to already be working on the PUNS over the summer. Bob would like to look into what happened to the scholarship that existed for individuals who were deaf-blind.

IV. Standing Reports

1. LeCOBDA

We had a good turnout for the May 21st Le COBDA meeting. We met at the Hershey Store in Chicago for a delicious chocolate sampling and a talk about the various types of chocolate, making of chocolate, and the history of the Hershey Chocolate Company. The club paid for the

presentation and chocolate sampling. Members enjoyed visiting the gift store and purchasing Hershey souvenirs. Suggestions were given of various restaurants in the area, and members and their SSP's dispersed for lunch. There will be no meeting in June. On July 9th we will meet at the Lighthouse and discuss the 21st Century Communications Act.

Submitted by Catherine Klein

2. SSP Task Force – no report at this time

3. IDHHC – no report at this time

V. Agency Reports

1. **HVEIO** - Hearing and Vision Connections ended on March 31st 2011. Gail Olson was hired as the coordinator for a new and very similar program, called Hearing and Vision Early Intervention Outreach, effective June 1, 2011. All the contact information remains the same. Parent Institute starts today. On June 20-23 is Bridges, a summer mini-camp will be held.

2. **ISBE** – no report at this time.

3. Philip Rock Center/Project Reach Agency Report - June 2011

Annual IEP's in progress

The PRC student's annual IEP's are scheduled and will take place over the next four weeks. At the IEP's PRC staff, home district personnel and the parents review the student's progress on present goals and look at placement and goals for the coming school year. We look forward to upbeat and productive meetings. One of our students, Kyle Burt, will transition on June 9 to Kreider Services. Krieder, which is located in Dixon, Illinois, provides adult vocational and residential to disabled adults. We will miss Kyle and wish him the very best in his new adult placement.

Life Safety Audit

The initial meeting with the architects took place on May 9, 2011. The onsite visit with the engineers will take place in the near future. The initial recommendations will have to do with replacing the fire panel and some detectors and door closers, bringing the lighting up to code and replacing some doors. Additional recommendations will be addressed in the 3 year plan PRC will submit to the state.

Summer School

The dates and hours of summer school have been announced. Summer school will run from 9:00 A.M. until 1:00 P.M. Monday through Friday, beginning July 1 and ending July 29, 2011. Teachers are in the midst of planning activities and outings now. The summer session will culminate with an Open House and Ice Cream social planned for July 28 from 1:00-3:00 P.M. The district #20 board members are cordially invited to attend.

Project Reach

Continuation Report

Project Reach has completed the annual continuation report. A full report is available in PDF format upon request. The majority of data demonstrate being within timelines to meet or exceed the outcomes of the objectives of the grant. Examples include:

- 93% alignment between needs identified with initial referrals and the focus of services provided;
- 88% of child-based technical assistance leading to increased child skills;
- 95% of Project Reach – eligible children receiving early intervention getting those services in the natural environment;
- 2,469 service providers or family members receiving information generated by the National Consortium of Deaf-Blindness;
- 96% of evaluations from the New Dreams Conference (a family-learning conference) rated the experience “good” or “excellent”;

In addition, families attending New Dreams found that these sessions increased their knowledge of strategies to promote literacy learning for their child (4.63 of 5.00, SD .55) as well as their ability to create networks and supports (4.85 of 5.00, SD .42). Family members also found this activity to be of high quality (4.64 of 5.00, SD .57), relevant to being a parent of a child who is deaf-blind (4.60 of 5.00, SD .58), and useful in their daily lives (4.74 of 5.00, SD .44).

Census

Project Reach submitted the Illinois portion of the 2010 National Deaf-Blind Child Count early this month. This required child count reports anonymous, demographic data on the children, age birth – 22, served by Project Reach. This year 457 children/youth were reported as eligible, an increase of 32 children/youth from 2009. Of these children/youth:

- 44% are transition age (age 14-22 years)
- 6% are early intervention age (birth – 2 years)
- 56% are male
- 24 reside in DuPage County
- The most common causes of deaf-blindness are CHARGE syndrome (35); prematurity (54) and rare syndromes (66).

Intervener Training

Project Reach is taking part in a community of learning regarding the use of intervention for children and youth who are deaf-blind. Intervention is the process of giving a person who is deaf-blind information in a format that they can understand so that they can then make decisions, interact with others, and explore their world. This process is provided by a service also called intervention, provided by an intervener. The intervener is usually assigned to one person who is deaf-blind, and is often considered a paraprofessional, but with college training in deaf-blindness. Project Reach is exploring programs that provide this training as well as possible models to bring this training to Illinois.

- 4. DRS –** During the week of May 23, DRS sponsored a four day training program specifically designed for rehabilitation counselors for the deaf and rehabilitation counselors for the blind. The training Coordinator was Sister Bernadette Wynne of the Helen Keller National Center. Sister Wynne is recognized across the country for her expertise in the field of deaf blind and she has been training professionals across the country for over 25 years. Some of the topics covered were: Causes of deaf blindness, Etiology of deaf blindness, Case study involving deaf blind cases, Hearing Loss as a disability, Communication strategies, Mobility techniques, Panel on the four different cultures, Employment Strategies, Technology as applies to deaf blind, Use of

interpreters, and the benefits of an SSP. The training also included consumers who discussed their life as a person with deaf blindness and responded to questions. The outcome of the training is not only a better understanding of deaf blind, but also to facilitate a closer working relationship between RCD counselors and BBS counselors. The closing challenge was to “raise the bar for deaf blind persons”.

5. DCFS – no report at this time.

Faith motions to adjourn our meeting. Rose seconds the motion. Meeting ends at 12:45 p.m.