

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

Minutes

August 27, 2014

PRC, Glen Ellyn, Illinois

MINUTES

Members in Attendance: Bob Griffith (Chair), John Jun, Catherine Klein, Gail Olson (Vice Chair), Eliza Ellett, Roseann Slaght, Joann Hiatt, Ingrid Halverson, Becky Patton (not yet appointed member)

Members Absent: Shelle Hamer (Secretary), Seth Harkins

Members Attending by Phone: Marcia Breese (not yet appointed member), Derrick Phillips (not yet appointed member)

Regular Attendees Present: Elizabeth Klein, Lori Clampton, Joan Rushing, Lori Clampett, John Miller, Michele Clyne

Regular Attendees Attending by Phone: Brandi Hayes (IDHHC, replacing John Miller)

Guests Present: none

Called to order 10:06 a.m.

I. Minutes of April 3, 2014, 2014 meeting at ICRE-Wood Discussion: In old business under Legislation under hearing aid info, "hearing can provide more than 15 db GAIN, and 200-6000, should be "cycles per second." Motion to accept with changes made by Gail Olson. Second by Rose Slagt. Motion passed.

II. Old Business

1. Website Discussion: Our website is one of most significant things this board has done to get information out. Really needs to be updated. Bob has identified a number of issues and distributed a list. Eliza stated that many of the things on that list are on the site. Sometimes, users browser is outdated and needs to be updated. Eliza Ellett said that the website is in html so it is very difficult to make changes despite several attempts to revise. She has a friend who may be able to help for a fee (approx \$100). Eliza has paid to keep the website going \$100. Michele Clyne stated that she believed that we had determined other funds to keep the website going. Reach funded one URL . Eliza funded .org, but .com is our main URL. She let .net go because no one uses .net. Changing text is not that difficult, but there is no cutting and pasting and moving info, or adding new info such as new links. Rose expressed concern that Eliza is covering the cost of the website. If she needs for us to pay \$100 for assistance, we should pay that. We did ask the State Board to pay \$175. Lori C says she cannot make that decision but will pass on the request. John Jun requested clarification of who's budget our board is under. The Project Reach advisory board is under the

Project Reach budget and covers such things as travel for members. They could pay for the website if it's okay that they do not pay other items. Reimbursement requires receipts. Eliza needs permission for someone off the board to work on the website and to teach her how to make changes. We cant use a Wizzy Wig format because it's not an accessible format. HTML is not what most people use any more. She needs instruction. Eliza will give Michele a receipt for what she has spent on the website so far. We do need a more long term solution to this problem. **Rose makes a motion that Project Reach reimburses Eliza for what she has privately paid so far, pays the \$100 fee to her friend to teach her how to make changes and makes paying website our boards financial priority for use of our Project Reach funds. John Jun seconded. Motion passed.** Eliza requested permission to have authority to add links to other resources to our website as she sees fit. **Gail made a motion that we give Eliza authority to add links and resources related to D/HH and blindness as she deems appropriate. Second by Rose. Motion passed.**

2. Board Vacancies. We have not heard anything official on Marcia Breese appointment from DCFS (DCFS parent/consumer vacancy). We have not heard anything regarding the appointment of Derrick Phillips (DHS DRS position). Ingrid will follow up regarding Derrick. Another individual has expressed interest in becoming a member. Bob passed around the resume of Jeffrey Borhman who has moved to Illinois in June (DHS consumer/family position). He would be filling a DHS consumer /family position. Joan Hiatt (DHS/DDD vacancy). Becky Patton (DCFS Staff vacancy). Eliza Ellet was appointed by the Governor as parent.
3. Legislation Updates. DRS did not have a legislative representative on staff so he has no updates. No other issues were brought up.

III. New Business

1. Welcome and Introductions
 - a. New board members (pending): Marcia Breese, Joan Hiatt and Becky Patton.

Becky is replacing Marsha Northrup at DCFS (staff). She introduced herself and said that she has been with DCFS since 2006 and has been caseworker on foster care side as well as with intact families, and has been an investigator. Many changes she'd like to make in this position. Her new position requires a lot of training and education for herself and workers in the field. Becky worked at ISD for 7 years as dorm parent and educator aid. She has worked at IDHHC. So far, with few referrals, she is finding that some of the children are deaf with hearing parents, and hearing children with deaf parents. She is anxious to learn more about DB issues.

Joan Hiatt has been designated by DHSDDD to represent DB issues at Division of Developmental Disabilities. We are happy to have her on board! Began career as audiologist in hospital and school settings. Worked at Jack Mabley Center on part time basis to do hearing evaluations and stayed for 15 years. There exists a large population there of Deaf or Blind or DB who have lived there their whole lives. Sister Bernie from Helen Keller Center and Joan began a transition protocol to move

them into community based services such as Kreider Center and a group home in Sterling. She has worked on a sign language DVD for staff at Jack Mabley center. Currently, she is working with DHS in program curriculum development and training. She can make that DVD available to others. Becky Patton would like a copy.

She provided an update to the PUNS document and the inclusion of a statement regarding Deaf Blindness on the PUNS (Prioritization of Urgency of Need). There have been issues about the length of time families remain on the waiting PUNS waiting list. A summary of the "Life Choices Project" was distributed. It builds on the existing system and looks at 6 primary functions of the system. The PUNS will remain in the system but will be more streamlined and accessible. The system is also divided into six teams, including the PUNS and Community Based Service enrollment. The hand out includes a website to learn more about the Life Choices project. www.dhs.state.il.us/page.aspx?item=70504 Gail Olson shared her experience as a parent moving through the PUNS process. Once you are selected off of the waiting list it's a long process that requires a lot of persistence and follow up. Joan added that it's the "luck of the draw" how skilled the Service Coordinator/facilitators.

Marcia Breese is the Coordinator of the Illinois School for the Deaf Outreach program. She was asked to share information in the area of Usher Syndrome. She had no information to share.

2. Discussion of PRC Strategic Plans: Michele Clyne provided information on the background of the document and how it was developed through a process of self reflection. We discussed how many children are currently in the program which is difficult to answer. There are current applications in process. Approximately 17 beds could be made available. As more children enroll, the building would need to be re-configured based on their needs. They are looking at how to get permission from ISBE to accept out of state students. Bob has seen situations that the kids move to Illinois from out of state and when they turn 18 years old, they are not longer their parents responsibility and they stay in Illinois (from Wisconsin and other neighboring states). Michele agreed that this point needs to be included in the Plan to be developed by the State board of Ed to be shared with other state boards of education. There needs to be an agreement /vehicle for how they are transitioned to adult services. John Jun mentioned that it is an ongoing issue and that we need a regional center for Deaf Blind Services. It's not just an Illinois issue, but a national issue (for mental health, Deaf Blind and other very low incidence populations). We need a strategic plan nationally, that includes something like a regional co-operative for children and adults. John talked about the rate of children statewide receiving Deaf/HH services and that DB is even a lower number. Bob is concerned about putting kids and adults together in the same program (intensive transition program). Michele clarified that funding allows services only up to age 22. Gail commented that she was impressed by the sheer honesty of the reflection process. Rose commented that she would love to see the inclusion of respite services that is so imperative for the health of families. Michele commented that their service funding is only for educational services and they cannot replicate what DHS does (respite). They

could, however, create something like a summer school, summer educational program that may result in an evaluation report, etc. that still provides a sense of respite to families.

Ingrid shared information about the SSP (Support Service Provider) task force that they are working at the IDHHC. This is not to be confused with the Intervener training program. Michele elaborated on the Intervener training efforts. The Intervener trainings are free and there a number of ways you can sign up for them, including through Project Reach where you receive coaching through a cohort and CPDU certificates. The training is not for the consumer to learn how to use an intervener. It is geared for individuals who want to become an intervener; however there are individuals who are DB who are taking the courses.

Bob suggested that the main question is whether PRC will be here in 10 years, so the fact that they are creating a creative strategic plan is to be applauded. Many programs across the country is facing this same question. Michele said that it's important that PRC expands its reach (summer camp, what they can offer the community, out of state students, etc.).

Rose Slagt shared hand outs about three upcoming events/services:

- Upcoming Training on Health Care reform by ARC of Illinois
- Info about an October moms retreat in Rockford (moms of kids with disabilities birth to death)
- The Arena of Dreams – a therapeutic recreation center near Chestnut Mountain in Galena (horseback riding, aqua therapy, etc.)

Bob shared information about our final report goal to work with State Agencies to appoint liaison on matters regarding DB. Bob and Gail met with the Department of Aging and they agreed to appoint a staff member. That still needs to happen. The agencies we want to have a liaison with are DHS/DDD (Joann Hiatt), DHS/ DRS (Ingrid Halverson), Department of Aging (undetermined), DHS Division of Mental Health (Jessina Williams), Illinois State board of Education (we need to know who that will be), DCFS (Becky Patton) , IDHHC (Brandi Hayes?) and Department of Veteran Affairs (we need to meet with them). At some point, we would like to gather all of those state agencies appointees for a joint meeting. Bob will continue to work to get those appointments finalized.

IV. Standing Reports

1. LeCOBDA: Catherine submitted it online
2. IDHHC/ SSP Task Force: Still in the process to determine funding for SSP's. It's a slow process. They conduct three meetings a year. Bandi Hayes elaborated that they're researching other state programs and how funds are allocated. Attention is being shifted to looking at resources that are already established in Illinois. Illinois law doesn't recognize the SSP n the ADA law. Decision made to begin going o the public and requesting a change in the terminology, such as "guide", rather than SSP. Joan Rushing agrees that it's been a long road. The issue is to come up with funding. Met with the Center for Independent Living to

go to municipalities around the state to determine what happens to the money obtained by handicapped parking fines. Rose asked if SSP task force had considered going after foundation funding. Joan added that they are also advocating getting the term DeafBlindness out to the public, to let them know that there are people out there in their communities who are D/B. Ingrid why we couldn't use funds through the 1115 combined Waiver funded through Medicaid. Joan thought that Texas was the only state that had a Waiver specific to DB. There exists a waiver for DB but an individual has to be financially eligible.

3. HKNC: Laura Thomas, HKNC, has a new position and HKNC is interviewing for a new Region 5 Helen Keller representative.

V. Agency Reports

1. HVEIO:

Gail reported that upon her retirement, her position will be replaced with two positions: one at ISD and one at ISVI. A FY 15 training calendar is in the works and can be found on the website www.bit.ly/HVEIO. She highlighted three events:

- Sept 8, 2014 ISVI-P (Illinois Summer Vision Instructional Partnership) held at ISVI with 85 participants from four states. The topic was Cortical Visual Impairment presented as an all day training by Beth Ramella from the Western PA School for Blind Children.
- Sept 19, 2014, the Changing Landscape of Pediatric Hearing Loss at University of Chicago Hospital. This is a collaboration between HVEIO and U of Chicago (Dr. Dana Suskind, ENT).
- February 18, 2015 IAER Preconference will be a collaboration between HVEIO and IAER with Dr. Mark Borchert from the Los Angeles Children's Hospital on the topic of Optic Nerve Hypoplasia. This will likely be open to national registration.

Gail added that she and Michele Clyne have been working with the National Center on Deaf- Blindness on the topic of the Early Identification and Referral of DeafBlind infants and toddlers. A White Paper was developed and will soon be nationally released. This board will want to refer to the findings and recommendations found in that White Paper.

Bob asked for an update on the ISD Usher Syndrome screening effort. Project Reach received a technical assistance referral from ISD and has been given to Carla Beck.

2. ISBE: No report.

3. PRC/ Project Reach: We reviewed the Strategic Plan for PRC. Other updates: Tod Williams and Michele Clyne attended the required meeting in Washington DC to learn about new regulations related to their funds. Next year, they will not attend a federal project meeting (will be held everyone other year). There will be a Deaf Blind Summit of D/B programs. Michele also talked about a project with Chicago Public Schools (CPS) to provide technical assistance for students who are D/B. Ingrid reports that Rehab Counselors of the Deaf have had difficulty getting into the Chicago Public Schools so this has been a great initiative. Eliza

is trying to find if there is a way that PRC can go into the schools and test to see if they would qualify for the DB status so that can be identified on the IEP as the primary disability so we can get a count. Michele reports that she deals with that issue frequently. Count currently is 413 birth to 22. Current count is 65 of children who have a combined sensory loss. The IDEA definition of deaf blind makes it difficult to have other disabilities added to the IEP. Project Reach doesn't go into schools to "test" students, but they are happy to serve kids who have dual sensory needs and will work to do what they have to do to determine disability. IDEA needs to be reauthorized with new definitions. Just because someone has a disability code on an IEP does not mean that code travels with them into adulthood. Eliza is interested in participating in some way as a parent on this coalition with CPS. Lori from ISBE states that they are continuously in conversation with other states regarding IEP constraints and how they inhibit or prohibit accurate documentation of disabilities. John said what we need is an "other" option on the IEP so that statistics can be collected. Michele said that Illinois Supervisors of Programs Serving Students who are Hearing Impaired received permission to add questions to the IEP related to communication which will lead to better documentation of students needs for hearing loss related information (this was an outcome of a request to have a Communication Plan added to the IEP in Illinois).

4. DHS/DRS: Ingrid informed us that DRS received permission to receive a DeafBlind unit at DRS. They will be hiring three rehab counselors for DB, an O&M specialist and an office support worker to be housed in Chicago. One counselor for Chicago, one for regions 2 and 3 (north western area of the state) , and one for Regions 4 and 5 (southern area of state).
5. DHS/ OMH/ODD: No report
6. DCFS: No report
7. ICRE-Wood: No report
8. Chicago Lighthouse for the Blind: Joan Rushing reported that they hosted a DB retreat at ISVI with 63 participants. 23 of them were DB. All others were committee people. A highlight was that they attended the Crazy Horse campground near Jacksonville where they had Olympic-type games for the individuals. Four days included lodging, food and activities for \$150. This will happen again biannually, in 2016. Talking about having it at ISD in 2016 where they will have access to Wi-Fi and video phones.

Cake was enjoyed by participants in honor of Gail Olson's retirement and her last meeting on the board. A letter by Governor Quinn to Gail Olson was read, in honor of her service to the board. Gail thanked everyone, made some parting comments and left a binder of board minutes from 2003 to present.

An announcement was made that Illinois State University (ISU) received a US Department of Education Grant to provide a graduate certificate program for teachers of the visually impaired entering the field of Early Intervention. Michele Clyne and Gail Olson of this board were instrumental in the writing of this grant application and will be involved in the program implementation. Others involved in the writing of the grant included Maribeth Lartz and Olaya Landa-Vialard of ISU and Mindy Ely (then of HVEIO and STARNET).

Next board meeting dates:

- October 2, 2014 (Bob may be out of State) **There was a motion by Catherine Klein to change the meeting. Rose seconded. Motion carried.** No date was selected.
- December 4, 2014
- February 5, 2015
- April 4, 2015

Motion to adjourn: 1:00 p.m. on motion by Gail Olson.

Respectfully submitted by Gail Olson, IABDB Vice Chair