

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

**Thursday, April 5, 2012
Philip J. Rock Center & School
818 Du Page Blvd.
Glen Ellyn, IL 60138
10:00 a.m. to 1:00 p.m.**

MINUTES

Members in Attendance: Robert Griffith, Shelle Hamer, Catherine Klein, John Jun, Marsha Northrup, Rose Slaght, Faith Young

Members Absent: Faye Manaster, Maria Roeters

Members Attending by Phone: Gail Olson

Regular Attendees Present: Michelle Clyne (PRC) , Ingrid Halverson (DRS), Karen Janssen (Interpreter), Elizabeth Klein (SSP), Catharine Rajacan (CART), Joann Rushing Chicago Lighthouse), Donna Stanton (Interpreter), Laura Thomas (HKNC)

Regular Attendees Attending by Phone: None

Guests Present: Paul Nijensohn (ISBE), Eliza Elliot (parent), Dr. Patricia Scherer (ICODA), Peggy Whitlow (PRC), Sandra Alexander (IL Department on Aging)

Robert Griffith called the meeting to order at 10:08 a.m. Every one briefly introduced themselves.

I. Minutes of February 2, 2012 Meeting

Robert Griffith corrected the Puns Update section to read "At the last meeting we discussed a recommendation to adding an addendum to the PUNS document." Robert Griffith moved to accept the minutes as corrected. John Jun seconded the motion. All were in favor. The motion passed.

II. Old Business

1. PUNS Addendum

Robert Griffith spoke with Mary Ploessi and she said they would take the recommendation to add an addendum to the PUNS document. A brief page was written to add the impact of deafness and blindness on a human being and how it impacts a person's ability to function in their environment. In previous meetings everyone was given a copy. Faith Young read the draft to the group. Rose Slaght said it was very good, but DD needs to be spelled out. Faith said it needs to be edited for typos, grammar and syntax. Robert Griffith

moved that the edited document should be presented to the developmental disability agency as a recommendation from IABDB. John Jun seconded the motion. All were in favor. The motion passed.

2. DBAW 2012 and BeMyVoice.com

Faith Young discussed a new idea for Deaf-Blind Awareness Week (DBAW) with Wally Pacheco at Engage Creative. The concept is to hold an Open House at the Philip Rock Center (PRC) sometime during the month of June in honor of DBAW. This would create greater community awareness of PRC and individuals who are deaf-blind and the issues they face. The idea came out of a stakeholders meeting as part of PRC's recertification process. Wally was receptive to this idea and thought ideally Engage could produce a video in advance and send it out early during DBAW inviting people to the event later in the week. Faith shared these discussions with Michelle Clyne who in turn discussed them with Peggy Whitlow. PRC is open to the idea, but the optimal dates will not work. Alternate dates were selected and a new plan was discussed with Wally. He said an Open House earlier in the month with a video sent out the week of Helen Keller's birthday, as usual could be good. His main concern was timing, as he relies on the generous donation of other's time and talents. He said it could work if we pre-tape some of the video. He has a vision already. He would like to tape the school and some segments in advance. Then he would have an idea of what they would need to tape the day of the event. This would also allow for voice-over to be prepared in advance. IABDB is supposed to work on a draft invitation for the event and then Engage will refine it with us. Assuming all are in favor, we will move ahead with this new plan.

The size and scope of the project was discussed and debated. Other options were explored and set aside. Peggy Whitlow was concerned about having 1,000 people in the building and on the grounds (in other words, a very large number). Obviously, parking and capacity is limited at the site. So they could best manage logistics, it was decided PRC would be in charge of the Open House, with support, as needed, from IABDB members. The Open House would be June 18, 19, or 20 during a three hour window. PRC envisions some activities and/or information stations and simple refreshments such as lemonade and popcorn. The Open House will be held on a very small scale and if successful, with much more advanced planning, a bigger Open House could be planned next year. IABDB would work with Engage Creative on the video and email campaign. Shelle Hamer moved to support PRC with a small open house and dovetail that with a deaf-blind awareness week campaign while supporting the Open House event with anything PRC needs. Catherine Klein seconded the motion. All were in favor. The motion passed.

The resignation of Faith Young from the Board creates two issues that need to be addressed. She is the owner of the BeMyVoice.com site. She pays for it, takes care of ICANN registration, etc. What are the expectations after she resigns? The same is also true for the Constant Contact account that we use to send out the DBAW campaign, although this past year she was reimbursed for the cost due to the availability of funds at the end of the Fiscal Year. As a side note, a further complication is that the ISBE website links to the BeMyVoice website.

A related issue is the posting of minutes in compliance with the Open Meetings Act (OMA). The Board decided minutes should be posted to the ISBE website as we could not guarantee minutes would be posted in a timely manner to the IABDB website. While Sarah Sebert immediately requested the minutes be posted to the ISBE website, it seems it took over a month for them to be posted, well beyond the two weeks required by OMA. How do we want to address this? Additionally, the ISBE website links directly to the bemyvoice.com website.

Paul Nijensohn asked where on the ISBE website the IABDB information was listed. Ms. Young informed him it is under Special Education Advisory Boards, then under Deaf and Hard of Hearing.

John Jun said since we're an ISBE advisory board we should advise ISBE to fix the situation.

Gail Olson said we should ask ISBE if we can become part of their website and if they can be timely about posting information.

Mr. Nijensohn said he has a webpage and some contacts so he may be able to help with timely postings. With Todd Williams being present and his contacts, a two person approach may be more successful.

Mr. Jun moved that the website posting be reviewed by ISBE to make it more expedient in the dissemination of information such as minutes, agenda, etc. and that options for continued posting of the other material currently housed on the BeMyVoice.com website be explored. Shelle Hamer seconded the motion. All were in favor. The motion passed.

Both Mr. Nijensohn and Mr. Williams will look into options for imbedding pieces of the BeMyVoice website into the ISBE website and report back at the June meeting. Ms. Young will provide exact financial costs for BeMyVoice website maintenance and Constant Contact account maintenance at the next meeting.

John Jun moved to amend the agenda to allow Sandra Alexander from the Department on Aging and Dr. Pat Scherer from ICODA to speak at this time then return to the remaining agenda. Shelle Hamer seconded the motion. All were in favor. The motion passed.

Speaker: Dr. Patricia Scherer, ICODA (see New Business for minutes of presentation).

Speaker: Sandra Alexander, Manager, Division of Planning, Research and Development, Illinois Department on Aging (see New Business for minutes of presentation).

3. Board Member Vacancies and Parent Application[s]

Eliza Elliot introduced herself as a parent applying for membership to IABDB. She has a three and a half year old daughter who is deaf-blind and goes to school fulltime in a deaf

classroom. Ms. Elliot works fulltime with IL Hands and Voices Guide by Your Side. She knows the hurdles parents go through having a toddler and going through the system. She lives in Chicago. Paul Nijensohn asked what school her child attended. She attends Bell School by Addison and Western. Rose Slaght moved we accept Eliza Elliot as the DHS Parent Representative to IABDB. John Jun seconded the motion. All were in favor. The motion passed. Robert Griffith will contact the governor's office notifying them that we approve of Eliza's application to IABDB.

4. Planned Medicaid Changes

Faye Manaster sent the following update regarding Proposed Medicaid Changes. She stressed now is the time to act. Individuals can subscribe to receive updates about all the new "Innovations." People can also submit comments and go to meetings. She emphasized that this is the first time Medicaid is showing a willingness to interact with the public. She said this is the time to step up to the plate and act, which she cannot stress enough, as 80-90 percent of people with disabilities are involved in the Medicaid system. She said this is truly an opportunity to have a seat at the table. Anyone can call or email Dale Mitchell. The University of Illinois is evaluating the Integrated Care Program.

The following is a summary of changes in the Medicaid arena.

1. HFS is still considering ending the Medically Fragile/Technology Dependent waiver for kids: <http://www.savemftdwaiver.com/>
2. HFS is planning a "pilot" for "dual eligibles"- people with disabilities who have both Medicare and Medicaid (a lot of other states have already done this) to put them in Medicaid Managed Care:
http://www2.illinois.gov/hfs/PublicInvolvement/cc/Documents/cc_capitatedmodelproposal.pdf
Public comment period is over, but comments are not yet posted on the HFS Innovations site: <http://www2.illinois.gov/HFS/PUBLICINVOLVEMENT/CC/Pages/default.aspx>
3. Most people on Medicaid will be in "Coordinated Care" starting in July: Here is link to April 11th videoconference info:
<http://www2.illinois.gov/hfs/PublicInvolvement/cc/Pages/041112.aspx>
4. UIC Family Clinic evaluation of the Integrated Care Program (Aetna Better Health and IlliniCare) is now underway. People who want to share feedback should contact Dale Mitchell:

Dale Mitchell, PhD
Clinical Assistant Professor
Associate Head for Administration
Director, Family Clinic
Phone 312-413-1504
Fax 312-413-1630
Email dalem@uic.edu
Office 208 IIDD

Bio

Dale Mitchell is a Clinical Assistant Professor and works on several projects for DHD. He provides overall coordination for the project that is evaluating a new Medicaid Managed Care pilot project in Illinois. He also assists the Family Clinic in their billing operations by writing and revising billing software they use. In addition, Dr. Mitchell teaches in the department's master degree program.

5. IL submitted a proposal to CMS last month to "start early" - in advance of the Affordable Care Act in 2014 to enroll childless-low-income adults in Medicaid- waiting for a response. This will enable a lot of uninsured adults with disabilities who are "not disabled enough for SSI" to get health insurance for the first time:

Proposed 1115 Waiver Demonstration Project to Cover the Uninsured

The Illinois Department of Healthcare and Family Services (HFS), in collaboration with the Cook County Board and the Cook County Health and Hospital System (CCHHS) has requested an 1115 waiver from the Centers for Medicare and Medicaid Services (CMS), effective July of 2012, to cover the current uninsured population that will become eligible for Medicaid in 2014. While this waiver application was written with a focus on Cook County, the waiver could provide for any willing county in Illinois to participate if HFS and CMS standards are met. This waiver will allow CCHHS to decrease its uninsured population and provide funds to improve the quality, coordination, and cost-effectiveness of the care it provides. The 1115 waiver would be entirely funded by local county resources and federal matching funds for eligible services.

- [Public Notice March 7, 2012](#)
- [Waiver Application Proposal \(pdf\)](#)
- [Submit Your Comments](#)

Rose Slaght added that if anyone is confused about anything they read in the above information links, call the Family to Family Health Information Center toll free at 866-931-1110.

5. Board Member Information Packets

Shelle Hamer reported that there is still a little more tweaking before the packets are complete, so she would like to wait until the next meeting to fully present. She did discuss the need for a presentation format that will allow for access for braille. Ms. Hamer thanked everyone who sent information for inclusion in the packets. Michelle Clyne asked if the packets will be available electronically. Ms. Hamer questioned best format for distribution. John Jun said multiple formats of distribution would be best.

6. Location of Official Records

Paul Nijensohn consulted with another ISBE board and discovered the other board keeps minutes, agendas, any works submitted for the their board, any other records required for audit purposes, information in reports which note activity and progress on nontraditional actions. Now that we know what we need, ISBE will take responsibility for storing the records. ISBE will notify us how many years of records they need.

7. IABDB Meeting Location

DRS have invited IABDB to use their district office conference room for meetings. Shelle Hamer asked where the district offices are located. Ingrid Halvorson said they are on the corner of Butterfield and Finley about 2 miles east of the Philip Rock Center. DRS can offer a larger room and parking is free. John Jun expressed concern that as a statewide advisory board with five meetings per a year, at least one should be in southern Illinois. Otherwise, he feels we are limiting possible public participation. Rose Slaght responded that traveling to southern Illinois is not practical for parents and Gail Olson is perfect example of how the public from other areas can join a meeting, on the phone. Ms. Olson added that the majority is from northern Illinois and that is probably because of where the meetings are located. She feels every board struggles with this problem, but as long as others can participate by phone, she is not too concerned about it, although she thinks the meeting location could be more centrally located, meaning the majority of people will be traveling. Ms. Hamer stated she would worry about the ability to get a quorum if we moved the location more downstate, especially since we struggle with that now. Michelle Clyne worried about not having a large enough budget for travel. Gail thinks that if we relocate, over time membership would change to include people from central and southern Illinois, thus requiring less travel, but initially it would be more costly. As for the issue at hand regarding our immediate location, Robert Griffith sensed everyone would like to stay put. Ms. Slaght said she would entertain the option of checking out the potential new meeting space on June 7.

Rose Slaght moved we move the June 7 meeting to DRS, providing the conference room is available. Catherine Klein seconded the motion. All were in favor. The motion passed.

8. Legislation Updates

A. HB3925—Child Vision and Hearing Test

Rule 19(a)-Re-referred to Rules Committee. That means that if does not come up by April 26it is dead.

B. SB2546—INS CD- Hearing Aid Coverage

Rule 2-10 Committee/3rd Reading Deadline Established as April 26, 2012

C. Nearly 246 AMC Theatres in Illinois will be equipped with technology to help residents with hearing and vision disabilities, under a settlement announced Wednesday by Illinois Attorney General Lisa Madigan.

As part of the settlement, Kansas City, Mo.-based AMC Theatres will provide personal captioning services and audio-description technology at all of its Illinois movie theaters, which include 460 movie screens. The services will be available by 2014 at nearly all theaters and at all listed showings.

The settlement is the result of concerns brought to Madigan's office by Equip for Equality, the federally funded agency that acts as an advocate for disabled residents in Illinois.

D. Bob: Major funding changes proposed to DORS home service program, which people who are deaf-blind may qualify for. The program is designed to keep people in their home who are at risk for institutionalization. The proposal has not been finalized, but the number of hours available may be changed on an individual and the score needed to qualify on the DON may go up to 37 instead of 29 based on need. Also, once a year, those people in the program if they scored lower than 37 may not be allowed to continue in the program. Additionally, those who are mentally ill and do not have any other disability would not be qualified for the program. The department is also discussing a once per year recertification process. Ingrid Halvorson added that because their home service program is funded through general revenue funds and they don't receive any federal funds for that, the governor has asked all of the directors, of course, to say how they're going to address the budget crisis. So what's proposed is that their home service program will develop a new tool to assess an individual's needs. So instead of having the DONs, the determination of needs, they're going to develop a different tool that is more current. The DON was developed 30 years ago and doesn't adequately reflect a person's needs in the home today, especially when you take into account technology and other advances. So the proposal is that a person scoring between 29 and 36 may not be eligible to receive home care. This is not set in stone. Current customers scoring in that range will continue to receive services unless during the reassessment it's determined that they do not have that higher score of 37, or whatever that number is determined to be. Ms. Halvorson explained that people with mental illness are no longer receiving services under the waiver because it was discovered that the waiver is for physical disabilities only, not mental illness, not developmental disabilities. The Division of Rehabilitation Services is working with the Department of Mental Health and the Division of Developmental Disabilities to ensure all the people who need home services will be receiving those services, but under the proper division. They are also working with the Department on Aging, who sets the service cost maximum. DRS service cost maximum is larger than the Department on Aging service cost maximum, so they are working that out. They are trying to standardize the costs across the state.

III. New Business

1. Closed Session Minutes Review

Gail Olson needs to research the procedure for opening the closed minutes. Faith Young moved to postpone the closed session minutes review until the June 7 meeting. John Jun seconded the motion. All were in favor. The motion passed.

2. Dr. Patricia Scherer, "The Changing World of Deafness Coalition on Advocacy, Public Awareness and Funding"

Dr. Scherer shared information about the Sharing information about the consortium and news of a new capital funding project just finalized yesterday, April 4, 2012. The new funding project will begin April 15 and will include the following.

- A 70-acre, seven building development that will house a variety of resources used by all people in the area of disabilities as well as community members.

- An arts center to house the International Center on Deafness and the Arts.
- A neuro-diagnostic, neuro-science based diagnostic center (medical, biomedical, educational, and psychological). We are hoping to overlap all these disciplines for a total study of the child, with recommendations of how they would learn the best.
- A graduate university with a master's degree and doctorate degree in advanced studies. The program will begin with advanced studies in deafness and deafness and multiple problems. The intention is to eventually spread to all disabilities for children.
- A model school for children with deafness and multiple problems, serious multiple problems. This school will be neuro-science based, but it will also be a practicum site for doctoral students and for medical students. It will provide a way for everyone to learn and to utilize new information.
- A model high school for gifted and talented children.
- A convention center with a small hotel for visitors. This will allow for conventions, meetings, etc.
- A physical recreation center so everyone can maintain their health while they are on the campus.
- A remodel or rebuild of the current psychiatric hospital with the unit for deaf children in which ICODA is located, depending on upcoming site meetings with the donor.

The plan will take time and involves buying a property with one major building on it, to which ICODA will relocate. Heads of each of the five area disciplines will be hired. The two-year period during which the buildings are being built on the property will be a planning period. This is a private endeavor. ICODA has been a private organization, but it has taken state and federal funds, worked hand-in-hand with any state agency, any public school, and residential school. They have no intention of changing that. This will be a continued partnership, despite the new project being privately funded by a Chicago Pulmonologist.

Dr. Scherer and a neuroscientist recently wrote a chapter for a college text book that was published in Europe. It is her hope it will be distributed in the United States as well. The neuroscientist wrote about what neuroscience is and what it can do for people outside the research lab. Dr. Scherer wrote about what neuroscience did for a group of deaf children when it was applied to deaf children with serious multiple disabilities. Both Dr. Scherer and the neuroscientist are invited to speak at the World Health Congress in Geneva Switzerland on May 1. Following that Dr. Scherer was invited to speak at the University of Dubrovnik, which has had a deaf program for a long time.

ICODA started a coalition in October 2011 called the Changing World of Deafness Coalition, designed to develop advocacy for children and make the public more aware of deafness and its impact on others. If there is poor awareness of deafness, there is even less awareness of deaf-blindness. There is a tremendous crisis in the whole country. This was created by the idea that the cochlear implant cured deafness, compounded by the recession. The population of children with multiple problems has gone in the last 20 years from 6 percent of deaf children to 50 percent. At the same time, universities have not changed the way they train teachers in all those multiple problems. So, there is a crisis

facing the entire country. Dr. Scherer, as someone who trains teachers of the deaf, who have gone on to assume roles throughout the country as heads of state programs in deafness and heads of major universities, reached out to her contacts and asked if others were also having problems. These representatives from across the country joined together to create a national think tank, with representation from Virginia, New York, the state of Washington, Oregon, California, Illinois, Missouri, Washington, D.C., Florida, Maryland, South Carolina, and Indiana.

Deafness has no famous person out there bringing in the millions of dollars. They are looking for organizations and states that wish to join the coalition. The goal is to amass people and money to be able to do the right thing by children. Finances are bad everywhere. The coalition is developing a plan, starting with a national conference in the fall.

Robert Griffith asked if Dr. Scherer sees children who are hard-of-hearing benefitting and how? Dr. Scherer said absolutely and told a story to illustrate her point.

3. Sandra Alexander, Manager, Illinois Department on Aging, Planning, Research and Development Division

Robert Griffith introduced Sandra Alexander, manager of the division of planning, research and development of the Illinois Department on Aging. Ms. Alexander will talk about the services the Department of Aging offers older adults, services that are available to the deaf-blind population as well and provide feedback to the Board as to what the area agency on aging network could use in terms of additional support or assistance with the challenges and issues they face working with the deaf-blind population.

The Illinois Department on Aging serves and advocates for older Illinoisans and their caregivers by administering quality and culturally appropriate programs, and they float partnerships and encourage dignity and quality of life. They serve over 2.2 million older adults in the State of Illinois and that number is constantly increasing.

Programs include the following.

- Community care program, which is designed to be an alternative to nursing home placement. Key components of this program are comprehensive care coordination, which is a care manager who can come into a person's home and do an assessment to determine what the needs are, develop a plan of care, and then proceed with either referrals to outside services or to other community care program services provided through a network of private contractors. In-home services, which is an individual who can come into the home for a number of hours a day, depending on the need to provide housekeeping, meals, meal preparation, laundry, transportation, etc. Adult day services are provided at contracted centers around the state where older adults can go for half a day or full day while the caregiver is working. The older adult would receive meals, socializations, activities and frequently a nurse is available to manage medications. Emergency home response systems are pendants or wrist bands with an emergency button. Wearers press the button in an emergency to set off a response system that starts with perhaps a neighbor or an adult child that can go over and check on the older adult. If this person cannot be reached, the system dials 9-1-1. Presently about 73,000 people (on a monthly basis) are served in this program.

- Forty percent of the Department on Aging caseload reports vision impairment. Nine percent of their population reports a hearing impairment.
- The Elder Abuse, Neglect and Exploitation program is contracted out to private providers that investigate allegations of physical abuse, emotional abuse, financial exploitation, and self-neglect in addition to other types of abuse.
- The Department on Aging responds to about 12,000 reports annually. With a \$9 million budget.
- The Long-Term Care Ombudsman program investigates and resolves the complaints of older adults living in nursing homes. They are not a regulatory body for nursing homes, which falls to the Illinois Department of Public Health. The ombudsmen also perform family and resident outreach, and develop family and resident council meetings.
- The Circuit Breaker Pharmaceutical Assistance program processes over 400,000 circuit breaker tax relief grants to older adults who are income eligible. Eligible individuals receive a very small grant, under \$100. This division also determines the eligibility for the Illinois Cares Rx program, a pharmaceutical assistance program. The program itself is administered under the Healthcare and Family Services department, but the Department on Aging determines eligibility for this program. The Department on Aging also determines eligibility for the reduced license plate program, the disabled ride free program and the senior ride free program.
- The Senior Help Line, established in 1991, receives about 120,000 calls per year from individuals, older adults, family caregivers or professionals around the state—looking for information about available services. Referrals are made to Department on Aging and community services (either private or nonprofit). The Senior Help Line does have TTY capability as well as bilingual services.
- The Department on Aging receives federal funding from the Older American Act. This money is distributed to the 13 area agencies on aging, each responsible for a particular region of the State. DuPage County is served by area II, which is the Northeastern Illinois Area Agency on Aging. It is located in West Chicago and is headquartered in Kankakee. This area agency serves an eight-county region in the suburban, or collar, counties of Chicago. Older American Act funds support information and assistance, congregate meals, home delivered meals, transportation, senior center activities, counseling and support, and legal assistance programs.

While all the previously mentioned programs are available to all aging adults, including individuals with deaf-blindness, the IL Department on Aging has the following programs and services available to all persons who are deaf-blind.

- Senior Help Line with TTY accessibility
- Aging Disability Resource Center Grant. This grant will allow all area agencies on aging to be able to provide information on resources and services to enable all people seeking help regardless of their age or disability, to navigate their own homes and communities. The IL Department on Aging is focused on helping people stay in their own homes and communities rather than being placed in institutions.

- For FY13, anticipate adding assistive technology waiver service to the core service offerings. This would enable people to receive up to \$500 per year to purchase assistive technology not covered by Medicare or Medicaid, such as medication adherence machines.

The following is a list of suggestions made by our Area Agencies on Aging that would help them to better respond to the needs of persons who are deaf/blind. Also included are a link to the Department on Aging website, as well as a link to a list of our 13 Area Agencies in Illinois.

- Accessibility of materials in Braille or large print; ASL interpreters, videos in ASL
- Awareness of accommodations that agencies can make to increase/improve access to those who are blind/hearing impaired; information on ADA amendments
- Availability of counselors who are blind/deaf in order to reach this population with information
- Skills training for agency staff
- Resources that can be shared when people need more than the Aging network services
- Education on auxiliary aids, services and assistive technology

Department on Aging website: <http://www.state.il.us/aging/>

List of Area Agencies in Illinois: http://www.state.il.us/aging/2aaa/aaa_list.htm

Laura Thomas of the Helen Keller National Center explained HKNC has a regional office in Illinois and they have aging adults and an aging adult specialist who does quite a bit of training for case coordinators who also do life programs and social service providers and adults that have the dual hearing and vision loss. Ms. Thomas offered her business card and HKNC as a resource. She also mentioned the Illinois Memorandum of Understanding and how the 30-year transition is one of the goals for next year.

Faith Young questioned whether the IL Department on Aging can be used as a resource to help people with disabilities, including developmental disabilities and deaf-blindness stay or move back home or into their home communities. Ms. Alexander discussed the Pathways to Community Living demonstration project, in which the IL Department on Aging is involved along with the Department of Human Services (DHS), Division of Developmental Disabilities, Healthcare and Family Services, Department of Mental Health, and DHS Department of Rehabilitation Services. Individuals who have been placed in nursing homes for at least 90 days, that have been on Medicaid for at least one day, regardless of their age, are eligible to be moved back into the community if they would like to and can be so moved safely. In 2012, IL Department on Aging transitioned 75 older adults out of nursing homes under this program. Once an individual is identified by a referral source, Department on Aging goes to the nursing home, talks with the client about the program and determines interest. If the client is interested, a transition coordinator is assigned to develop a plan of care to ensure the person can be served in the community safely. The Department on Aging can also help with one-time expenses up to \$4,000 for costs associated with setting up a household, such as security deposits, a ramp, etc...

Laura Thomas promised to follow up with Sandra Alexander about support and resources Helen Keller National Center could provide the Department on Aging.

4. Officer Slate

Robert Griffith announced we have three positions open, chairperson, vice chairperson and secretary. John Jun nominated Mr. Griffith for chairperson. Shelle Hamer seconded the motion. All were in favor. The motion passed.

John Jun nominated Gail Olson as vice chairperson. Shelle Hamer seconded the motion. All were in favor. The motion passed.

Rose Slaght nominated Shelle Hamer as secretary.

Discussion: Ms. Hamer was concerned that she could not take notes fast enough for the pace of the meeting. Mr. Griffith offered up the idea of the print out from the CART reporter. The CART reporter informed the group there is an additional small charge for the print out. Todd Williams agreed that ISBE will pick up the expense. Ms. Hamer agreed this was an acceptable solution.

Faith Young seconded the motion. All were in favor. The motion passed.

5. Letter to ISBE Re: Official Replacement of Sarah Sebert

Todd Williams, ISBE, attended the meeting and notified the Board that Paul Nijensohn will be the official ISBE replacement for Sarah Sebert.

6. Miscellaneous

Faye Manaster reported last night a problem with Aetna Better Health, which is part of the Managed Care pilot program. She wanted this issue shared with the Board. Last week she was told they required 72 hours for an interpreter, so she set up an interpreter for her daughter's medical appointment (a neuropsychologist) according to their requirements. Then yesterday, keep in mind the appointment is today, Aetna Better Health called and said they did not have an interpreter for her, as their policy is two weeks for a tactile interpreter. Since she made her request well beyond the 72 hours she was originally told but within the two weeks they were just telling her now, they refused to provide and interpreter. Additionally, they would only use one company, DCI, to hire interpreters. She questioned them how she is supposed to set anything up because she asked the requirements in advance and was told one thing and now was being told something different. She further questioned how she can give anything to case managers, so she requested their policy in writing. They refused to provide their policy in writing stating they are not allowed to give their policy in writing to her. The man she spoke with at Aetna asked her why she or another family member just doesn't interpret for her at the medical appointment.

Ms. Manaster wanted the Board to be aware of this because everyone is eventually moving to managed care and this is just one example of the type of problem individuals who are deaf-blind will have with the providers.

Robert Griffith stated it was his opinion it is up to the legal department of the Illinois Deaf and Hard of Hearing Commission (IDHHC) to address circumstances when persons are being denied interpreter services, as they are the interpreter licensing and monitoring body for the State.

Ingrid Halvorson suggested contacting not only IDHHC, but Equip for Equality, ADA and Great Lakes.

Todd Williams suggested contacting the Office of Civil Rights.

Mr. Griffith said to have her start with IDHHC and they can advise her on what other activities to follow up on. He requested a follow up from John Miller for the next meeting.

Mr. Griffith announced the following people have completed Open Meetings Act training.

- Shelle Hamer
- Faith Young
- Robert Griffith
- Gail Olson

Anyone who has not completed Open Meetings Act training should do so as soon as possible.

Finally, the Governor's Office has sent everyone vetting paperwork that needs to be completed and turned back in. Everyone other than Mr. Griffith said they did not receive any paperwork. Mr. Griffith said he would follow up with Joan Thomas and get back to us.

Ms. Halvorson announced the address of the DRS District Office as 2901 South Finley Street, Downers Grove. She said it is on the corner of Finley and Brock.

IV. Standing Reports

1. Le COBDA

At the February LeCOBDA meeting, the Club honored SSPs, volunteers, and interpreters with Valentine cards and boxes of candy. Discussion was held and members voted to increase the yearly dues from \$10 to \$15.00. Pizza and salad lunch was enjoyed and members received Valentine candy.

On March 10th, the LeCOBDA members enjoyed a St. Patrick's Day lunch of corn beef, Reuben, and turkey sandwiches. During the business meeting, members were reminded that we would be voting for president and vice president and members should send in their nominations. Ballots will be sent with the April newsletter and the results will be announced at the May meeting. Discussion was held concerning where the club would meet for an April meeting outing. Members were asked to send in suggestions to Joann Rushing, head of the Deaf-Blind Program at the Chicago Lighthouse. The scheduled program of a demonstration of exercises for people with disabilities was canceled due to an accident to the instructor. The group enjoyed an afternoon of Braille Bingo with lots of prizes.

2. SSP Taskforce

No report given.

3. IDHHC

No report given.

4. HKNC

The State of Minnesota is developing an on-line training for their long-term care coordinators. This is proportional to our PASS service coordinator services. The training is free. All you have to do is sign up and take the class. It consists of seven different modules and you learn as you go. Laura Thomas said it would be nice if some of us could learn from their program and then share the information. Ms. Thomas said she would send Faith Young the link to this program information.

Helen Keller in New York is working on developing a new video and it's about time as their existing one is old. Ms. Thomas thinks from the clothing that it dates back to the 1970s. They are filming on the floor, different views, different perspectives, out in the community, that kind of thing. The new video should be ready this fall.

The Deaf-Blind Retreat is coming up this June. It's the last week of June, which coincides with Helen Keller's birthday. Ms. Thomas will send out the link to that. She requested everyone to spread the word, to encourage all of their colleagues and people they run across to attend. They are trying to reach all individuals who would benefit from this. It's bigger and greater and more awesome than ever!

Finally, Ms. Thomas announced she is bringing Ingrid Halvorson to New York with her to co-present on the Illinois Memorandum of Understanding and to inform everyone there about it. She is very excited about that.

V. Agency Reports

1. HV/EIO

HIGHLIGHTS:

The National (EHDI) Early Hearing Detection and Intervention Conference was held in St. Louis March 5-6, 2012. Several ISD and HVEIO staff attended, presenting and working this conference.

Illinois EHDI Day, where parents and providers are honored in celebration of Early Hearing Detection and Intervention was held March 9, 2012 in Chicago. HVEIO staff attended

Planning for Parent Infant Institute is well under way at ISVI.

ISVI Opening Doors: June 6-9, 2012 (duration expanded by one day). Kevin O'Connor, professional motivational speaker and father of adult son with visual impairments has been secured as Keynote speaker.

Bridges DTH / Summer DTV Summer Mini Camp is being cosponsored by Hearing and Vision Early Intervention Outreach, DSCC, ISU Early Intervention Graduate Certificate Program and Philip Rock Center Project Reach. The agenda has been set for the June 25-26 event with Kevin O'Connor as Keynote and special guests from the Illinois Early Intervention Training Team.

Upcoming CALENDAR OF EVENTS:

- **Parent Conferences** in vision and hearing.
 - North of Eighty Conference for Parents of Children with Hearing Loss
March 24, 2012, Rockford
 - South of Seventy Conference for Parents of Children with Hearing Loss
April 14, 2012, Mt. Vernon
 - Southern Vision Conference
March 17, 2012, Mt. Vernon (CANCELLED)
 - Northern Vision Conference
April 17, 2012, Rockford
- **Functional Vision and Hearing Screening Training**
 - February 1, 2012, Sangamon Co Health Dept., Springfield (completed)
 - March 14, 2012, Batavia Library
 - NEW DATE: April 25, Springfield
- **Every Day Sign Language for Young Children**, Feb 16, 2012 Bloomington, for STARNET I and III (completed)
- **IAER Preconference** for DTV's and DTO&M's February 15 in Schaumburg. Agenda has been established. (completed)
- **ITHI Preconference** for DTH's March 1 in Springfield. (completed)
- **National Early Hearing Detection and Intervention Conference** in St. Louis March 4-6, 2012 in St. Louis. (attended, exhibited and worked)
- **National Deaf Education Think Tank Meeting**, TBD, Spring 2012 Chicago (postponed to fall, 2012)
- **Annual Illinois Parent Leaders Collaboration Conference**, April 28, 2011, Spaulding Pastoral Center, Peoria. Paula Kluth is the featured presenter. HVEIO in charge of exhibits.
- **Opening Doors, Parent Infant Institute** at Illinois School for the Visually Impaired June 6-9.

Submitted by: Gail Olson, Program Coordinator 3/12/12

2. ISBE

No report given.

3. PRC/Project Reach

Project Reach Report March 2012

Project Reach staff are preparing to complete the Grant Performance Report for continuation Funding, Fiscal Year 2012. This report will include updates on all Project Objectives, as well as the five federal program measures 1) quality, 2) relevance, 3)

usefulness, 4) cost per unit, and (for the first time) 5) meeting timelines. A full copy of the report, once approved and submitted by ISBE, will be available.

On November 29, 2011, PRC and Project Reach staff joined two parents at the ISBE Budget Hearing in Chicago. Each parent shared details of the services received in either the school setting, or through the service center.

The 2012 Project Reach Family Directory was recently completed and distributed electronically and in hard copy (as needed/requested). The directory serves as a means for consenting, participating Project Reach eligible families as a general resource, and to connect families to other families across the State of Illinois who may have a child with a similar diagnosis.

Project Reach is also continuing to collect data for the NCDB required Deaf-Blind Child Count. This count provides anonymous child information to NCDB, who uses the information to compile statistics for OSEP and other organizations and for the general public. 2011 data submission will be completed by May 1, 2012.

4. DHS/DRS

No report given.

5. DHS/OMH/ODD

No report given.

6. DCFS

No report given.

VI. 2011-2012 Meeting Dates

The remaining meeting for the year is as follows.

- Thursday, June 7, 2012

The remaining meeting will take place at the Philip Rock Center in Glen Ellyn.

John Jun motioned to adjourn the meeting. Shelle Hamer seconded the motion. The meeting was adjourned at 1:16 p.m.

Recorded by: Faith Rosenshein Young, Acting Secretary