

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

Agenda

April 1, 2010

James R. Thompson Center

100 W. Randolph Street, [Room 9-039]

Chicago, IL 60601

10:00 a.m. to 2:00 p.m. (lunch break included)

Conference call in #: 1-888-278-0296

Access code: 9679887

Attending in person: Rose, Michelle, Laura F., Robert Griffith, Mindy Joy, Catherine Klein, Darryl Washington, Marsha Northrup

Attending by phone: Faye Manaster, Laura Thomas, Todd Williams, John Miller, Gail Olson, ((10:40)

Faith Young (10:45)

Meeting started 10:25, technical difficulties initiating host call. Introductions were made.

Now have a quorum.

I. Minutes of February 4, 2010 Meeting

Marsha moved and Gail seconded, with some minor corrections. Approved

II. Old Business:

1. 2009 Annual Report

Laura solicited recommendations for the Annual Report. Changes from previous discussion were discussed, including :

PUNS deafblind questionnaire

Added Objective 1 to Goal 2

Will provide model language to urge the adoption of consistent language in the definition of deafblindness and add it to the questionnaire.

Goal 3: Objective read

Goal 4: Facilitate communication among agencies and support groups

Support and participate in Chicago Lighthouse Deaf-blindness events

Laura's report had been distributed earlier in the week through Michelle's email. Is the report ready to be sent? Are there changes to the grid? Under guests will add John Miller, Mindy Joy.

Darryl Washington said the State of Illinois identification cards (secretary of state) does not allow somebody to be both deaf and blind. Bob Griffith said the definitions are legislatively mandated and secretary of state could not change independently.

Gail – add addendum to report with the various definitions of deaf-blindness, or add a goal that we will provide a document that provides information on all of the definitions that are currently being used.

Laura feels that Goal 2 and Objective 2 covers this issue, and feels we need to get the report out ASAP. Laura feels we can develop an action plan at the next meeting. Rose suggested we collect stories as such as Darryl's in that process.

Gail Olson moved to submit the report, Faith seconded

Laura Thomas – FYI – AADB sent out 2 days ago a news brief with their definition of deaf-blindness. It is on their website.

Faye – has issues with the definition. Faye read the definition aloud. Faye said that her issue is with the word "maintain", rather than "develop" or a similar words that pertain to a person who is born Deafblind.

Laura F – maybe in June we will send correspondence in June to AADB with our concerns.

Faye other concern "any varying degree" of VI may conflict with definition of legal blindness.

Rose – this is why it is a good idea to gather all definitions of deaf-blindness.

2. Helen Keller Deaf-Blind Awareness Week Campaign

Faith – group has met several times by phone, gathered several profiles (2 have gone on to Wally), Laura and Michelle told group of two others in process. Next steps – next week Jody and Faith will work on the action list to be included in the blast emails, then send around for other's to see.

3. Demographics for DB List

Did not get any feedback yet. Want to create a targeted email list. Data from last campaigns showed that people interested had high click rate to website. A high rate of people did not even open the emails. Not getting them into the hands of the right people. We need to know who to send it to so that we can purchase the right names. Maria asks if we know who replied, and Faith said can only track individual emails, not gather demographics. Darryl asked if the website was blind friendly, and Faith said that a test run with her sons screen reader did work. Darryl said he uses Jaws. Darryl asked if the target audience is persons who are blind. Faith said target is general public to change misconceptions. Laura said while that is correct, we should check the site for accessibility.

Michelle will ask the Philip Rock Center receptionist to test the website.

Faith – profiles have graphics, second video has closed captioning.

Laura – is there a list? NIA might be able to entertain the cost of the list.

Faith – legislators did not open emails. Difficult to get email lists that are accurate.

Mindy Joy – same thing happened to her, tried to invite legislators to deaf-blind retreat but all were deleted.

John Miller – always good idea to have a back up to email, with hard copy letter and phone call, try and arrange meeting.

Laura – Ryan Croke might be an option, and Rose said maybe sending out a DVD would be helpful.

Maria – has this gone out to local media?

Mindy Joy – Laughing about sending it to Oprah because Oprah has declined requests to be on Oprah.

Oprah's boyfriend will be presenting at the ARC convention and is the sibling of somebody with a disability.

Faith – sending individual items take money and time. Faith sent out press releases previously and only got a little local press.

Darryl is willing to be on committee.

Faith trying to make a point that this needs to be done quickly. Needs to hit in June.

Gail – more than what we can handle as a group, feel we need to narrow it down.

Faith agreed.

Laura we have limited funds.

Gail speaking, hard to justify funds for hard copy mailing.

Laura Thomas – can focus on a smaller process, hit a few specific agencies and groups, maybe a PSA of 30 seconds, then do DVD when you having more money and time

Laura – good suggestions, we have already spent a lot of time pulling this together, we need more volunteers.

Gail – agrees

Faith – can do other things in future years. This year we are adding the action.

Michelle – what lists did we use last year, and buy one more, add PR list.

Maria – can it be put on Facebook?

Have a blanket release, goes on You Tube, can go on Facebook. Maria will look into it, making a Fan Page for Be my Voice.

Faith – can search under Aubrey and Deaf-Blind to see you tube.

Maria – will set it up within the next two weeks.

Laura - Can links go onto our agency websites?

Darryl – can this go out in Braille?

List does not indicate if people read Braille. Michelle – can we distribute in Braille in LaCOBDA.

Laura Thomas – we could do a free mailing.

Laura F. It is an email campaign.

Faye agrees with Laura and Darryl.

Gail feels this needs to be email this year.

Mindy Joy agrees with Gail.

Faith reminds us the focus is the population at large.

Laura – time requires that this be finished by sub committee.

III. New Business:

1. Governor's proposed Medicaid Managed Care pilot

Faye Manaster discussed HFS's plan for a Medicaid Managed Care Pilot, and has sent some resources which explain this issue in greater detail.

These are the resources:

The Arc of Illinois- Can Insurance Managed Care Plans be Trusted? <http://www.thearcofil.org/pastissues/document.asp?did=2204>

The Arc of Illinois- presentation on Medicaid Managed Care Pilot <http://www.thearcofil.org/document.asp?did=2276>

The Arc of Illinois- Advocates Oppose Medicaid HMO Plan <http://www.thearcofil.org/pastissues/document.asp?did=2153>

In addition, this is a letter to the editor of Crain's Chicago Business written by Tom Wilson from Access Living.

Managed care another hurdle for the disabled

“With so much emphasis on whether or not a pilot managed-care program will save Illinois money, the concerns of the thousands of people with disabilities who will be forced into the program have been forgotten (“Illinois credits program changes with \$300M Medicaid savings,” ChicagoBusiness.com, April 27). Historically, due to restricted provider networks, managed-care systems limit access to physicians best equipped to address specific disability concerns. Many people with disabilities have spent a lifetime developing relationships with providers who understand their issues. Managed care may put people with disabilities under the care of physicians who have limited experience with specific disabilities.

In addition, by stressing cost savings, the state puts pressure on program administrators to keep costs low, perhaps sacrificing quality of care. One vulnerable area is access to durable medical equipment, an area traditionally targeted for reduction by managed care.

In terms of cost saving, there is no more cost-effective model than consumer control. By putting control into the hands of the consumer, the state will eliminate the middle person and any unnecessary overhead that comes with managed care. By doing so, the state also puts an emphasis on the independence of people with disabilities, something that, down the road, will have a much more dramatic effect on the bottom line than managed care. “

2. ISD and ISVI Governance update

Gail sent out email with most recent update. Most recent recommendation would be that they would remain in DHS, but a new Division (possibly a brand-new Division). Group looking at what needs to happen legislatively. May happen in new fiscal year. Jacksonville legislators very involved and supportive. Will not go under ISBAE or Higher Ed.

Mindy Joy – What is the rationale for going out of DRS?

Gail – Doesn't know everything, but DRS is not an educational entity and this has caused problems in the past. Problems with contracts and other issues which are a detriment to the schools. Summary documents are available from Gail.

Mindy – please send

Marsha – please send

Robert – DRS has a central management services which cause lots of procurement issues. Wouldn't a switch to some other DHS have the same problems?

Gail – Doesn't know. But the group has agreement.

Faye – would like to know how many students are at ISD, ISVI, unilaterally placed by parents, paid tuition from districts, students with MH who are on PUNS.

John – many issues waiting for approval. Illinois Deaf Council advisory committee agree to moving out of DRS and set up a board for education and try and figure out which legislative requirements or executive order would be exempt from hiring process and if that fails, Ill Board of Higher Education. His understanding that ISVI wants to be under IBHE. Curious for an update.

Gail –another meeting Monday with ISD and ISVI small group, at first ISVI wanted to be under IBHE, but later unanimous vote to be under DHS.

Marsha – Back in the 60's, ISD was under DCFS

Gail – and at one time ISBE

Laura – why ask about parental vs. SD placements

Faye – are there choices, are placements being made because of lack of choices, helps develop data portrait of trends we need to be involved with. Are the schools safety valves for parents who would otherwise make other choices if funding was available.

Laura – the IEPs would contain narrative information, finally an IEP team decision, sometimes go at certain times in a child's education.

Gail – often due to wanting a certain peer group, deaf teachers, etc.

Faye – we need more information – if people were offered something besides a waiting list if they had other options. Maybe choose residential because they do not have child support waiver.

3. Nomination committee for board positions

Jody and Laura are willing to serve for another year.

Bob moved that officers continue, Maria seconded.

Jody was applauded for her work on the minutes. Faith also recognized her for her work with committee minutes for the awareness committee. Gail offered to nominated for vice chair. Bob moved that she become vice chair, Rose seconded. Unanimous except for abstention from Gail.

IV. Standing Reports

1. **LeCOBDA** – faith reading Gerrie's report. Proud of Kelly Medina of Mokena who participated in Shamrock shuffle. Has two main goals – plan more activities, 2 raise more funds. Will have bazaar in April 10 meeting. Received request for donation from Blinded veterans. February 3 SSPs provided certificates, all given gifts.
2. **SSP Task Force** – Mindy – has been put on hold as there is still some confusion. Will be set up again later in the summer. Another report is the deaf-blind retreat (3rd) June 9-12, have about 19 SSP/interpreter students who have expressed an interest. Have 7 deaf-blind people, need more deaf-blind campers! Deadline April 30. Will also have a Wednesday all day training, campers arrive Wednesday night.
3. Robert – there is a home in Jacksonville that houses a number of people who are deaf-blind, Alvin Eades, or a new one? VOA home has also signed up.
4. **IDHHC** – John Miller – commission will have meeting May 20, 1:00, will be live on website. Feel free to participate. Annual conference for interpreters and educational interpreters on May 21 and 22, open to all. Illinois Deaf Committee will work with deaf-blind retreat and get people professional development credits.

Have had a bit of a cut, worried about projections for next year. Want to be sure legislation knows.

Laura Thomas – I understood that Mindy, Joanne, and I will be doing a 3 hour deaf-blind presentation at your conference.

Mindy – not on the agenda, but not sure if board members are aware ILADB , Karyn is still working on setting up bylaws, more specific information after April 23.

V. Agency Reports

1. Hearing & Vision Connections

Report sent. 1 vision conference done, 2 more to go. IL family Leaders May 1. Funding same boat as everybody else. Not sure if/when contracts will be approved. Do not want contract, just employees. Will cause them great trouble. Waiting game. Faith – what will happen? Will be regular state employees, and no positions available to absorb current staff, and if they do, budget fixed and will not support the additional costs of state employees. Everybody currently part time employees without benefits. ISD laid off 6 teachers. If DHS moves ISD, HVC goes up for bid and some universities may be interested.

Laura – last newsletter lovely.

NIA – hosting the North parent conference.

2. **ISBE** – no report at this time.

3. **DHS** – Bob distributed all RCD positions currently filled but one. As of 12 2009 total of 76 people in deaf blind , 37 in cook. Deadline for ARRA RFPs tomorrow. Vocational rehabilitation offices relocated: Quincy, Freeport, Kankakee, soon Benton and East St. Louis. Passed out DRS calendar with successful case studies. Lions Deafblind Camp for deaf adults at camp Reynolds woods, Dixon, IL June 13-19. Looking for more persons who are deaf-blind to participate. Faith – in the past were there problems with transportation. Mindy – used to voluntarily get the CLS van, but they were picking up non CLS clients. The Deafblind retreat is June 9-12, People will be tired going from one retreat to another. Robert – when deaf-blind camp started 13-14 years ago, Lions themselves provided buses. Some Lions personally used their own cars. They can no longer provide transportation. All programs for the deaf-blind transportation is always an issue.

Laura Lions is not providing transportation.

Jerri had sent an email asking them to provide, since other state Lion Clubs do.

Darryl – in the past, CLH would provide transportation to the rendezvous point to Lions buses.

Mindy – tried to get in touch with Allen Wilson about the date, but he did not respond and the dates were set in conflict.

Motion – Robert asks Chair of IABDB to send letter to Lions Illinois Van Stone asking if they could provide assistance in transportation to Lion's Camp. Catherine seconds.

Mindy – Should she have been contacting Van Stone instead of Allen Wilson?

Could you send me Van stone's contact information.

Laura also needs it.

Darryl – can one get by public transport to Dixon?

Laura Thomas – Maybe ask Lion's what transportation is available in Dixon?

Faith – could we ask Lions to coordinate with other Lion's club members to coordinate and provide door to door services with campers.

Robert – most of the deaf-blind people who come to the camp are brought by family, friends, neighbors, can we just ask them to readdress the transportation issue.

Faith may be letter opens a dialogue discussing the concern of the deaf-blind that transportation is a barrier to participation, could that be discussed.

Laura called the vote –

Bob amended explore the possibility of providing transportation

Faith – That the chair of IABDB write IL Lion's Foundation director Van Stone to share concerns expressed by individuals who are deaf-blind regarding the lack of transportation to Lion's Camp.

Robert and Catherine agreed. Cc Gerrie

Approved unanimously

4. PRC/Project Reach

Faith is on the list and personally decided not to ask for the money.

Philip Rock Center report:

E newsletter was distributed

Annual report moving through channels at ISBE

National Coalition invitation to join

5. DHS/DRS – no report at this time

6. DHS/OMH/ODD – no report at this time

7. DCFS

DCFS is now establishing an advisory council in June for services for persons who are deaf. 2 people hearing, 3 deaf. Service providers who have been involved in DCFS. DCFS has closed several offices. There are over 20 different job openings. Lots of changes going on.

Laura F – next meeting June 3. Laura concerned about construction on congress. Are there some alternate meeting sites? Could we do Philip Rock?

Laura Thomas – linc has a free network, computer as video, Chicago Lighthouse has conference room, Have established a national SSP task force in cooperation with AADB, has a list of all of the program providers, (funding sources, training programs, etc)

Mindy will check into if we could have a meeting there. Also let us know that Julie Somers is in training as Rehab counselor for the deaf under DRS. Could Julie be involved in these meetings?

Rose motions to adjourn and Gail seconds.

Schedule of Upcoming 2009-2010 Meetings

Next meeting June 3, 2010