

ADVISORY COUNCIL ON BRAIN INJURIES MEETING January 21, 2011

Iowa Lutheran Hospital Conference Rooms A&B Lower Level B Des Moines, IA

MINUTES

1. Welcome/Introduction

Jack Hackett, Chair

Members participating:

Tom Brown, Family Member

Pat Crawford, Exceptional Persons Inc, Prevention Task Force Chair (via phone)

David Demarest, On With Life, Services Task Force Chair

Emily Emonin, Family Member, Secretary

Jack Hackett, Iowa Health Des Moines, Chair

Kellie Harmon, Parent, Vice Chair

Kathy Herron, Family Member

Sue Lewis, Family Member

Michael Hall, VA

Donald Heckert, Survivor (via phone) Dave Johnson, Survivor (via phone)

Karen Wilson, Survivor (via phone)

Members not in attendance:

Dennis Byrnes, Survivor

Jill Crosser, Goodwill Industries

Connie Holmes, VA

IDPH staff participating:

Ousmane Diallo, IDPH

Megan Hartwig, IDPH, Brain Injury Program

Ex-Officios:

Binnie LeHew, IDPH

Toni Merfeld, Dept of Ed

LeAnn Moskowitz, DHS

Toni Reimers, Dept. for the Blind

Theresa Armstrong, DHS

Others:

Geoff Lauer, BIA-IA

Ben Woodworth, IACP

Meeting was called to order at 10:08 a.m.

Jack welcomed all participants, thanked those who braved the weather and thanked Lutheran Hospital for providing meeting space.

2. Agenda/Minutes

Jack Hackett, Chair

Motion to accept the October 15, 2010 minutes; Demarest moved, Hall seconded approval of the minutes. The motion carried

Emonin moved to approve the meeting agenda; Herring seconded; motion carried

3. Task Force Reports

Various Members of ACBI

Administrative Rules Task Force

Heckert motioned to accept the Administrative Rules Task Force Minutes; Demarest seconded; motion carried.

Emonin reported the task force has met and has received guidance from Heather Adams to refrain from using bylaws and place everything in administrative rules. Binnie shared information regarding the revision process.

Prevention Task Force

Harmon reported the prevention card game mailing has been completed. There have been no responses for the survey monkey for feedback. The cards will continue to be distributed through the tote bags and community organizations. Crawford commented that Harmon may continue to distribute the cards.

Harmon also noted all links on the IDPH ACBI webpage are up-to-date and in working order. She would like members to review the website and send an email of recommended changes to Megan. She also noted the Council has some flexibility to be creative with the appearance and to add other items and more pages if desired. She would like to discuss the website more in-depth at the April ACBI meeting.

Action: Review the IDPH ACBI website prior to the April 15, 2011 meeting.

Services Task Force

Demarest provided an update on the Cognitive Rehabilitation Task Force. The task force would like to increase access to the services and funding for this service in Iowa. The task force plans to use a consultant to facilitate the following items:

- Planning and facilitating the TF to address the relevance of the 2008 retreat findings
- Identify action steps to be taken
- Identify priority items
- Draft a report

Executive Task Force

Hackett discussed the State Planning process conversation from the Executive Task Force meeting the previous evening. The State Plan needs to be redeveloped per the HRSA grant work plan. There needs to be a strategy for the new plan and the current plan needs to be extended until the new plan is in place.

Brown moved to extend the current plan through March 2013; Emonin seconded; motion carried.

Action: ACBI members are to review the current state plan and think about the items that have not been completed.

The Executive Task Force will be developing the State Plan task force, if there are members interested in being a part of the process Hackett directed them to contact Megan Hartwig. Emonin discussed the handout that listed the previous state plan task force. Herring would like to see some new families involved in the process through the BIA-IA connection. Hackett suggested that the ACBI would want a broad perspective and the task force should include other groups which are not currently represented on the Council, example: law enforcement, EMS, providers, etc. Emonin stated that interested individuals need to understand the time commitment involved in the process. Wilson shared the importance of domestic violence being represented in the plan. She would like to be a part of the process. Karen will send Megan contacts of professionals in the DV field.

Action: Council members who are interested in being involved with the State Plan task force or know of others who are interested should contact Megan via email.

The group discussed how the state plan has been developed in the past. There was much discussion regarding membership of the new task force. Brown would like to see the task force made up of at least 51% of survivors and family members. He stated the plan is a public health plan to develop a comprehensive service delivery system for BI services to serve the people with BI and their families and needs to follow the motto "nothing about us without us". Commented that providers sometimes think they know how best to serve, but people are the experts in their own lives and know what they need. Harmon commented that family members are personally affected and often live in their own "bubble", she pointed out the need to have survivors and families from a variety of circumstances. Hall noted that Mayo has been doing self-advocacy work and wondered if those folks who have been through the Mayo training could be involved with the planning. Emonin was concerned about finding people who have an interest to make up the 51%. Wilson wants to make sure family members are included. Johnson would like to work on the DV problem because of his own background. Emonin commented on the need for a strong facilitator so the process is successful.

Brown moved that as the State Plan Task Force is developed that it be comprised of a simple majority of brain injury survivors and family members of brain injury survivors; Wilson seconded; motion carried. Voting in favor: Johnson, Wilson, Heckert, Brown, Lewis. Against: Hall, Demarest, Herring, Emonin. Abstain: Harmon.

Johnson reported on his meeting with Governor Branstad. Those in attendance were Dave Johnson, Geoff Lauer, Tom Brown, Julie Fidler Dixon, and Theresa Harms (Advocacy Strategies). The meeting went will and Johnson believes the Governor is open to hearing continually from constituents regarding their concerns. He believes the Governor knows who the brain injury community is.

Hackett made and announcement from the Executive Task Force regarding the availability of funds to support scholarships for five people to attend the BIA-IA conference in March.

Action: Email Megan if you are interested in attending the BIA-IA conference.

4. ACBI Budget Update

Binnie LeHew, IDPH

LeHew shared a handout with the group. She included HRSA information. The report was for expenditures through the end of December. The Council budget is on target. Contractors are on target for spending. She shared the current HRSA year ends March 31, 2011. We expect carryover again as approximately a third of funds have been spent. There were no questions regarding the budget report.

5. Healthy Iowans Plan

Binnie LeHew, IDPH

LeHew led the group discussion. The group made the following recommendations to include in the plan.

- a. Expanding the registry to include acquired brain injury and stroke
- b. Support for falls prevention
- c. Inclusion of brain injury into local CHNA/HIP
- d. Including brain injury as a specific disability so efforts to address access are not only limited to physical disabilities
- e. Access to comprehensive care annually though out a person's lifetime due to the unique needs of people with brain injury.
- f. Cognitive Rehabilitation expanded as a funded service.

Action: LeHew and Hartwig to submit ACBI recommendations to Healthy Iowans planning group.

6. HRSA Report

Megan Hartwig, IDPH

Hartwig provided and overview of the HRSA grant's continuing application and gave members a handout that summarized with the next step will be.

The national grantee meeting in March requires three people in attendance to include the state project manager. There are funds available to support two Council members. It is a three day meeting; participants can go to visit their congressional representatives to advocate for brain injury.

Action: Let Megan know if you are interested in attending the federal grantee meeting by Wednesday, January 26, 2011.

7. IDOC Report

Megan Hartwig, IDPH

This report was given after lunch with the rest of the state agency reports.

8. Lunch

Emonin moved the business portion of the meeting be adjourned; Harmon seconded; motion carried.

Meeting adjourned at 12:15 p.m. reports from agencies and service and training providers will take place after lunch.

9. Recap of ACBI business meeting

Reporting portion of the meeting began at 1:05 p.m.

Dr. Diallo gave an update on the brain injury services survey. A letter went out in November and invited participation. The survey will go out by the end of January. There should be a report at the April meeting. The survey addresses many issues.

LeHew shared about the core injury grant she is co-writing for. Funding would allow IDPH to have a staff person to oversee all injury prevention programs. LeHew would like a letter of support from the ACBI and BIA-IA. The application is due in early February.

Dr. Miller-Meeks started on Friday, January 14, 2011. BIA-IA would like to request that she address the crowd at the BIA-IA Hill Day.

10. State Agency Reports/Updates

Department of Human Services

IME—Moskowitz shared IME has started doing prior authorizations for waiver services that cost more than the statewide median. They have identified several services that fit that they are able to better understand the integrity and appropriateness of services. There have been some anxieties about services being taken away but it is being managed. Medicaid in general is involved in the MHDS network on the Employment First project. There is a lot of exciting work happening to improve employment of persons with disabilities. Moskowitz shared about the transition specialists who work with people who are helping the options counseling at the Department on Aging and the Aging & disability Resource Centers (there are currently two ADRCs; one in Waterloo and one in Sioux City). There is consideration to add this option for the nursing home population through Money Follows the Person program (it is currently only available to persons who live in an ICFMR). People residing in an ICFMR will be asked if they would like to live in the community; if yes, they are referred to an options counselor to look at options and determine if there are resources for the person to be able to live in the community. If so, they will be offered help with transitions planning. They are considering looking specifically at people with BI who may be going into a facility.

The waiting list for the Brain Injury Waiver has moved down from 880 to 664 with the additional funds that were provided—it helped, but is still very inadequate. There are some individuals who have contacted her to use the reserve slots from out of state or facilities, so she is happy about that. Moskowitz reported there are currently 252 children and 409 adults served by the BI waiver. It would take approximately 9.25 million dollars to eliminate the waiting list. Growth is on average between 15-30 people each month; that growth would be considered when projecting future costs. If there was a general Personal Attendant Care service on Medicaid, there would be fewer people using the waiver—this may be something that occurs with health care

reform. There are 116 people accessing individual personal attendant care and 114 receiving those services from an agency.

Woodworth asked if there are still people coming back to the waiting list. Some decline the waiver when their name comes up because they are eligible for the Intellectual Disability waiver. Many other come onto the waiting list because they are on the Ill and Handicap waiver and they can receive more services through the BI waiver.

MH Division—Armstrong gave an update on the Olmstead work. She handed out a workplan for the next 18 months. She emphasized that Olmstead is a living document. It can be found at MHDSStateplan.org. DHS has an internal Olmstead committee. The plan listed things they felt could get done and would get done. She highlighted the following from the plan.

- The children's mental health crisis service has been a struggle, but Magellan and DHS are in partnership to help provide this emergency crisis work in North East Iowa right now.
- They are working with groups including COMPASS, BIA-IA and UI-CDD to be sure there is information for cross-referral.
- They will be working on building community capacity for supported employment in the coming year.
- DHS has had an initiative to prepare for systems change between substance abuse and mental health; they want to look at more co-occurring disorders than just the I-Part Team at Glenwood.

Emonin asked about the difference between the definitions of mental illness as used in the document. She'd like to see definitions included. She also wondered if brain injury was added to some of the sections when reference to "other disabilities" was mentioned.

Department of Education

Merfeld shared the Department of Education has been awarded a 14 million dollar grant. This will provide 3.6 million per year to work with local education agencies and AEAs to address social and emotional education and climate for children. There is a need to educate the whole child and support the needs of students and educators. The hallmark of the grant is to create a survey different from the Iowa Youth Survey. They may adapt another piece to add to it dealing with social and emotional education. They will survey parents and educators in addition to students. Scores from the schools will be posted so there is some public accountability.

Department of the Blind

Reimers shared the most current issue of *The White Cane* department magazine. She shared the department works with individuals who are blind, some which can be the result of brain injury. The department wants people to be employed through customized employment. They also work with individuals' secondary disabilities. They teach people how to advocate for themselves. The department serves all individuals with blindness and progressive eye disorders such as macular degeneration. They can assist with job retention issues with people to help them stay employed.

Vocational Rehab

Megan shared Kathy Winter's written report.

Department of Corrections

Hartwig shared the report provided by Katrina Carter-Larson.

11. Member Questions

Specific member questions were addressed during each agency report.

12. Reports from service and training partners

Brain Injury Association of Iowa

Lauer shared BIA-IA was audited and it went well. The Board of Directors has had some transition. There are three new board members. The board is planning a strategic planning session in the summer. Staff has been stable for a year. The total staff is currently 7.5. There are two staff in Iowa City and five in Urbandale.

Lauer discussed the continued work with Mayo Clinic looking at the impact of advocacy training for individuals with brain injury. He shared that Hill Day is February 3rd and BIA-IA conference is in March one of the main themes is changes in acute care and rehab. Lauer shared copies of written report.

Iowa Association of Community Providers

Woodworth shared written report that was handed out to ACBI members.

13. Public Comment

There was no public comment

14. Reminders/Adjourn

The report portion of the meeting ended at 3:04 p.m.

Minutes submitted by Megan Hartwig

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