

Maine Newborn Hearing Program Advisory Board

Date: September 26, 2007

12:00 to 4:00

Members Present: Romy Spitz, Karen Hopkins, Eileen Peterson, Kristen Shorey, Louise Packness, Harriet Gray, Deb Stroud, Karen Perry, Karen Harrison, Carrie Ouellette

Program Staff: Betsy Glencross, Toni Wall, Katie Blanchard

Interpreters: Mary Jane Grant, Tina Morrison

Guests: Vivian Mikhail, Cindy Brown

Members Absent: Dr. Brenda Medlin, Michelle Markie, Richard Aronson, Annette Bowman

Moderator: Betsy Glencross

Scribes: Katie Blanchard, Toni Wall, Betsy Glencross

I. Welcome and Introductions.

Led by Karen Hopkins, Co-chair. Extended introductions were done due to many new board members present.

II. Minutes from June 4, 2007 accepted.

III. Program Updates

- **MNHP** – Betsy Glencross
 - Board info:
 - Everyone was asked to update their contact information.
 - Julia Bell resigned and Lisa Glidden rescinded her application due to work conflicts
 - Betsy is working with the Governor’s office to assure that Board members are appointed to the correct seats.
 - Birth Facilities and Newborn Screening:
 - Ballard House started screening again in July. They are doing a great job and they are very excited about what they have done.
 - Exploring the possibility of some reward/certificate kind of program for facilities that are doing a good job at hearing screening. Betsy is working on this.
 - CDC Site Visit: Toni and Betsy attended the Regional CDC site visit in NH in August. The purpose is for the CDC to review our program and the grants. It has been 2 years since the last one was held. We got good feedback from the CDC as well as from other states. The response to our work was very favorable. We are expecting a formal report and will share it with the Board when it is received.
 - Data-Sharing with other New England States: We are hoping to sign an agreement to share data with the other New England states. Right now, babies screened in Maine but born in another state, we can’t share their data, and likewise, a baby born in Maine but screened in another state, we don’t get their data. The Attorney General’s opinion is that we should be able to do this fairly easily. It does require a change to the MNHP legislation. Work is already proceeding on this.
 - Newsletter: we are hoping to get one started this year. There were questions on whether or not this had been done in the past. There were also questions on the audience for the newsletter, what types of articles/information would be included in it. Further details will be presented at the next meeting. It is in the ‘planning phase’ right now.

- Sustainability: Both of the grants currently funding the MNHP are due to end in 2008. The CDC/EHDI grant which funds salaries, equipment, database, etc. runs ends in June, the HRSA Grant which funds several of our contracts, training, educational opportunities and materials ends in August. Toni and Ellie Mulcahy are working on what can be done to continue the program.
- Discussion:
 - What about how hospitals deliver the message about screening results.
 - We had discussed this at the June meeting and a sub-committee was supposed to be formed to work on this. We will review the previous minutes and follow-up at the next meeting.
 - Questions on how the hospital reward system would work and what areas would be included in determining who is doing a good job. Betsy is still working out the details. Further info to follow.
 - Questions on screening results and definitions. What is the current data for hearing screening, referrals and hearing loss? What does 'referred' mean?
 - Rates for 2006: 96.5% screened. Of those screened, 2.5% referred.
 - Rates for 2007: 96% screened, Of those, 2.5% referred.
 - Hearing loss data is minimal. We only have received Audiology reports for approx 30% of those children who referred.
 - Some known issues that affect our screening rate are: home births, babies screened out-of-state, babies who die prior to screening.
 - Referred means that the infant did not receive a "Pass" on both ears.
 - Data-sharing between agencies in-state
 - Karen Hopkins would like to have a sub committee to work on this
 - One form for all 3 agencies (MNHP, ECFS, CDS) to use and pass on to one another.
 - There is legislation in effect now (PL 2007, C.450) that is supposed to have a group looking at this issue. Cindy says the group hasn't taken shape as of yet. She will follow-up on this and let us know what is happening. Cindy and/or Toni will let the Board know who is in charge of this group and what is going on with it.
- **ECFS – Karen Hopkins**
 - Karen is going to the Next Steps Conference in MA on Nov 8&9. Since Betsy is not allowed to travel out-of-state except for Grant-mandated items, Karen will take several MNHP handouts for her table.
 - ECFS is still looking for a part-time Consultant. Pass along suggestions to her.
 - ECFS is seeing many children now with conductive loss.
 - They are very busy starting up after the summer vacation.
 - Audiologists are hesitant to refer families directly to CDS. They are asking ECFS to make the referrals for them.
- **CDS – Cindy Brown**
 - Still many changes going on. CH 180 is no longer. New rules since beginning of August.
 - Cindy is working with new forms and the AG to learn the key points.
 - By October all of CDS will be using new forms.
 - Coaching families and colleagues childhood hearing loss.
 - New video is now available
 - Romy would like to know if they are captioned. Cindy wasn't sure. (***) need follow-up at next meeting on this)
- **hear ME now! – Carrie Ouellette**
 - Pam Dawson was hired as the new Executive Director in July 2007

- They are very busy with new programs starting and getting Pam up-to-speed with everything. (They have: Auditory program for preschoolers B-3 developing spoken languages skills. Integrated programs 3 and up. Work with folks with cochlear implants. After-care program.)
- **Maine Chapter of Alexander Graham Bell (AG Bell) Association** – Carrie Ouellette
 - Carrie is the president-elect. They are having a Full membership meeting Sunday October 14 from 2-5 She brought informational handouts.

IV. Action Items from Previous Meeting:

- **Audiology Info**
 - Reporting mandate (changes to MNHP legislation). The legislation is now in effect. The rules need to be written.
 - Reporting Form. This is ready to be launched but we need to wait for the new Audiology Consultant to be hired to help implement this and get the info out to audiologists and other providers.
 - Consultant. The position has been vacant since Kathryn Girardin resigned effective Aug 31st. Toni plans to seek a sole-source contract and not go the RFP route. Letters will be sent to all licensed audiologists. Eileen said she could help get the word out when we are ready.
- **Parent Materials**
 - The new flipcharts were mailed out to all Board members in July.
 - Several requests for sending out more of them: Karen Hopkins would like to have 50 of each. Carrie Ouellette would like to have 10 of each. Eileen would like to have 10 each of the flip charts. Eileen can email the audiologists to let them know what to look for. Betsy to send a cover letter and copy of the covers of the flipcharts to Eileen. Cindy Brown would like to have 17 of each and she would like Betsy to make a cover memo for site directors.
- **Other Legislative Updates.** (Note: all of the legislation passed during the 1st session became law in September, if not already enacted by emergency legislation)
 - Resolve 2007, C 133 (Work Group for Early ID and Intervention)
 - Pam Dawson was tasked with obtaining the funding for this work group. They needed to raise approx \$9,000. Pam reports to Toni and Betsy that they are close on getting the necessary funds. We do know that several people have been appointed to this group. The group is made up of 7 legislators plus 6 service providers. They are supposed to be ready to report to the Legislature by December 2007.
 - PL 2007, C 452 (hearing aids). Insurance companies are now required to pay for hearing aids for children up to age 21.
- **Specialty Provider List:** No work has been done on this since the last meeting. The minutes from June reflect what has been done to date.
- **Parent Consultant** – Vivian Mikhail
 - MNHP began a contract with Maine Educational Center for Deaf and Hard of Hearing (MECDHH) this summer. Vivian Mikhail has been hired for this position.
 - Main focus to offer support to families and helping with those children we don't have follow-up results for. She is going to work on those families that lost-to-documentation (working with ChildLINK database, follow-up with families whose children did not pass hearing screening.
 - Also working with those families whose children have been identified with risk factors for later onset of hearing loss. (e.g.: family history, infection, syndromes, etc.) She is working with Parent Consultants in other states to get more help in this area.

- She is also working to form the Maine Chapter of Hands and Voices. This is a parent-driven organization that serves to support families whose children have a hearing loss.
 - Their motto is “What works with you child is the right choice for you.”
 - There are 3 meetings around state to be held in October.
 - They also hope to establish the “Guide By Your Side” program which provides additional support for families.
- **Prenatal Brochure** – This item was tabled until next meeting due to time constraints.

V. New Agenda Items

- **Advisory Board Guidelines**
 - The Board worked on the Guidelines document which had been reviewed by the Attorney General’s office. Some suggested changes were made to the document. Betsy will have the AG’s office review the new changes and if they are OK, she will update the document to reflect those changes.
- **Advisory Board Elections**
 - Louise Packness was elected as the new co-chair. Karen Hopkins has now completed her service. Romy will assume Karen’s position as the Chair and Louise replaces Romy as the co-chair with the understanding that she will assume the Chair position next fall.
- **2008 EHDI Conference**
 - Is Feb 25-26, 2008 in New Orleans. We are not sure right now if there will be an opportunity for a Board member to be sent by MNHP as in the past. However, a decision will likely need to be made on who is going prior to the December meeting. Betsy will assume that all Board members want to be considered for selection to attend unless she hears otherwise from individual members.
- **MNHP Feedback Survey:** This was tabled due to time constraints.
- **Meeting dates for 2008:** Due to time constraints we were not able to set the dates for 2008. Betsy will send out a separate mailing, hopefully using something like Meeting Wizard, to get input on dates. We need to get these set prior to our next meeting due to facility and interpreter needs.

*****Next Meeting: Monday, December 3rd 12-4 PM at the Senator. Agenda will be sent out approximately one month prior to the meeting.**