



PUBLIC MEETING NOTICE

Universal Newborn Hearing Screening Program Advisory Meeting

Monday, June 24, 2019
4 p.m. - 5:30 p.m.

Posted: June 12, 2019 8:19 a.m.

Last Updated: February 5, 2020 12:55 p.m.

Address

250 Washington Street, Public Health Council Room, 2nd floor, Boston, MA 02108

Directions

(<https://maps.google.com/?q=250+Washington+Street%2C+Public+Health+Council+Room%2C+2nd+floor%2C+Boston%2C+MA+02108>)

Overview

Please note the time change!

Please also note that you may be asked to show identification before entering the building. Please inform the security guard that you are attending the Universal Newborn Hearing Screening Program Advisory Committee meeting.

Meeting Minutes

Quorum was reached for this meeting.

Appointed members present

- Jennifer Bentley
- Joan Butterfield
- Michelle Eisan-Smith
- Jennifer Fleming
- Marly Kenna
- Delvina Labrecque
- Kathy Manfield
- Jane Stewart
- Sarah Stone

Appointed members not present

- Aimee Knorr
- Marty Lapointe-Malchik
- Christine Majeskey

UNHS Staff in attendance

- Martha Morris
- Amarilys Triana Walsh

Others in attendance

- Regan Andrade
- Oanh Bui
- Elaine Gabovitch
- Cheryl Glovsky
- Suzanne Gottlieb
- Todd Higgins
- Lauren McGrath
- Nassira Nicola
- Pat Noga
- Laura Pomponi
- Tim Riker
- Max Spolidoro
- Jack Stewart
- Kimberley Warsett

Materials distributed

- Agenda
- Draft minutes from October 22, 2018 meeting
- UNHS Program material - Audiologic diagnostic appointments: risk factor algorithm for birth hospitals
- Massachusetts Universal Newborn Hearing Screening Program 2017 Data
- Conference flyer – Clarke Mainstreaming Children with Hearing Loss Conference
- Conference flyer – Boston Children’s College Transition Seminar
- Conference flyer – Boston Children’s Transitioning from Early Intervention to Preschool workshop
- Conference save the date flyer – The Learning Center’s Guide to Providing Services to Deaf and Hard of Hearing Infants and Toddlers Conference

Welcome and introductions

Kathy Manfield, Chair, welcomed the group and introductions were made. Communication protocols were reviewed.

Meeting Business: Notes were distributed from the October 22, 2018 meeting. Jennifer Bentley made a motion to accept, and Delvina Labrecque seconded. The vote to accept was unanimous.

Finalized Massachusetts Universal Newborn Hearing Screening Program 2017 Data: Martha Savaria Morris, Ph.D., Epidemiologist for UNHS presented on this topic. Birth rates are still declining in the US and that is true in MA as well. In reviewing the 2017 data, 560 babies did not have a documented screen. Babies who were deceased and homebirths contributed more than all other factors. Program activities will extend to educating midwives, as to date they have mostly focused on families after the baby is born. The program recorded its lowest lost to follow up rate of 3.2%. Race, ethnicity, insurance type and mother’s age were not related to the babies who were lost to follow up. 148 babies were identified as being deaf and hard of hearing. 2/3 of those babies had bilateral hearing loss, and moderate hearing loss is most frequently noted. The program had an all-time high of 86% of babies enrolled in Early Intervention. Factors associated with enrollment into early intervention by six months of age included bilateral, more severe levels of hearing loss.

Universal Newborn Hearing Screening Program Update: Sarah Stone showed the committee a new visitor card that was created by MCDHH and available for free to order. It was announced that the current project of the Learning Community is evaluating the website to better meet the needs of providers. UNHS is involved with a statewide CMV workgroup, and the next group meeting is September 18th. Joan Butterfield also gave a brief description of the Early Intervention Specialty Summit for Vision Loss and Deaf and Hard of Hearing that was held on June 19th.

Deaf ACCESS: Adapting Consent Through Community Engagement and State-of-the-Art Simulation: Tim Riker from Brown University presented on the work he has done with Melissa Anderson from UMass Medical School. Their research was funded by NICHD. Background was provided on health disparities in the Deaf community. Barriers for recruitment of the Deaf community in data collection include informed consent, random digit dial surveys don’t include videophones and are most often in English. Health related vocabulary of Deaf individuals parallels non-English speaking US immigrants. This study sought to do three things: 1. Promote Deaf engagement in research about the Deaf community, 2. Increase Deaf

participation in general population biomedical research and, 3. Generalize findings to improve research accessibility for members of the general population. The project was led by a Deaf majority team. 6 of the 8 members were Deaf and 7 of the 8 are fluent in ASL. Phase 1 included community forums. 3 forums were held in the fall of 2016. Participants were over the age of 18 and were held in Deaf spaces. Video was utilized for data collection. Video was analyzed in ASL without translation into English or a transcript from an interpreter. 22 individuals participated. Findings from the participants included: research for the general public wasn't for them, general mistrust of researchers, results were not shared with the Deaf community and researchers don't give back to the Deaf community. The second phase was focus groups. Four focus groups of six people each were held. Findings included: need for system change, additional training for researchers and interpreters, evaluation of informed consent forms, and more Deaf focused research is required. Phase three was the creation of a 40 minute training video. The audience is hearing researchers and hearing staff with little to no experience or interaction with the Deaf community. It was piloted at UMass. Research briefs were disseminated in ASL and English. Limitations of the study included lower than expected community turnout, and replication is needed. The overall goal of the team is to increase Deaf participation in research as participants and as investigators. Additional information can be found at www.umassmed.edu/zzz-archive/DeafYes/ (<https://www.umassmed.edu/zzz-archive/DeafYes/>) or www.facebook.com/DeafYESCenter (<https://www.facebook.com/DeafYESCenter>).

Adjournment: Marly Kenna motioned to adjourn the meeting. Jennifer Fleming seconded. The committee vote was unanimous.

Agenda

1. Welcome and Introductions: Kathy Manfield, Advisory Committee Chair
2. Meeting Business
 - Meeting notes from October 22, 2018
3. Finalized Massachusetts Universal Newborn Hearing Screening Program 2017 Data, Martha Savaria Morris, Ph.D., Epidemiologist, Universal Newborn Hearing Screening Program
4. Universal Newborn Hearing Screening Program Update: Sarah Stone, Director, Universal Newborn Hearing Screening Program
5. Deaf ACCESS: Adapting Consent through Community Engagement and State-of-the-Art Simulation: Timothy Riker, Lecturer in American Sign Language, Brown University
6. Adjournment

