

Improving Loss to Follow-up Rates Diagnostic Center Guidelines for 2011



2011 National Early Hearing Detection and Intervention Conference

Atlanta, Georgia

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MA DPH Approved Audiological Assessment/Diagnostic Centers (ADC)

- Required by Chapter 243 of the Acts of 1998 – Birth facilities refer families exclusively to these centers
- Significantly lowers “lost to documentation”
 - “newborn infants whose hearing screening test results indicates the need for diagnostic audiological examination shall be offered such examination at a center approved the Department”
 - “such centers shall maintain suitable audiological support, medical and education referral practices in order to receive such approval”
 - “if no third party payer is liable for such costs, the Commonwealth shall make reimbursement for the cost of such follow-up diagnostic examination”
 - Approved ADC shall accept state approved rates

Development of 2011 Guidelines

- 3rd edition
- Lessons learned from the field
- Joint Committee on Infant Hearing
- Guidelines developed in collaboration with the following:
 - CDC Fellow (pediatrician working at DPH)
 - Focus on sedation policies
 - DPH Advisory Committee (AAP Champion, otolaryngology, audiology, families, others)
 - DPH Approved Audiological Diagnostic Centers
 - DPH Health Care Quality
- Reviewed, edited and approved by the Advisory Committee
- Final Approval - DPH Medical Director (pediatrician)
- Disseminated late 2010, protocols due 1/31/11

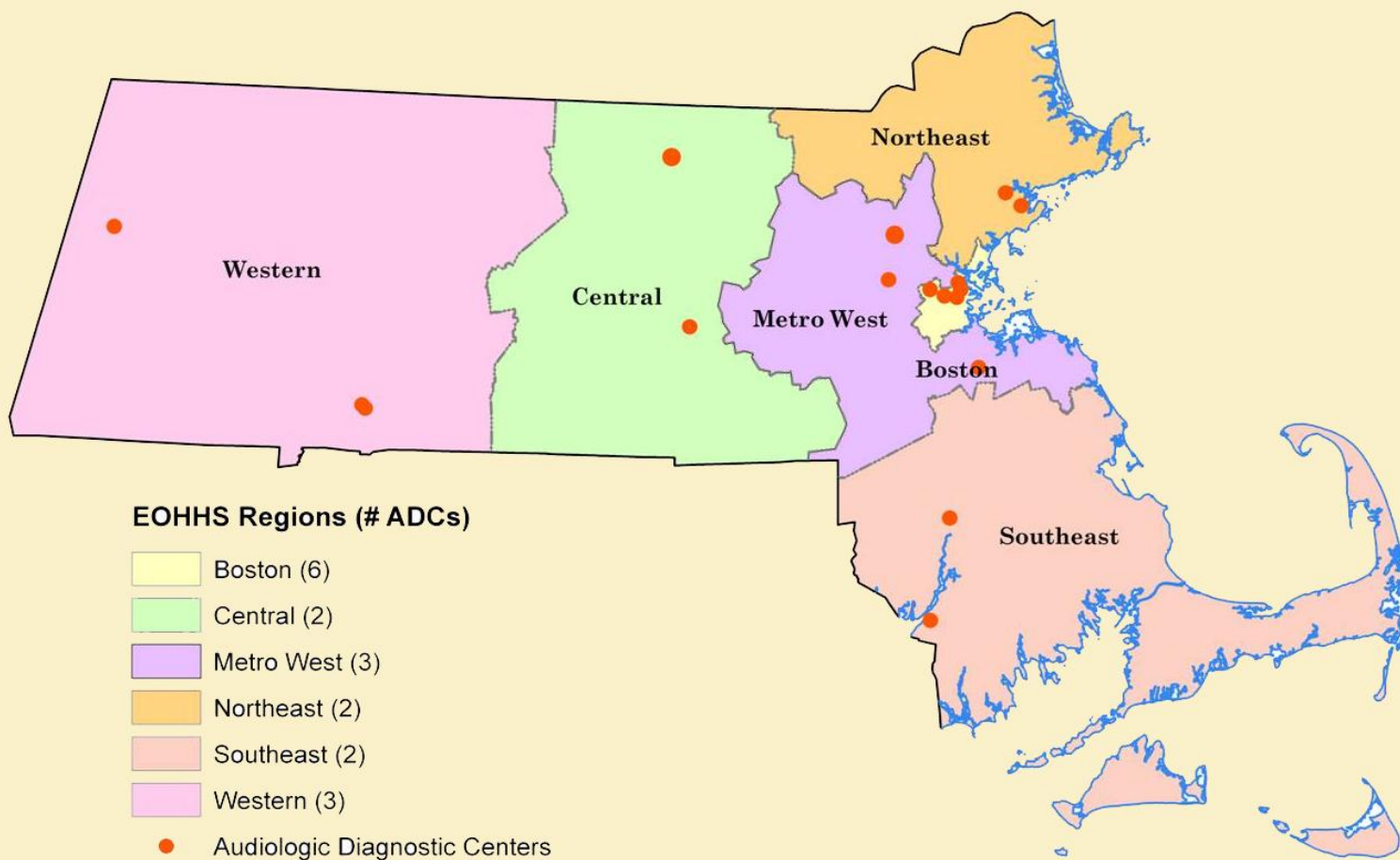
Approval Process for Guidelines

- ADCs develop and submit written protocols to DPH for initial approval
 - Submitted every five years
 - New centers or changes in level - ongoing review and approval
- Staff/consultants review protocols
 - Written summaries provided with missing information or further clarification
- Final approval granted – currently 29 approved centers across the state

Levels of Centers

- Level 1: Serve children birth to 6 years. Offer sedated and non sedated Auditory Brainstem Response (ABR) testing in addition to other traditional pediatric test procedures.
- Level 2: Serve children birth to 6 years. Offer non sedated ABR testing in addition to other traditional pediatric test procedures.
- Level 3: Serve children 6 months corrected age (CA) to 6 years. Offer traditional pediatric test procedures, but not ABR testing

Level 1 and 2 DPH ADCs



Level 1 Anesthesia/Sedation

- Process for credentialing staff
- Assurance that the following are met
 - AAP, Guidelines for Evaluation and Preparation of Pediatric Patients Undergoing Anesthesia
 - AAP, Guidelines for Pediatric Perioperative Anesthesia Environment
 - AAP, Guidelines for Monitoring and Management of Pediatric Patients During and After Sedation for Diagnostic Procedures
 - Practitioners skilled in airway management and cardiopulmonary resuscitation
 - Availability of age- and size appropriate equipment and necessary medications needed to sustain life in the event of an unexpected adverse event

ADC Staffing

- Contact person (audiologist in a leadership position)
- Person responsible for responding to DPH data reports
- Audiologist – must be licensed in MA and must have an annual pediatric caseload of children under six years of at least 10%
- Audiologist externs – must meet ASHA and AAA standards and prohibited from submitting audiological results
 - Automated e-mail and mailing lists
 - Disseminate numerous e-mail blasts

Hearing Testing Procedures

Only two screens allowed by birth facilities (MA refer rate 1.8%)

- Both ears tested regardless of refer results
- Diagnostic ABR required for all NHS refers
- Equipment verifiable through departmental records/site visits
- Child and family history
- History of adverse events (sedation/anesthesia)
- Risk indicators
- Verification of hearing aid(s) using electro-acoustic measures
- Parental report of auditory and visual behaviors and communication milestones for infants 6 to 36 months
- Testing in a calibrated sound field

Testing Procedures Continued

- ABR using air-conducted tone bursts and bone-conducted tone bursts when indicated
- Frequency-specific ABR testing to determine degree and configuration of HL in each ear (hearing aids)
- Click-evoked ABR testing using both condensation and rarefaction high intensity level single-polarity stimulus
- OAEs
- Tympanometry (1000-Hz probe tone)
- Pure-Tone, Visual Reinforcement, Conditioned Play, and Word Recognition Audiometry
- Speech-detection and recognition measures

Other Requirements

- Verifiable Calibration of Equipment
 - ANSI Standards
- Americans with Disabilities Act
 - TTY, interpreters
- Culturally and Linguistically Appropriate Services (CLAS)
- Interpreters for families whose preferred language is other than English
- Follow-up for risk indicators
- Counseling family about sibling testing
- Newborn screening protocol (e.g., homebirths, infants that only had one screen)
- Agreement to bill any available insurance and state is payer of last resort

Management Plan for Confirmed Hearing Loss

- Family
 - Family choice guides decisions
 - Communication options and technology
 - State, local, parent to parent resources
- State Programs and Resources
 - Parent Information Kit (PIK)
 - Referral to EI and other state programs (e.g., DPH Hearing Aid)
 - Referral to MA Comm. for the Deaf and Hard of Hearing
 - Medical Home (ADC provides assurance of on-going communication)
 - Plan to coordinate appointments (e.g., developmental, speech language, genetics, cardiology, nephrologist, counseling, mental health)
 - Referral to assess visual acuity by a pediatric trained ophthalmologist

Quality Assurance/Quality Improvement

- Average time to first appointment
- Annual statistics
- Quarterly tally of children below age six
- Number of missed appointments
- Timeliness of reporting data
- Documented responses to UNHSP question lists
- Average number of appointments to achieve diagnosis
- Percent of NHS referrals that did not receive testing

Data Agreement

- Required data agreement - closes the loop on missing data/lost to documentation
- Informed Consent (consent forms provided by UNHSP)
- Aggregate data submitted for non-consents
- Reporting criteria
 - Through sixth birthday
 - All referrals from newborn hearing screening
 - Known risk indicator(s)
 - Missed appointment
 - Later diagnosed with hearing loss and passed a newborn hearing screen
 - Policy for long term otitis media
 - Out of state residents
- Procedure for submitting data (electronic/fax)

Consent Data

	Total Evaluations	Total non-consents (%)
2008	3262	59 (1.8)
2007	3182	78 (2.5)
2006	2580	58 (2.2)

Data Collected

- General demographics, including two telephone numbers and medical home
- Audiological procedures
- Ear specific testing results
- Known HL indicators
 - Family history, in utero/congenital infection, neonatal indicators, other conditions
- Other medical/technology referrals
- Resources provided (e.g. PIK, referral to EI)
- Missed appointment
- Audiologist performing the evaluation
- Notes

EHDI ADC Meetings

- Required to meet with MA EHDI 3 x annually and meeting minutes disseminated
 - Annual EHDI Data, Guidelines and Regulations, Data Requirements, National Position Statements
- Extensive list of presentations provided
 - (e.g., genetics, Ushers, Medical Conditions Associated with HL, Shared Reading Program, Challenges for Deaf/HOH Students and their Parents in the Educational Environment and How You Can Help, Factors Associated with HL in ECMO Graduates, Infant Brain Development, Coverage for HA in the MA Medicaid Program, Technological Advances in Hearing Screening and Diagnosis, Pediatric Ophthalmology, Cochlear Implant Centers Panel, Hearing Loss and Down Syndrome)
- Excellent networking opportunity
 - Good way to keep providers current on what is happening in the state
 - Knowledge is shared through presentations and discussion
- Constituency building for EHDI initiative

Data Reports

- Summary of Annual Data
 - Infants with confirmatory diagnosis
 - Diagnosis pending
- Reports/question lists every other month
- >3,000 tracking forms submitted annually
 - Electronic and fax reports

MA EHDI Data

- >77,500 occurrent births
- 99.5% screened
- 1,405 (1.8%) referred
 - 1010 unilateral referrals
 - 395 bilateral referrals
- 202 diagnosed with hearing loss (14.4%)
 - 100 unilateral referrals diagnosed with HL (1/10)
 - 46 of the 100 unilateral referrals diagnosed with hearing loss have bilateral hearing loss
 - 102 bilateral referrals diagnosed with HL (1/4)
- 4.2% lost to follow-up

Age (in months) at diagnosis of hearing loss

Year of Birth	Number Diagnosed with Hearing Loss	Median Age at Diagnosis (in months)	Average Age at Diagnosis (in months)
2004	225	1.15	2.32
2005	207	1.20	2.04
2006	226	1.25	2.35
2007	212	1.13	1.71
2008	202	1.10	1.90

Questions?