

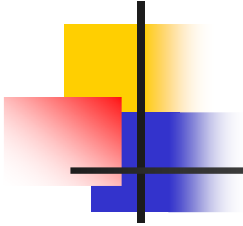


Assessing and Encouraging Compliance with 2007 JCIH Recommendations

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- What has NJ EHDI done to encourage adoption of JCIH recommendations?
- How is NJ EHDI assessing compliance with JCIH recommendations?
- Where does NJ EHDI still need to focus efforts on improving adoption of JCIH recommendations?



Auditory Neuropathy/Dyssynchrony

JCIH Update:

Expanded definition

What has NJ EHDI done?

- EHDI forms did not include AN/AD category. When diagnosed, it was usually written in “other” field
- July 2008 version of report forms (paper and electronic) added AN/AD
- Ongoing education to Audiology community

How is compliance?

- Since July 2008, 3 cases of AN/AD reported on revised form

Form changes: AN/AD

Old Form

DIAGNOSTIC AUDIOLOGIC EVALUATION																	
Ear-Specific Results: <table border="0"> <tr> <td style="text-align: center;"><u>Right</u></td> <td style="text-align: center;"><u>Left</u></td> </tr> <tr> <td><input type="checkbox"/> Normal Hearing</td> <td><input type="checkbox"/></td> </tr> <tr> <td><input type="checkbox"/> Conductive hearing loss (transient)</td> <td><input type="checkbox"/></td> </tr> <tr> <td><input type="checkbox"/> Conductive hearing loss** (permanent)</td> <td><input type="checkbox"/></td> </tr> <tr> <td><input type="checkbox"/> Sensorineural hearing loss**</td> <td><input type="checkbox"/></td> </tr> <tr> <td><input type="checkbox"/> Mixed hearing loss**</td> <td><input type="checkbox"/></td> </tr> <tr> <td><input type="checkbox"/> Other: _____</td> <td></td> </tr> </table>		<u>Right</u>	<u>Left</u>	<input type="checkbox"/> Normal Hearing	<input type="checkbox"/>	<input type="checkbox"/> Conductive hearing loss (transient)	<input type="checkbox"/>	<input type="checkbox"/> Conductive hearing loss** (permanent)	<input type="checkbox"/>	<input type="checkbox"/> Sensorineural hearing loss**	<input type="checkbox"/>	<input type="checkbox"/> Mixed hearing loss**	<input type="checkbox"/>	<input type="checkbox"/> Other: _____		OR	<input type="checkbox"/> Ear-specific information not obtained on this date. <input type="checkbox"/> Reassessment scheduled in: <input type="checkbox"/> 1 Mo <input type="checkbox"/> 2 Mo <input type="checkbox"/> 3 Mo
<u>Right</u>	<u>Left</u>																
<input type="checkbox"/> Normal Hearing	<input type="checkbox"/>																
<input type="checkbox"/> Conductive hearing loss (transient)	<input type="checkbox"/>																
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		Degree of Hearing Loss (re: DSHPSHWA): <table border="0"> <tr> <td style="text-align: center;"><u>Right</u></td> <td style="text-align: center;"><u>Left</u></td> </tr> <tr> <td><input type="checkbox"/> Mild (21-40 dBHL)</td> <td><input type="checkbox"/></td> </tr> <tr> <td><input type="checkbox"/> Moderate (41-70 dBHL)</td> <td><input type="checkbox"/></td> </tr> <tr> <td><input type="checkbox"/> Severe (71-90 dBHL)</td> <td><input type="checkbox"/></td> </tr> <tr> <td><input type="checkbox"/> Profound (+90 dBHL)</td> <td><input type="checkbox"/></td> </tr> </table>		<u>Right</u>	<u>Left</u>	<input type="checkbox"/> Mild (21-40 dBHL)	<input type="checkbox"/>	<input type="checkbox"/> Moderate (41-70 dBHL)	<input type="checkbox"/>	<input type="checkbox"/> Severe (71-90 dBHL)	<input type="checkbox"/>	<input type="checkbox"/> Profound (+90 dBHL)	<input type="checkbox"/>				
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New Form

PEDIATRIC AUDIOLOGIC EVALUATION (PAE)																			
Ear-Specific Results: <table border="0"> <tr> <td style="text-align: center;"><u>Right</u></td> <td style="text-align: center;"><u>Left</u></td> </tr> <tr> <td><input type="checkbox"/> Normal Hearing</td> <td><input type="checkbox"/></td> </tr> <tr> <td><input type="checkbox"/> Conductive hearing loss (transient)</td> <td><input type="checkbox"/></td> </tr> <tr> <td><input type="checkbox"/> Conductive hearing loss* (permanent)</td> <td><input type="checkbox"/></td> </tr> <tr> <td><input type="checkbox"/> Sensorineural hearing loss*</td> <td><input type="checkbox"/></td> </tr> <tr> <td><input type="checkbox"/> Mixed hearing loss (SN/trans. cond.)</td> <td><input type="checkbox"/></td> </tr> <tr> <td><input type="checkbox"/> Mixed hearing loss (SN/perm. cond.)</td> <td><input type="checkbox"/></td> </tr> <tr> <td><input type="checkbox"/> Auditory Neuropathy/Dyssynchrony*</td> <td><input type="checkbox"/></td> </tr> </table>		<u>Right</u>	<u>Left</u>	<input type="checkbox"/> Normal Hearing	<input type="checkbox"/>	<input type="checkbox"/> Conductive hearing loss (transient)	<input type="checkbox"/>	<input type="checkbox"/> Conductive hearing loss* (permanent)	<input type="checkbox"/>	<input type="checkbox"/> Sensorineural hearing loss*	<input type="checkbox"/>	<input type="checkbox"/> Mixed hearing loss (SN/trans. cond.)	<input type="checkbox"/>	<input type="checkbox"/> Mixed hearing loss (SN/perm. cond.)	<input type="checkbox"/>	<input type="checkbox"/> Auditory Neuropathy/Dyssynchrony*	<input type="checkbox"/>	Other Results: <input type="checkbox"/> Soundfield responses at 1, 2 and 4K are ≤ 30 dB HL with present OAEs, bilaterally. <input type="checkbox"/> Probable permanent hearing loss in at least 1 ear, further testing needed. <input type="checkbox"/> Unable to determine hearing status of each ear at this visit.	
<u>Right</u>	<u>Left</u>																		
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Screening/ Rescreening Protocols

JCIH Update:

ABR on NICU, Rescreening recommendations

What has NJ EHDI done?

- Current Rules allow:
 - hospitals to select electrophysiologic method
 - outpatient follow-up practices at the discretion of the provider
 - New rules (2010) will mandate ABR for NICU (>5d), ABR re-screen for ABR refer, and bilateral rescreen
- Encouraging implementation through:
 - Site visit discussion
 - Electronic report form changes
 - Quarterly reports - hospitals get reports comparing their stats to state avg. with newly added "JCIH" stats



Online Reporting Changes

- To encourage compliance with JCIH recommendations, in July 2008, the Web-based EHDI outpatient reporting system was updated
- Updated system will not allow saving of a form that indicates a “non-JCIH-compliant” exam
- Since compliance is not currently mandated, non-compliant exams can still be submitted on paper

Online Reporting Changes

REASON TESTING WAS REQUIRED

Not Screened Previously
 Returned for Ear-Specific Results

Refer Result on Previous Screen

OAE
 ABR
 BOTH
 UNKNOWN
 RIGHT EAR
 LEFT EAR
 BOTH
 UNKNOWN

Risk Indicator Code: [VIEW](#)

Hospital readmission in 1st month of life for:

Hyperbilirubinemia w/exchange transfusion
 Culture positive sepsis
 Other hospitalization

Other:

Name of Outpatient screening/Audiologic Evaluation Facility:

DHSS/EHDIP

Address:

PO BOX 364

City:

TRENTON

State:

NJ

Zip:

08625

OUTPATIENT SCREENING RESULTS/RECOMMENDATIONS

Method:		Findings:		Screening Recommendations:
Right	Left	Right	Left	
<input type="radio"/> TEOAE	<input type="radio"/>	<input checked="" type="radio"/> Pass	<input type="radio"/>	<input checked="" type="radio"/> Pass, no further evaluation required, unless future clinical indication or parental concern
<input checked="" type="radio"/> DPOAE	<input checked="" type="radio"/>	<input type="radio"/> Refer	<input type="radio"/>	<input type="radio"/> Pass, risk indicator follow-up: PAE by 24-30 mo. of age (more often if needed)
<input type="radio"/> ABR	<input type="radio"/>	<input type="radio"/> Can not screen (ear canal atresia)	<input type="radio"/>	<input type="radio"/> Referral to physician with re-screening following medical intervention
<input type="radio"/> BOTH	<input type="radio"/>	<input type="radio"/> Did not screen	<input checked="" type="radio"/>	<input type="radio"/> Did not pass, refer for complete audiologic evaluation
<input type="radio"/> Uncheck	<input type="radio"/>	<input type="radio"/> Uncheck	<input type="radio"/>	<input type="radio"/> Pass, risk indicator reported in error, discharge from follow-up
				<input type="radio"/> Uncheck



Online Reporting Changes

Windows Internet Explorer



2007 JCIH Position Statement recommends for rescreening a complete screening on both ears, even if only 1 ear referred on initial screening

2007 JCIH Position Statement states Infants in the well-infant nursery who fail automated ABR testing should not be rescreened by OAE testing and passed because such infants are presumed to be risk of having a subsequent diagnosis of auditory neuropathy/dyssynchrony.

OK

Windows Internet Explorer



2007 JCIH Position Statement recommends ABR screening for babies with NICU admission.

OK

Screening/Rescreening Protocols

- How is compliance?

Report is for babies born between 1/1/08 and 12/31/08

Rates:

	NICU ABR Screening		Inpatient ABR Refer with Outpatient ABR		Bilateral Rescreen for Unilateral Refer	
	Eligible babies: NICU > 5 days, screened, & discharged home	% of eligible babies having ABR performed (instead of OAE)	Eligible babies: referred inpatient ABR screen, d/c home, & had outpatient rescreening*	% of eligible infants having outpatient ABR screening (instead of OAE)	Eligible babies: unilateral inpatient refer & discharged home	% of eligible babies having bilateral outpatient testing (instead of unilateral)
NJ Total	5034	89.1%	553	64.9%	1080	95.9%

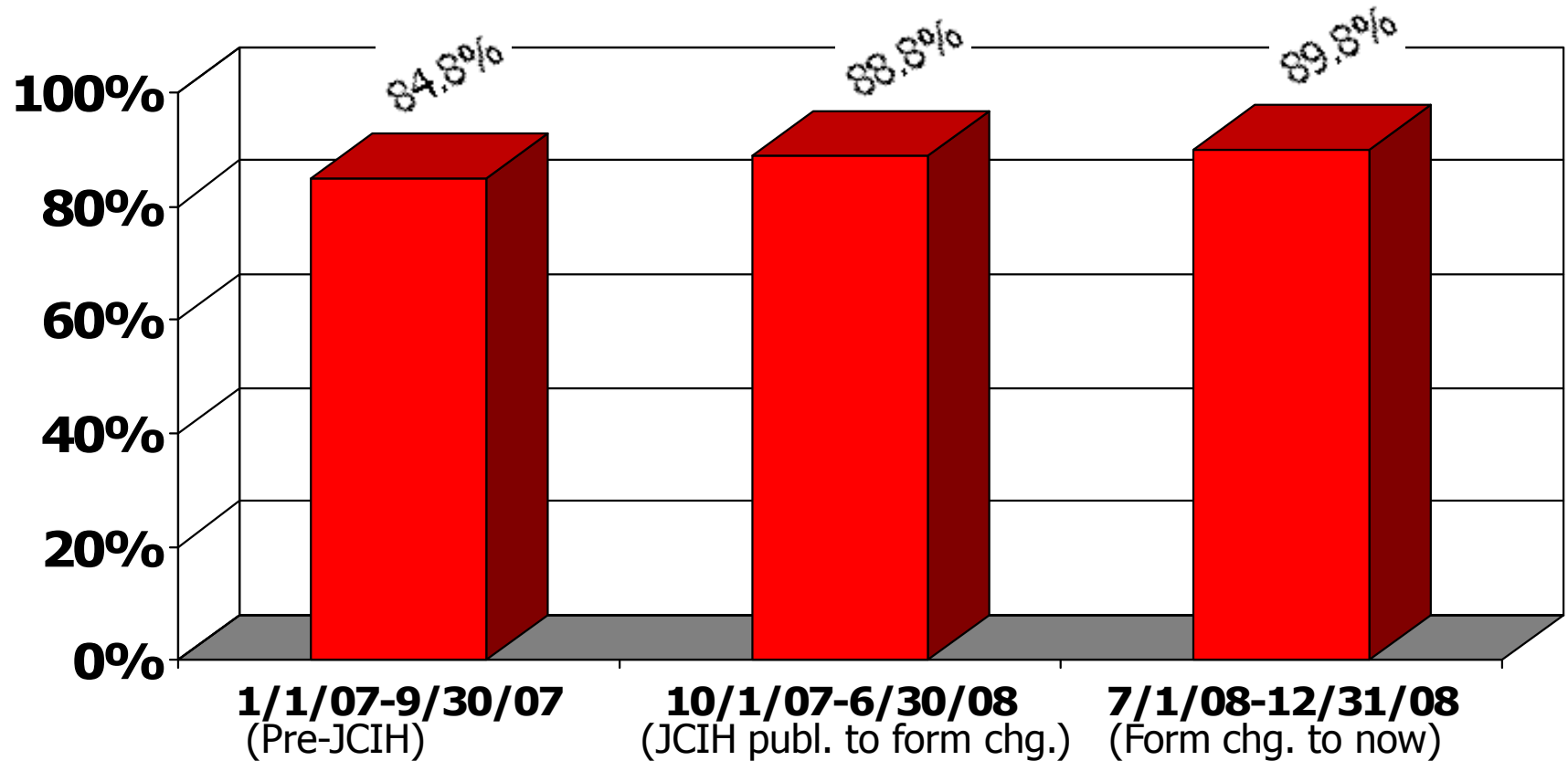
Statewide Ranges:

Low:	0.0%	0.0%	0.0%
High:	100.0%	100.0%	100.0%
% of hospitals w/ eligible infants at 100%	35.0%	13.9%	67.3%

Sample Hospital	419	99.3%	41	87.8%	21	100.0%
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ABR on NICU

% of screened NICU (>5d) babies having ABR



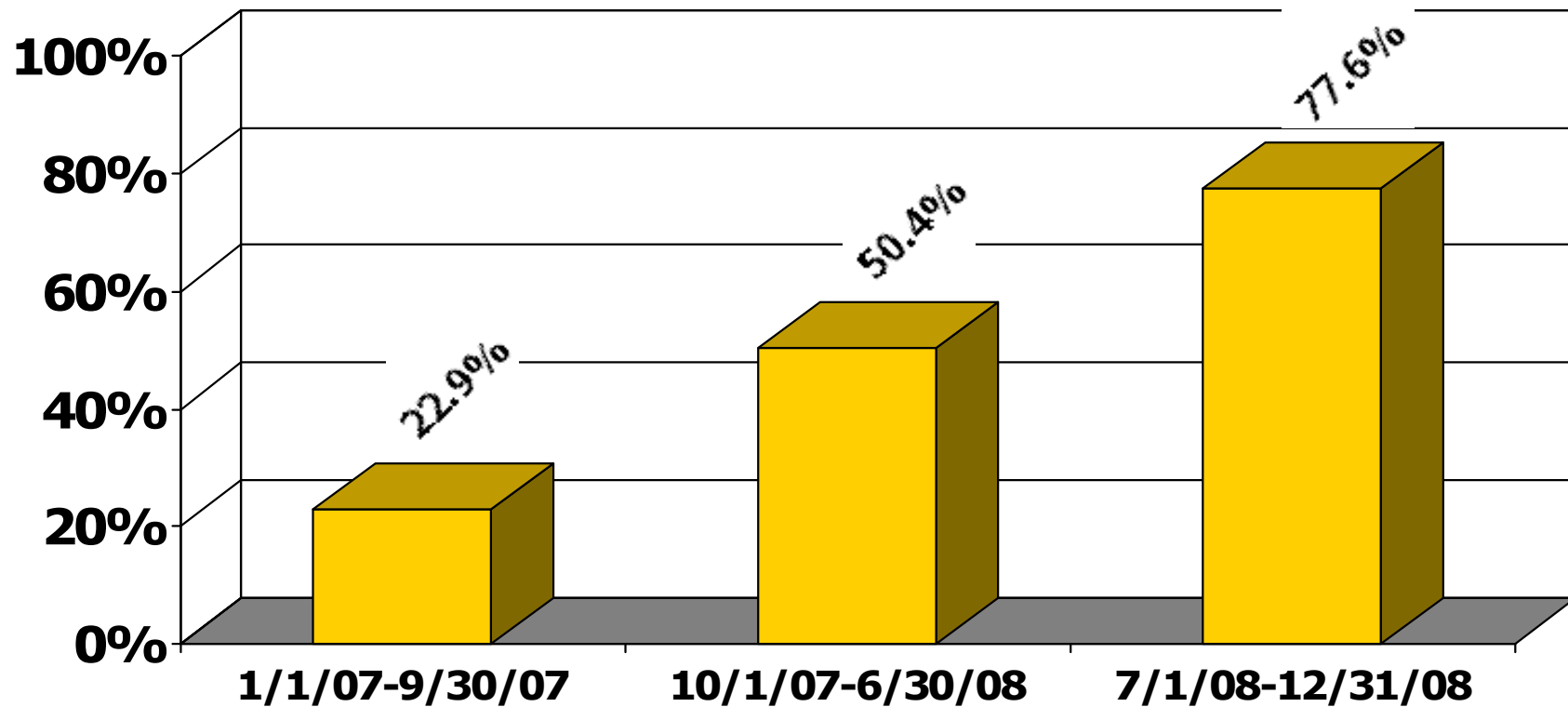


ABR on NICU

- 20 NJ hospitals (38%) have “Intensive” bassinets
 - Some others have “Intermediate” bassinets – they will not be held to the ABR standard
- As of Feb. 2009, for the Intensive nurseries:
 - 8 do ABR on all babies
 - 7 do ABR on NICU, 2-stage on NBN
 - 3 do ABR on NICU only, OAE only on NBN
 - 2 do OAE on all
 - 1 ABR equipment purchase pending
 - 1 administration will not approve ABR equipment purchase without a “mandate”
- Due to Quarterly Report, one hospital identified substantial EBC data entry issue (still entering OAE after started doing ABR)

Outpatient ABR on ABR Refer

Of referred ABR who had outpatient f/u, % with ABR



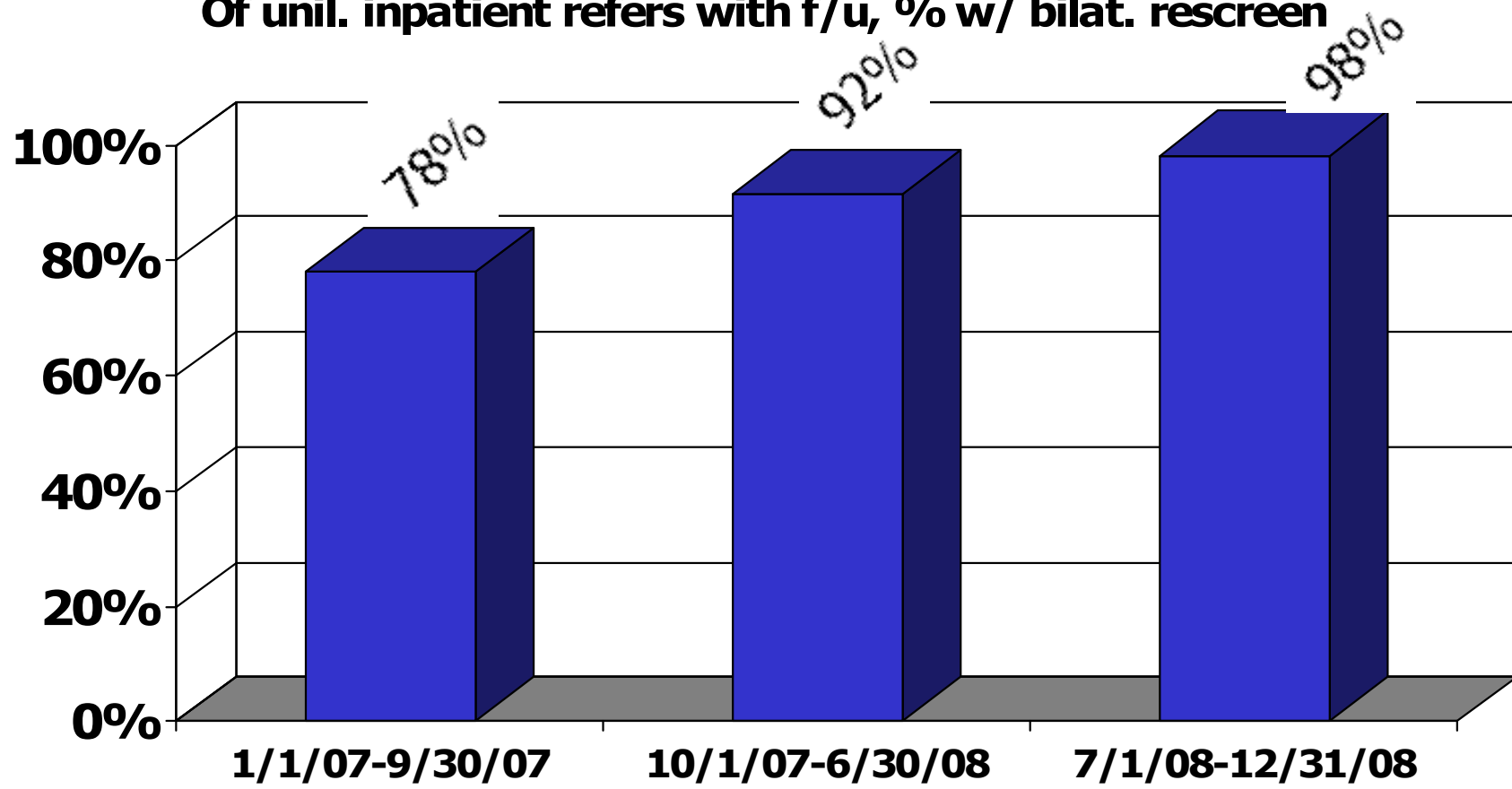


Outpatient ABR on ABR Refers

- 24 (of 53) NJ hospitals use ABR exclusively
- Of these, only about half (11) have in-house audiology services
- Several hospitals without audiology services are beginning to establish procedures for outpatient ABR rescreening by nursery screeners as a result of lack of ABR at follow-up locations

Bilateral Rescreen on Unilateral Refer

Of unil. inpatient refers with f/u, % w/ bilat. rescreen





Screening/ Rescreening Protocols

JCIH Update:

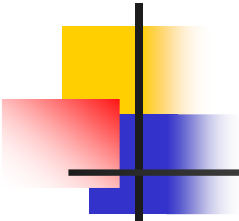
For readmissions in the first month of life ... a repeat hearing screening is recommended...

What has NJ EHDI done?

- Educating/encouraging hospitals to perform rescreen via hospital visits/conference calls
- Plan to add to 2010 Administrative Rule update
- Line added to outpatient form as “reason for testing”

How is compliance?

- Since July 2008, 13 outpatient f/u forms submitted w/ readm. checked as reason for testing
- Difficult to monitor/track compliance. State EHDI program usually unaware of readmissions



REASON TESTING WAS REQUIRED

- Not Screened Previously
- Returned for Ear-Specific Results
- Refer Result on Previous Screen
 - (OAE ABR BOTH UNKNOWN) RIGHT EAR LEFT EAR BOTH UNKNOWN
- Risk Indicator Code:
- Hospital readmission in 1st month of life for:
 - Hyperbilirubinemia w/exchange transfusion
 - Culture positive sepsis
 - Other hospitalization
- Other:

Name of Outpatient screening/Audiologic Evaluation Facility:



Diagnostic Audiology Evaluation

JCIH Update:

- Audiologists with skills and expertise in infants
- ABR as part of evaluation for children hearing loss
- Reevaluations for risk factors should be customized
- Fit amplification device within 1 month of diagnosis

What has NJ EHDI done?

- Pediatric Hearing Health Care Directory
http://www.state.nj.us/health/fhs/ehdi/documents/audiologist_directory.pdf
- Ongoing education to audiologists
 - Email distribution list, site visits, teleconferences
- Risk indicator changes: education, form changes



Diagnostic Audiology Evaluation

How is compliance?

- Hard data not available
 - No national certification for pediatric audiology – Directory is self report that they see children <3
 - Starting a procedure for follow-up letters to audiology facilities after diagnosis of HL to inquire if ABR done and date of HA fitting
 - Dec 2008 meeting w/ Medicaid Quality Assurance office re: known issue with limited availability of Hearing Aid Dispensers able to fit infants in many HMOs



Risk Indicator Changes

What has NJ EHDI done?

- NJ Administrative Rules (issued 12/2005) read
8:19-1.8 High-risk indicators
 - (a) **The JCIH Position Statement identifies risk indicators** that require periodic audiologic monitoring to detect progressive or late-onset hearing loss. Upon receipt of the notice required in N.J.A.C. 8:19-1.9(f)1 of the presence of these risk indicators, the **infant's responsible physician shall ensure the monitoring of these infants in accordance with the time intervals and other protocols identified in the JCIH Position Statement.**



Risk Indicator Changes

- NJ Rules also read:

"JCIH Position Statement" means the "Year 2000 Position Statement: Principles and Guide-lines for Early Hearing Detection and Intervention Programs," of the Joint Committee on Infant Hearing (JCIH), **incorporated herein by reference, as amended and supplemented**, published in Pediatrics, Vol. 106, No. 4, at 798 (October 2000), available by ...



Risk Indicator Changes

- With wording of the current Rules, hospitals, audiologists and pediatricians were required to immediately comply with revisions upon publication
- The EHDI program
 - distributed the JCIH Statement to hospital and audiology contacts advising compliance with the new risk indicators/intervals
 - discussed risk changes during annual hospital site visits/conference calls
- EHDI forms (paper and electronic) were modified to reflect new risk indicators in July 2008

Risk Indicators – Online Form

Old Pop-up Box

http://njiis-train.doh.state.nj.us - Risk factor Pop Up - Microsoft Internet

RISK INDICATOR CODES

- Parental concern regarding hearing, speech, language and/or developmental delay
- Conditions requiring the use of extracorporeal membrane oxygenation (ECMO)
- Hyperbilirubinemia at a serum level requiring exchange transfusion
- Family history of permanent childhood hearing loss
- Postnatal infections associated with sensorineural hearing loss including bacterial meningitis
- Neurodegenerative disorders, such as Hunter syndrome or sensory motor neuropathies, and Charcot-Marie-Tooth syndrome, etc
- Recurrent or persistent OME for at least 3 months
- Persistent pulmonary hypertension of the newborn associated with mechanical ventilation
- Stigmata or other findings associated with a syndrome known to include a sensorineural hearing loss or Eustachian tube dysfunction
- Syndromes associated with progressive hearing loss such as neurofibromatosis, osteopetrosis, etc
- In utero infection such as cytomegalovirus, herpes, rubella, syphilis and toxoplasmosis (TORCH)
- Head trauma

*** To document an error in a previously reported risk factor, please use the appropriate "Followup" (SCH-3) form**

Done

New Pop-up Box

Risk factor Pop Up - Windows Internet Explorer

http://njiis-train.doh.state.nj.us/njiis/jsp/riskfactorpopup.jsp?version=1

Internet Explorer is currently running with add-ons disabled

RISK INDICATOR CODES

- (CO) Caregiver concern* regarding hearing, speech, language or developmental delay
- (HX) Family history* of permanent childhood hearing loss
- (EC) Neonatal intensive care of more than 5 days with use of extracorporeal membrane oxygenation (ECMO)*
- (AV) Neonatal intensive care of more than 5 days with use of assisted ventilation
- (OT) Neonatal intensive care of more than 5 days with exposure to ototoxic medications (gentimycin and tobramycin) or loop diuretics (furosemide/lasix)
- (NI) Neonatal intensive care of more than 5 days
- (HB) Neonatal intensive care (of any number of days) with hyperbilirubinemia that requires exchange transfusion
- (TO) In utero infections such as CMV*(cytomegalovirus), herpes, rubella, syphilis and toxoplasmosis (TORCH)
- (CR) Craniofacial anomalies, including those that involve the pinna, ear canal, ear tags, ear pits and temporal bone anomalies
- (PF) Physical findings, such as a white forelock, that are associated with a syndrome known to include a sensorineural or permanent conductive hearing loss
- (SY) Syndromes associated with hearing loss or progressive or late onset hearing loss,* such as neurofibromatosis, osteopetrosis and Usher's syndrome; other frequently identified syndromes include Waardenburg, Alport, Pendred, and Jervell and Lange-Nielson*
- (ND) Neurodegenerative disorders*, such as Hunter syndrome or sensory motor neuropathies, such as Friedreich's ataxia and Charcot-Marie-Tooth syndrome, etc
- (PI) Culture-positive postnatal infections associated with sensorineural hearing loss* including confirmed bacterial and viral (especially herpes viruses and varicella) meningitis
- (TR) Head trauma, especially basal skull / temporal bone fracture* that requires hospitalization
- (CH) Chemotherapy*
- (OM) Recurrent or persistent OME for at least 3 months
- (PH) Persistent pulmonary hypertension of the newborn associated with mechanical ventilation
- (ST) Stigmata or other findings associated with a syndrome known to include a sensorineural and/or conductive hearing loss or Eustachian tube dysfunction
- (MN) Postnatal infections associated with sensorineural hearing loss including bacterial meningitis

*** These conditions are of greater concern for delayed-onset hearing loss and may require more frequent monitoring.**

Done Internet 100%



Risk Indicators

How is compliance (risk changes)?

- During 2008 hospital reviews, most policies and parent materials were compliant w/ new recommendations. Those that were not were counseled to update their policies
- Some hospitals still need to update parent materials (“... every 6 months...”)
- New boxes (Chemo, NICU > 5d) ARE being checked - but too soon to track compliance with 24-30 mo. exams



Medical Evaluation

JCIH Update:

- Refer for genetics and otolaryngology & ophthalmology w/ pediatric hearing loss experience

What has NJ EHDI done?

- Ongoing pediatrician education efforts
- Current Rules (8:19-1.11(d)) read: When a diagnosis of permanent hearing loss is made, the responsible **physician shall advise the parents** of the importance **of medical and audiologic evaluations consistent with** the recommendations of **the JCIH Position Statement**, and shall make appropriate referrals...
- Pediatric ENTs to be added to Pediatric Hearing Health Care Directory by June 2010
- Check boxes on follow-up report form to prompt required recommendations



Medical Evaluation

Additional audiologic evaluation in: weeks / months

If additional testing is to be performed at a different facility, Please indicate name:

**Hearing loss diagnosed on: **Registered with SCHS Registry/Case Mgt. Services on:

Recommended Referral (Check all that apply) check all of these*

<input type="checkbox"/> Pediatrician*	<input type="checkbox"/> Genetics Evaluation*	<input type="checkbox"/> Hearing Aid services*	<input type="checkbox"/> Early Intervention/Case Management*
<input type="checkbox"/> Otolaryngologist*	<input type="checkbox"/> Ophthalmologist*	<input type="checkbox"/> Parent Support Services*	<input type="checkbox"/> Speech/Language Pathologist*
<input type="checkbox"/> Craniofacial/Cleft Center	(e.g.NJ Parent-to-Parent)		<input type="checkbox"/> Other: <input type="text"/>



Medical Evaluation

How is compliance?

- Forms submitted with dx of perm. HL:

	2007	2008
■ % with genetics box checked:	57%	60%
■ % with otolaryngology box checked:	86%	95%
■ % with ophthalm. box checked:	41%	48%

- This is audiologist recommendation, so \neq MD referral
- May not get checked if already had that evaluation

- Currently unable to track that specialty visits actually occurred. May be available in case management system under development



Early Intervention

JCIH Update:

- Children with any degree/laterality should be considered eligible
- Central referral points of entry that ensure specialty services for infants with confirmed hearing loss.
- Services by professionals who have expertise in HL
- Both home-based and center-based intervention



Early Intervention

What has NJ EHDI done?

- Any degree/type/laterality of HL has been a diagnosis of presumptive eligibility since 1993 (when EI transferred from DOE to DHSS)
- Single point of entry for all EI services established in 2008 (888-653-4463). Previously entry was county-based (21 counties)
- Each of the many agencies that provides EI services (and not the State EI program) are responsible for ensuring their providers qualifications, so NJ EHDI can not verify “experienced” providers. certified teachers of the Deaf and are employed by some EIPs
- Center-based services are provided by several EIP agencies, primarily those serving only children w/ hearing loss, so center-based available only in certain areas of New Jersey
- Developed “Guidelines for EI Service Providers of Children with Hearing Loss” which includes 2007 JCIH recommendations – document is still undergoing administrative review



Surveillance and Screening in the Medical Home

JCIH Update:

- ...regular surveillance...in the medical home ...of global development...; refer when concern

What has NJ EHDI done?

- Included in ongoing pediatrician education
 - Currently doing presentations at Pediatrics Department business meetings
 - Ongoing collaboration with AAP Chapter Champion



Communication

JCIH Update:

- Ensure results conveyed to the parents and the medical home
- Provide resource information
- Ensure infant is linked to a medical home
- Information communicated in a culturally sensitive and understandable format
- Screening, diagnostic and habilitation information transmitted to the medical home and the state EHDI coordinator.
- Families aware of all communication options and available hearing technologies



Communication

What has NJ EHDI Done?

- Current EHDI Rules require:
 - Hospitals to provide all screen results (including pass) to parent both “face-to-face” and “in writing”
 - Hospitals to provide all screen results in writing to the “responsible physician”
 - Hospitals to provide information to parents on centers that perform pediatric audiologic testing



Communication

- Current EHDI Rules require:
 - DHSS to provide parent information for distribution by hospitals in languages “most representative of the NJ population”. Can Your Baby Hear? and Your Baby Needs Another Test are provided in English, Spanish, Arabic, Korean, Polish, Portuguese
 - Submission of outpatient follow-up form to EHDI program (on paper form a copy is labeled for sending to the medical home)
 - Integration of outpatient reporting in NJIIS (immunization registry) also improved access to results by medical home.



Communication

- Family information on unbiased options is included in “Guidelines for EI Service Providers for Children with Hearing Loss” document (still under administrative review). Anecdotally, this is not currently happening in all areas.



Information Infrastructure

JCIH Update:

- States data-management and -tracking system
- Link between health and education professionals to ensure transition

What has NJ EHDI done?

- Maintained a tracking database of screening and outpatient follow-up results.
- NJ EHDI is “at the table” in discussions of a comprehensive electronic child health record.
- NJ EHDI has established relationships with DOE staff responsible for Deaf/HH children, however data sharing is not currently viable. EI does have formal transition process



Areas For Future Focus

- Update of rules to enforce screening/follow-up items as mandate vs. recommendation
- Improve appropriate medical follow-up evaluation
- Improve availability/awareness of “experienced” providers (audiology, medical, and EI)
- Full spectrum of communication options available and offered in unbiased manner
- Improve ability to track educational outcomes and transition into DOE services