THE DELAWARE EARLY HEARING DETECTION AND INTERVENTION BOARD

WORKING TOGETHER FOR THE BENEFIT OF ALL CHILDREN AND FAMILIES

Sharing Our Story
WHY EHDI?

- Educational Management
- 1980 New possibility of medical management of deafness
- 1984 Discovery of otoacoustic emissions
- 1994 Joint Committee on Infant Hearing recommends Universal screening
- 1999 Delaware Organizes Hearing Screening
- 2000 Joint Committee on Infant Hearing Benchmarks 3mos detection - 6 months intervention
- National movement to mandated Universal hearing screening
- 1 month – 3 month – 6 month era
PANEL MEMBERS - WHO WE ARE AND HOW WE GOT HERE

- **Isabel Rivera-Green**, Department of Public Health, Director of Children and Youth with Special Needs

- **Clare Consavage**, Parent/ Hands and Voices Guide by Your Side Coordinator

- **Dr. Shanda Brasheers**, Pediatric Doctor of Audiology

- **Dr. Michael Teixido**, Otologist, Cochlear Implant Surgeon

- **Tracy Neugebauer**, Delaware IDEA Representative, Department of Education

- **Laurie Kettle-Rivera**, Director of Statewide Programs for Deaf, Hard of Hearing and Deaf-Blind
AGENDA

• How we all fit into the puzzle of birth-3 services
• How we all come to work together
• Our goals going forward
• Question/Answer and discussion time
NEWBORN HEARING SCREENING (ISABEL)

• Delaware Department of Health & Social Services – Division of Public Health – Family Health Systems – Newborn Screening Program (NSP)
  • NSP receives the initial hearing screening test for every newborn born in Delaware.
  • NSP receives results from 7 birth facilities and midwives which serve families across our state including our Amish Community.
• Title 16 - Health and Safety Regulatory Provisions Concerning Public Health - Chapter 8A Universal Newborn & Infant Hearing Screening, Tracking & Intervention
• Chapter 808A – Governor Appointed Early Hearing Detection & Intervention (EHDI) Advisory Board
• FREE materials for Pediatricians, Audiologist, Families can be accessed at: www.DETHRIVES.org
NEWBORN HEARING SCREENING (ISABEL)
EARLY INTERVENTION (E.I.) SERVICES YEAR 2017 - 2015

Diagnosed Yr. 2017  Referred Yr. 2017  Enrolled Yr. 2017  Diagnosed Yr. 2016  Referred Yr. 2016  Enrolled Yr. 2016  Diagnosed Yr. 2015  Referred Yr. 2015  Enrolled Yr. 2015  Total with No E.I. Services in Yr. 2015
NEWBORN SCREENING PROGRAM (ISABEL) DIAGNOSED
# Improving Communication and Meeting The 1-3-6 Benchmark for Timely Identification of Hearing Loss in Delaware

## Nemours duPont Hospital for Children and DE State Department of Health

<table>
<thead>
<tr>
<th>Year</th>
<th>Event Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>2005</td>
<td>Began to require AABR with OAE to screen for ANSD even in well nursery</td>
</tr>
<tr>
<td>2007</td>
<td>Direct communication through EMR to state</td>
</tr>
<tr>
<td>2009</td>
<td>Nemours Collaboration Conferences</td>
</tr>
<tr>
<td>2011</td>
<td>Direct referrals to CDW for early intervention via state upon diagnosis</td>
</tr>
<tr>
<td>2013</td>
<td>GBYS</td>
</tr>
<tr>
<td>2015</td>
<td>EHDI Board becomes officially acknowledged by Governor’s office</td>
</tr>
<tr>
<td>2017</td>
<td>State drops OAE result as criteria for PASS / FAIL on screen.</td>
</tr>
<tr>
<td>2019</td>
<td>DHIN initiative</td>
</tr>
<tr>
<td>2019</td>
<td>Oz System adopted by all screening facilities</td>
</tr>
</tbody>
</table>

**Abbreviations:**
- AABR = Automated Auditory Brainstem Response
- OAE = Otoacoustic Emissions
- ANSD = Auditory Neuropathy Spectrum Disorder
- EMR = Electronic Medical Record
- CDW = Child Development Watch
- GBYS = Guide By Your Side
- EHDI = Early Hearing Detection & Intervention
- DHIN = Delaware Health Information Network
SCREENING AND DIAGNOSTIC TECHNOLOGIES (SHANDA)

- Screening in Delaware statewide = AABR
- Screening at Nemours (large NICU population + outpatient rescreens) = OAE, AABR & tympanogram
  - Diagnostics statewide (primarily conducted at Nemours)
    - Conducted after 2\textsuperscript{nd} failed screen (1\textsuperscript{st} outpatient fail)
    - Diagnostic, sleep deprived (for infants under 6 months) ABR
      - High intensity click ABR to evaluate neural integrity and rule out Auditory Neuropathy
      - Tone burst ABR to obtain frequency specific thresholds (500-4000 Hz)
      - Bone conduction ABR to identify type of hearing loss (when present) - sensorineural vs. conductive vs. mixed
    - OAEs and Tympanograms also obtained at time of diagnostic ABR
    - Earmold impressions obtained and amplification submitted to insurance
    - Referrals to ENT and early intervention made immediately and educational materials provided
SCREENING FOR RISK FACTORS

Late onset hearing loss is more prevalent than congenital!

<table>
<thead>
<tr>
<th>Class A Risk Factors</th>
<th>Class B Risk Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infections (CMV, herpes, rubella, syphilis, toxoplasmosis)</td>
<td>Family history of permanent hearing loss in childhood</td>
</tr>
<tr>
<td>Head malformations</td>
<td>NICU stay longer than 5 days</td>
</tr>
<tr>
<td>Diagnosis of any syndrome</td>
<td>Physical findings such as white forelock, abnormal head size, etc</td>
</tr>
<tr>
<td>Head trauma or temporal bone fracture</td>
<td>Mycin or diuretics</td>
</tr>
<tr>
<td>Confirmed bacterial or viral meningitis</td>
<td>Diagnosis of any neurological problem</td>
</tr>
<tr>
<td>Hyperbilirubinemia requiring blood transfusion</td>
<td>Mechanical ventilation:</td>
</tr>
<tr>
<td>ECMO assisted ventilation:</td>
<td>Class B – Behavioral test at 9 months</td>
</tr>
<tr>
<td>Chemotherapy or ototoxic exposure</td>
<td></td>
</tr>
</tbody>
</table>

Class A – Retest every 3 months initially

Rate of HL increases 3 times from birth to later in childhood!
OTOACOUSTIC EMISSIONS VS AUTOMATED ABR

Delaware has chosen to use the AABR as primary screening technology. Nemours also obtains OAEs as a way to screen for otitis media – the most common hearing disorder in children.

---

Permanent Hearing Loss

AABR: Sensitivity = 92% / Specificity = 93% (Brashears et al., 2013)

OAE: Sensitivity = 70% / Specificity = 61% (Bhatt & Chhangte, 2015)

AABR + OAE: Sensitivity = 98% / Specificity = 57% (Brashears et al., 2013).

---

Otitis Media

OAE: Sensitivity = 80% / Specificity = 40% (Brashears et al., 2013)
**MEDICAL SUPPORT (MICHAEL)**

- Medical Management of Hearing Loss depends on early identification
- Most kids with hearing loss have hearing parents
- Neurolinguistic Emergency! No delays
- There are many ways for an ear to break down
- Not all kids with hearing loss are (good) candidates
- Getting a cochlear implant is like buying a guitar
  - daily practice is necessary for successful language development
PART C AND PART B BIRTH MANDATE ELIGIBILITY AND SERVICES (TRACY)

Early Intervention Services in Delaware include four educational classifications that are considered Birth Mandate classifications under Part B (http://regulations.delaware.gov/AdminCode/title14/900/925.shtml):

- Hearing Impaired
- Deaf-Blind
- Visual Impairment including Blindness
- Autism

- Local Education Agencies (LEA-Part B) and Child Development Watch (Part C) are responsible for evaluating, determining eligibility and ensuring access to appropriate services in collaboration with each other.

- LEA’s can utilize Delaware’s Statewide Program for the Deaf, Hard of Hearing & Deaf-Blind to support the determination of eligibility.
Current Program Structure

Delaware Statewide Programs for the Deaf, Hard of Hearing and Deaf-Blind
Director: Laurie Kettle-Rivera

Assessment Center 0-21
Technical Assistance to LEAs 0-21 D/HH/DB
Family Education Statewide Birth-3
Direct Instruction Support to LEAs 0-21 District operated
Family Advocacy and Child Education Services (FACES) 18 mo-5 years NCC + Kent
Listening and Spoken Language Program Birth-5 years DOE operated

Statewide Coordinator DB: Mark Campano
Statewide Coordinator D/HH:

Statewide Coordinator D/HH/DB
School Leader/Principal: Daphne Werner
School Leader/Asst Principal: Courtney Cooper
Residential Program Admin: Eva Hartmann

Continuum of services for districts from Statewide, less involved (left) to more involved (right)
Where We Are Headed

Delaware Statewide Programs for the Deaf, Hard of Hearing and Deaf-Blind
Director: Laurie Kettle-Rivera

Statewide Outreach
D/HH/DB

- Assessment Center 0-21
- Technical Assistance to LEAs 0-21 D/HH/DB
- Family Education Statewide Birth-3
- Direct Instruction Support to LEAs 3-21
- District Inclusion (River School Model)
- Family Advocacy and Child Education Services (FACES) Kent+Sussex
- Family Advocacy and Child Education Services (FACES) 18 mo-5 years NCC +Kent
- Listening and Spoken Language Program Birth-5 Statewide
- Tuition Based Peers

Statewide Onsite
D/HH/DB

- Delaware School for the Deaf K-12
- Residential Program

School Leader/Principal: Daphne Werner
School Leader/Ast Principal: Courtney Cooper
Residential Program Admin: Eva Hartmann

Continuum of services for districts from Statewide, less involved (left) to more involved (right)
We are a parent-driven, parent/professional collaborative group that supports families without bias about communication modes and methods.

We believe that there is no one communication choice that will work for all children who are deaf or hard of hearing. We think families need access to good information that’s free from a sponsoring agenda or ideology.
To find your local chapter, go to:

www.handsandvoices.org

Find us on:

Free App

Parent Advocacy App for Deaf or Hard of Hearing

copyright © Hands & Voices 2016
WHAT WE HAVE LEARNED

• Common ground; common goals
  • All children and families deserve access to supports and services
  • All children should be on par with hearing peers; kindergarten ready
• Listen to each other, and get to know each other!
• Assume best intent
• Don’t be afraid to have hard conversations
OUR FUTURE TOGETHER

- Collaborative training for Child Development Watch to train Super Counselors
- Standardized resources and messages for families
- Enhancements to screening to detect late onset hearing loss
- Fix asymmetric access to resources in our urban and rural counties
THE TAKEAWAYS FOR FAMILIES

• Expect fast action! 1-3-6 requires hustle!

• Expect (Require? Demand?) all professionals to collaborate and communicate with you and each other

• Expect information sharing; provide appropriate releases to allow stakeholders to communicate with each other

• Expect to feel comfortable and supported by all members of your team

• Expect all members of your team to be on the same page with your goals