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

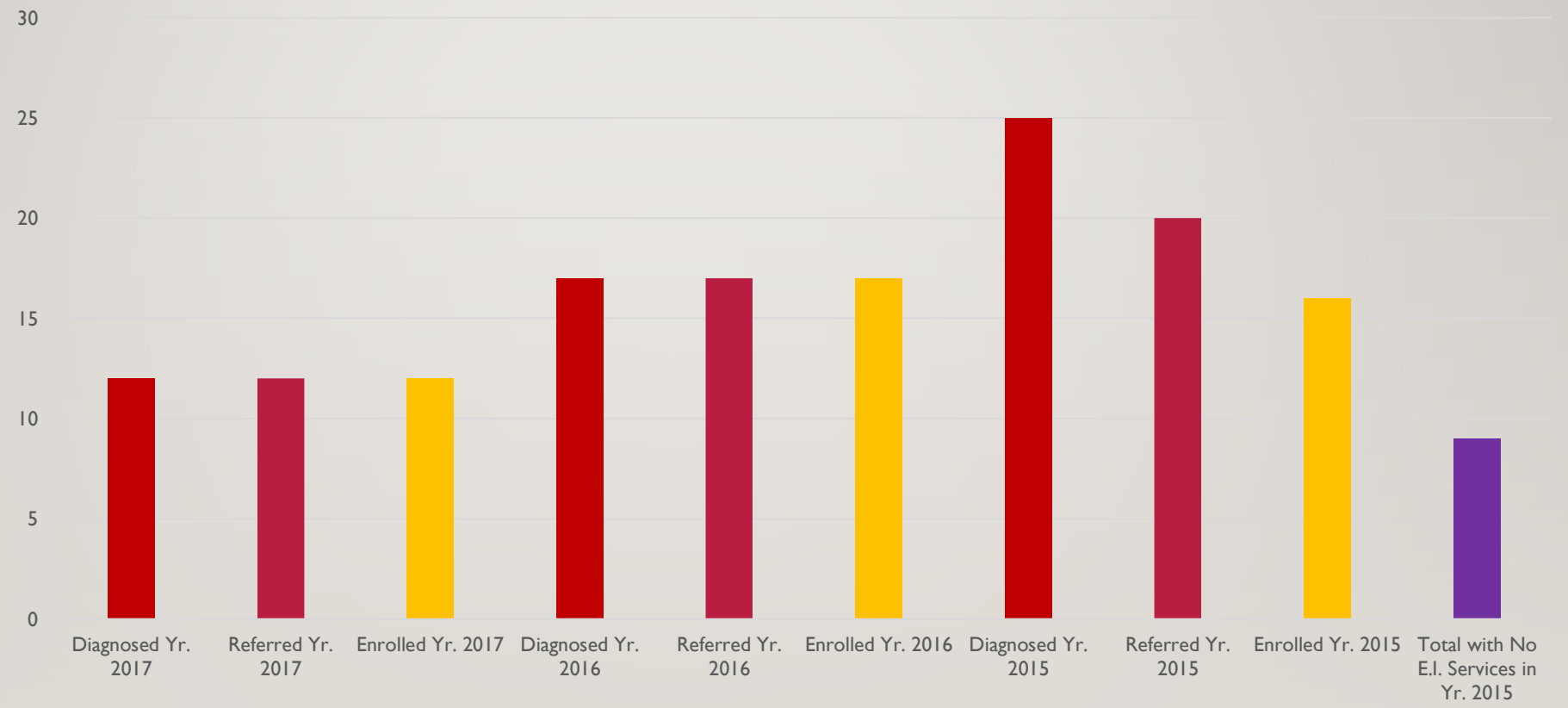
AGENDA

- 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

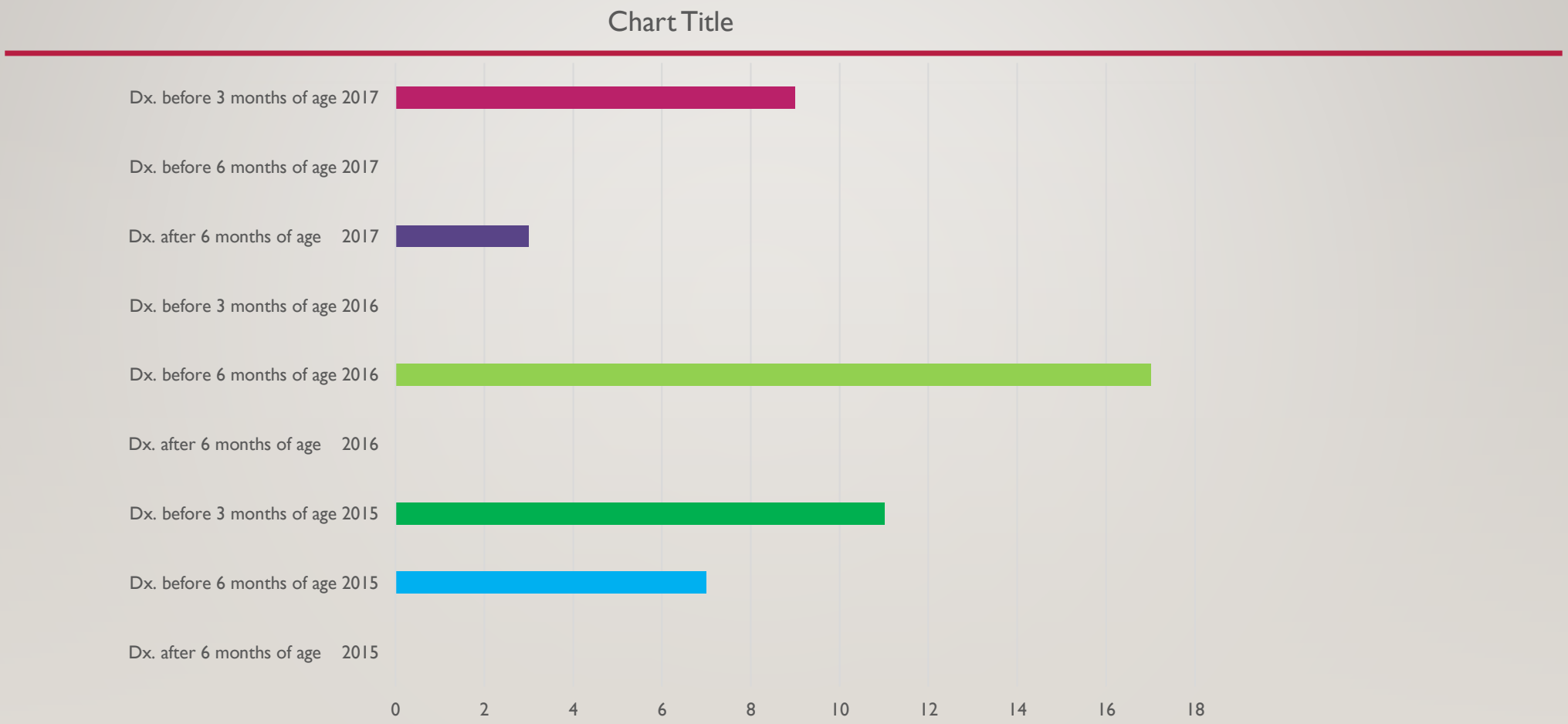
NEWBORN HEARING SCREENING (ISABEL)

- 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

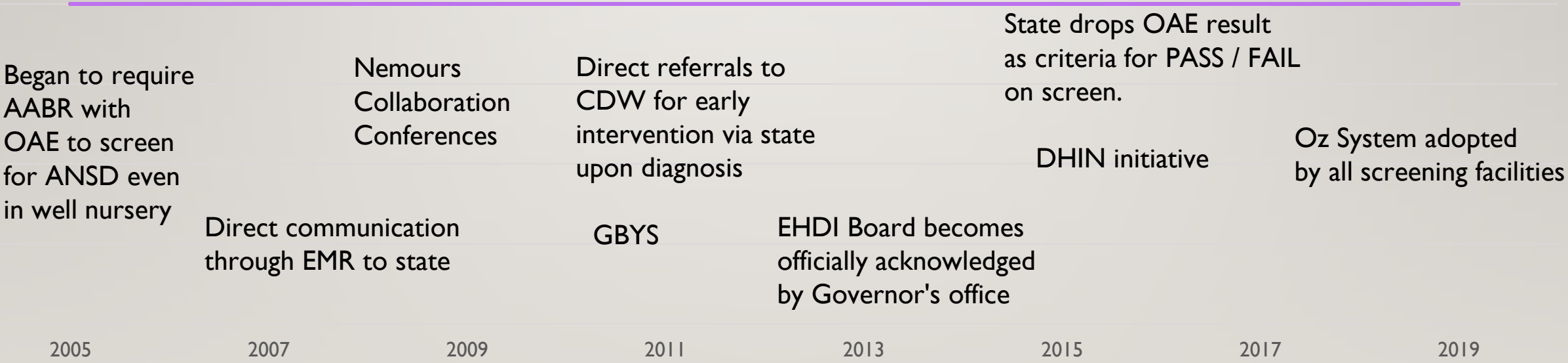


NEWBORN SCREENING PROGRAM (ISABEL) DIAGNOSED



IMPROVING COMMUNICATION AND MEETING THE 1-3-6 BENCHMARK FOR TIMELY IDENTIFICATION OF HEARING LOSS IN DELAWARE

Nemours duPont Hospital for Children ◀▶ DE State Department of Health



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

Nemours | Alfred I. duPont Hospital for Children
Nemours Children's Clinic

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 2nd failed screen (1st 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!

5 per 1,000 children	CDC's National Health Interview Survey, 1997-2005 [Read article]	3-17 years of age
1.4 per 1,000 babies screened (range 0 – 4.6 per 1,000 screened)	CDC's Hearing Screening and Follow-up Survey, 2009 [Data table]	Babies

Rate of HL increases 3 times from birth to later in childhood!

CLASS A RISK FACTORS

Infections (CMV, herpes, rubella, syphilis, toxoplasmosis)
Head malformations
Diagnosis of any syndrome
Head trauma or temporal bone fracture
Confirmed bacterial or viral meningitis
Hyperbillirubinemia requiring blood transfusion
ECMO assisted ventilation:
Chemotherapy or ototoxic exposure
Class A – Retest every 3 months initially

CLASS B RISK FACTORS

Family history of permanent hearing loss in childhood
NICU stay longer than 5 days
Physical findings such as white forelock, abnormal head size, etc
Mycin or diuretics
Diagnosis of any neurological problem
Mechanical ventilation:
Class B – Behavioral test at 9 months

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)

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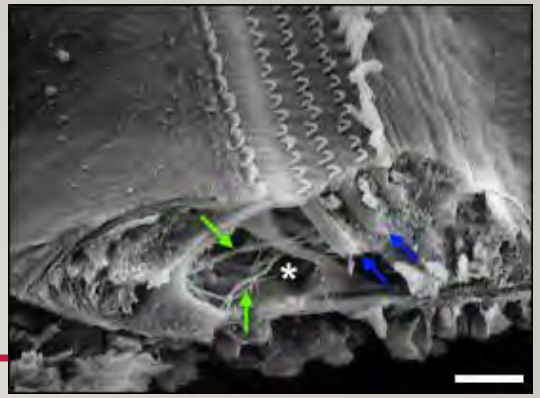
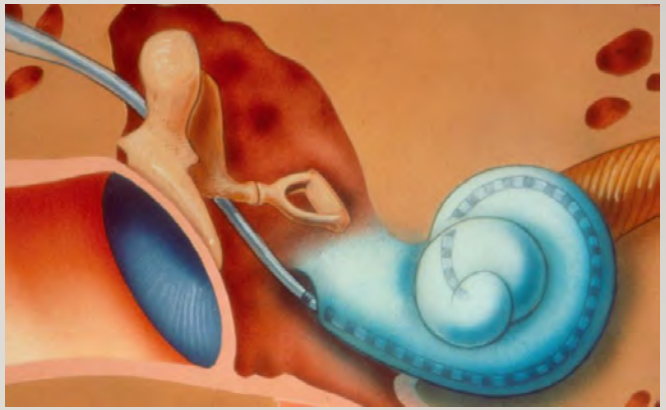
Nemours Children's Clinic

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

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 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 Onsite D/HH/DB

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

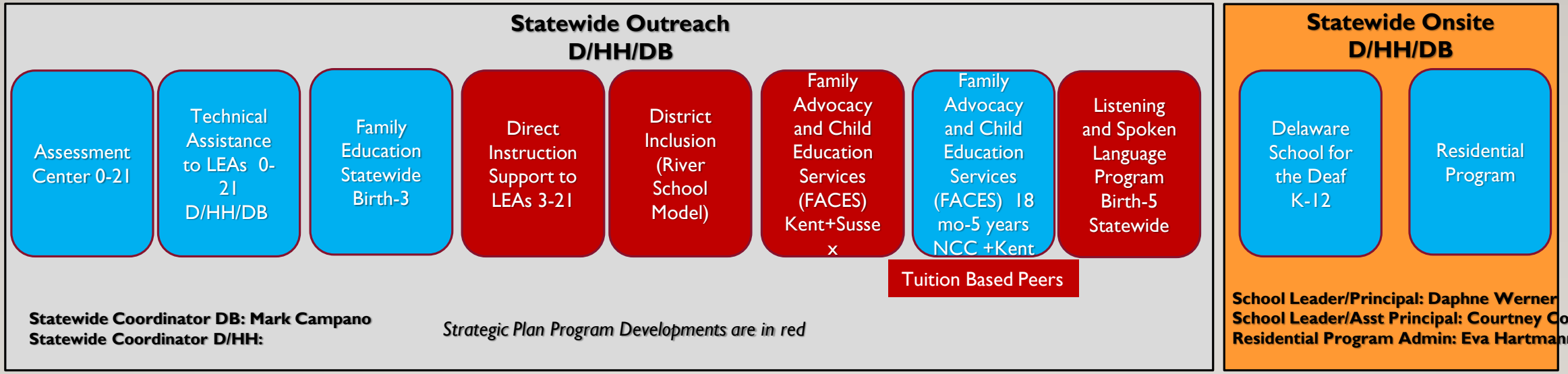
School Leader/Principal: Daphne Werner
School Leader/Asst Principal: Courtney Cooper
Residential Program Admin: Eva Hartmann

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



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

HANDS & VOICES™

Delaware Families for Hands and Voices

"What works for your child is what makes the choice right"

www.delawarehandsandvoices.com

ADVOCACY SUPPORT & TRAINING™

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.

GUIDE BY YOUR SIDE™

Hands & Voices Chapters

For info on a H&V chapter near you click a location marker on the maps below.
Stars indicate full chapters and dots represent start-up / provisional chapters.

Parent Advocacy App for Deaf or Hard of Hearing

NAD

HANDS & VOICES

AMERICAN SOCIETY for DEAF CHILDREN

GALLAUDET UNIVERSITY

LAURENT CLERC NATIONAL DEAF EDUCATION CENTER

Free App

To find your local chapter, go to:

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Find us on:

YouTube

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