

# THE WHO, WHAT, AND HOW OF EHDI LEARNING COMMUNITIES

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# Universal Newborn Hearing Screening and Intervention (UNHS) Program Updates

## Data Collection and Reporting Timeline

- Learning Community Impact Measures
- Initial Written Learning Community Report
- Non-Competing Continuation Progress Report

## Care Coordination

- A minimum of two care coordination technical assistance webinars
- Defining care coordination and care coordination plans



# UNHS Learning Community Overview

**Purpose:** Increase the knowledge and engagement of pediatric health care professionals and families within the EHDI system to assure that d/hh children are identified through newborn/infant hearing screening, receive evaluation, diagnosis, and appropriate intervention that optimize their language, literacy and social-emotional development.

**Participants:** Pediatric health care professionals from various organizations, clinicians, care coordinator, and a family member of a d/hh child(ren).



# UNHS Learning Community Focus Areas

## Focus Areas:

1. *JCIH 1-3-6 timeline*
2. *Significant risk factors for late-onset early childhood hearing loss*
3. *Peer to peer information sharing*
4. *Improving care coordination through the patient centered home family model*
5. *Partnering with state/territory Title V CYSHCN program*



# UNHS Learning Community Focus Areas

## Focus Areas (cont'd.):

6. *Providing family centered care*
7. *Developing collaborative leadership skills for members of family organizations*
8. *Engaging and including family partners in the child's health care*
9. *Developing possible strategies to link or integrate data systems*



# The Goal of the EHDI Learning Community

**To assist the EHDI program's in increasing the knowledge and engagement of EHDI stakeholders ...**

**to improve outcomes of children who are DHH ...**

**as measured by:**

30% increase in # diagnosed before 3 months of age

25% increase in # referred to EI before 6 months of age.

20% increase in #enrolled in EI services before 6 months of age.

## Topics addressed by the Learning Community will include:

1. JCIH 1-3-6 timeline recommendations
2. Risk factors for late-onset hearing loss
3. Peer to peer information sharing among participants
4. Improving care coordination for children who are DHH
5. Partnering with Title V CYSHCN programs on systems integration and family centered care coordination
6. Providing family-centered care that is culturally competent
7. Developing collaborative leadership skills for members of family organizations
8. Engaging family partners and pediatric clinicians
9. Linking newborn hearing screening data to programs such as vital records, immunization, and blood spot screening.

# Timelines for EHDI Learning Community

- September 30, 2017: LC organized and first meeting held
- April 1, 2018 and annually thereafter: Written report to MCHB about previous year's activities
- Every 6 months beginning September 30, 2018: Written report to MCHB about behavioral measures being identified by MCHB



# Logistics for the EHDI Learning Community

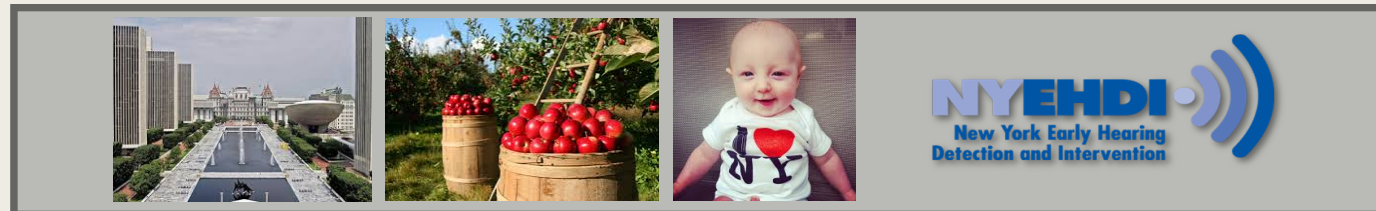
- How people are recruited makes a difference
- Group must be large enough to be inclusive, and small enough to be effective
- At least one in-person meeting is important for group cohesion and progress
- Not everyone will be equally committed or involved in all issues addressed by the Learning Community, but everyone needs to be committed to the overall goal
- At least one pediatric primary care provider must be included who is willing to provide data during years 2 and 3 about services provided to children who are DHH in his or her practice

# Tips for a Successful EHDI Learning Community

- Shared Values and Vision
- Collective Responsibility
- Reflective Professional Inquiry
- Collaboration
- Group and Individual Learning
- Mutual trust, respect and support
- Inclusive Membership
- Flexibility

# New York: Learning Collaborative Quality Improvement Initiative

- Lori Iarossi, EHDI Coordinator - [lori.iarossi@health.ny.gov](mailto:lori.iarossi@health.ny.gov)
- Alexandra Hamburg, Follow-Up Coordinator
- Marilyn Kacica, MD, MPH Medical Director, Division of Family Health
- Donna Noyes, PhD Co-Director, Bureau of Early Intervention (BEI)
- Kirsten Siegenthaler, PhD MSPH, BEI
- Pat Heinrich, RN, MSN– National Institute for Children’s Health Quality (NICHQ) QI Advisor
- Emma Hopkinson – NICHQ Project Specialist



# Best Practices



## ***Phase 1***

- Standardize the process for documentation of all newborn screening results in the hospital records
- Document and report the hearing screening results accurately to the NYEHDI program via the birth certificate
- Standardize communication with parents about newborn hearing screening results
- Identify the PCP/Audiologist before/at discharge

## **Phase 2**

- Schedule a follow-up appointment at the time that the infant does not pass the screening—before the family leaves the hospital— and stress its importance. Document the appointment in the EHR or tracking spreadsheet.
- Call the family before the diagnostic audiology appointment to verify the appointment time and place and include the reasons why the appointment is important.
- Use a fax-back form at the time of diagnostic evaluation to alert the PCP of the results and need for follow-up
- Use fax-back forms between all parts of the care continuum (audiology, PCP, specialists, early intervention)

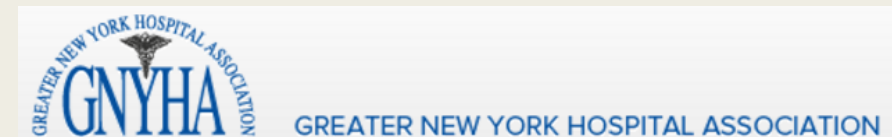
# Who?

## Recruitment Process

1. EHDI Program
2. NICHQ Advisors
3. Guidance Team (12 members)
  - Healthcare Association of New York State (1)
  - Greater New York Hospital Association (1)
  - Parent Representatives (2)
  - Representative of the Deaf Community (1)
  - Pediatrician (1)
  - Pediatric Otolaryngologist (1)
  - Speech Language Pathologist (1)
  - Audiology Professor (1)
  - Audiologist (2)
  - Early Intervention Official (1)
  - Early Intervention Provider (1)
- 16 Hospital Teams
  - Newborn Hearing Screening Manager
  - Birth Registrar
  - Audiologist



Healthcare Association of New York State  
Advocacy · Analysis · Education



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# How?

## **Learning Collaborate Framework**

1. Recruitment Process

2. Pre-Work package

- Describes Purpose, Goals and Benefits
- Describes Pre-work (formation of team, data submission process, QI process and PDSA cycles, development of AIM statement)
- Outlines Participant and EHDI Program roles
- Participant forms
- Storyboard template for sharing

3. Three In-person Learning Sessions – Share Storyboards

4. Monthly Coaching Webinars – Share PDSAs

5. Monthly One-on-one technical assistance calls – Discuss PDSAs

6. Informational Listserv for sharing and disseminating information

7. Celebration of Success at completion



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# What?

## **NYS Learning Collaborative 2015-2016**

### **Project Aim**

- Phase 1: Improve newborn hearing screening and follow-up outcomes
- Phase 2: Improve care among all providers that perform hearing screening and follow-up for infants.

The focus of these efforts over the past two years was to reduce loss to documentation (LTD) of initial and follow up hearing disposition for all infants in NYS by 5%.



# Data Reports

| Hospital Name                  | 2013 Annual Births | Missing Results For Reporting Period | August 2014 | September 2014 | October 2014 | Three Month Total |
|--------------------------------|--------------------|--------------------------------------|-------------|----------------|--------------|-------------------|
| ST LUKES ROOSEVELT RVLTV DV    | 6239               | 1387                                 | 100.00%     | 96.54%         | 76.55%       | 90.71%            |
| BROOKLYN HOSP CENTER           | 2282               | 467                                  | 93.97%      | 56.72%         | 87.83%       | 79.29%            |
| GOOD SAMARITAN HOSP SUFFERN    | 3064               | 434                                  | 60.29%      | 56.72%         | 55.14%       | 57.56%            |
| JAMAICA HOSPITAL MEDICAL CTR   | 2313               | 277                                  | 39.32%      | 49.13%         | 45.87%       | 44.32%            |
| MONTEFIORE NORTH (OLM)         | 2525               | 246                                  | 70.37%      | 21.97%         | 20.27%       | 37.22%            |
| MAIMONIDES MEDICAL CENTER      | 8494               | 228                                  | 10.51%      | 11.44%         | 8.24%        | 10.08%            |
| BETH ISRAEL MED CTR PETRIE CMP | 3877               | 197                                  | 22.75%      | 11.55%         | 22.12%       | 19.00%            |
| JACOBI MEDICAL CENTER          | 2385               | 195                                  | 29.73%      | 28.80%         | 20.63%       | 26.64%            |
| WINTHROP UNIVERSITY HOSPITAL   | 4833               | 161                                  | 13.90%      | 14.22%         | 8.86%        | 12.47%            |
| QUEENS HOSPITAL CENTER         | 1737               | 143                                  | 62.35%      | 15.44%         | 9.15%        | 30.30%            |
| LI JEWISH MEDICAL CENTER       | 6566               | 134                                  | 3.06%       | 12.46%         | 4.72%        | 6.74%             |
| BRONX-LEBANON CONCOURSE DIV    | 2236               | 121                                  | 18.27%      | 19.34%         | 24.56%       | 20.47%            |
| NY PRESBYTERIAN HOSP ALLEN PVL | 2044               | 120                                  | 4.74%       | 16.08%         | 38.73%       | 20.24%            |
| CROUSE HOSPITAL                | 3902               | 113                                  | 12.43%      | 7.95%          | 13.38%       | 11.15%            |
| ARNOT OGDEN MEDICAL CENTER     | 1405               | 106                                  | 3.01%       | 6.67%          | 84.40%       | 27.04%            |
| NYU MEDICAL CENTER             | 4768               | 105                                  | 15.72%      | 1.85%          | 4.20%        | 7.17%             |
| WOMEN AND CHILDREN'S HOSPITAL  | 2912               | 95                                   | 9.63%       | 13.04%         | 15.13%       | 12.48%            |
| NY DOWNTOWN HOSPITAL           | 2340               | 93                                   | 21.43%      | 14.89%         | 11.00%       | 15.68%            |
| BROOKDALE HOSPITAL MED CTR     | 1240               | 83                                   | 39.83%      | 36.96%         | 1.90%        | 26.35%            |
| LENOX HILL HOSPITAL            | 4159               | 82                                   | 8.24%       | 7.37%          | 6.55%        | 7.41%             |
| METROPOLITAN HOSPITAL CENTER   | 1167               | 82                                   | 42.35%      | 16.30%         | 29.25%       | 28.98%            |
| HARLEM HOSPITAL CENTER         | 1020               | 75                                   | 25.27%      | 25.51%         | 36.49%       | 28.52%            |
| BELLEVUE HOSPITAL CENTER       | 1251               | 74                                   | 15.75%      | 18.05%         | 19.85%       | 17.83%            |
| CITY HOSPITAL CENTER ELMHURST  | 3314               | 65                                   | 8.21%       | 5.51%          | 10.42%       | 8.01%             |
| NY PRESBYTERIAN HOSP           | 5784               | 63                                   | 5.41%       | 3.32%          | 3.98%        | 4.25%             |
| NASSAU UNIVERSITY MEDICAL CTR  | 1473               | 62                                   | 16.94%      | 14.41%         | 18.25%       | 16.67%            |
| ST BARNABAS HOSPITAL           | 1194               | 59                                   | 27.37%      | 14.14%         | 19.39%       | 20.21%            |
| SAMARITAN MEDICAL CENTER       | 1748               | 57                                   | 10.00%      | 14.97%         | 9.38%        | 11.47%            |
| STRONG MEMORIAL HOSPITAL       | 2991               | 51                                   | 7.61%       | 4.88%          | 7.89%        | 6.80%             |



# Recruitment Letter

The learning collaborative model that we are planning to initiate is an evidence-based practice shown to result in sustained positive change. The benefits of participating include training, technical assistance, resources and tools provided by national and state experts. A participating facility will assemble teams that will work together internally and with teams from other hospitals for nine to twelve months.

We hope that your hospital will take advantage of this opportunity to improve hearing outcomes. To learn more about this QI initiative, please join us for one of two scheduled Informational calls which will provide a project overview, an opportunity to meet the project team from the Department, learn about the learning collaborative model and ask questions.

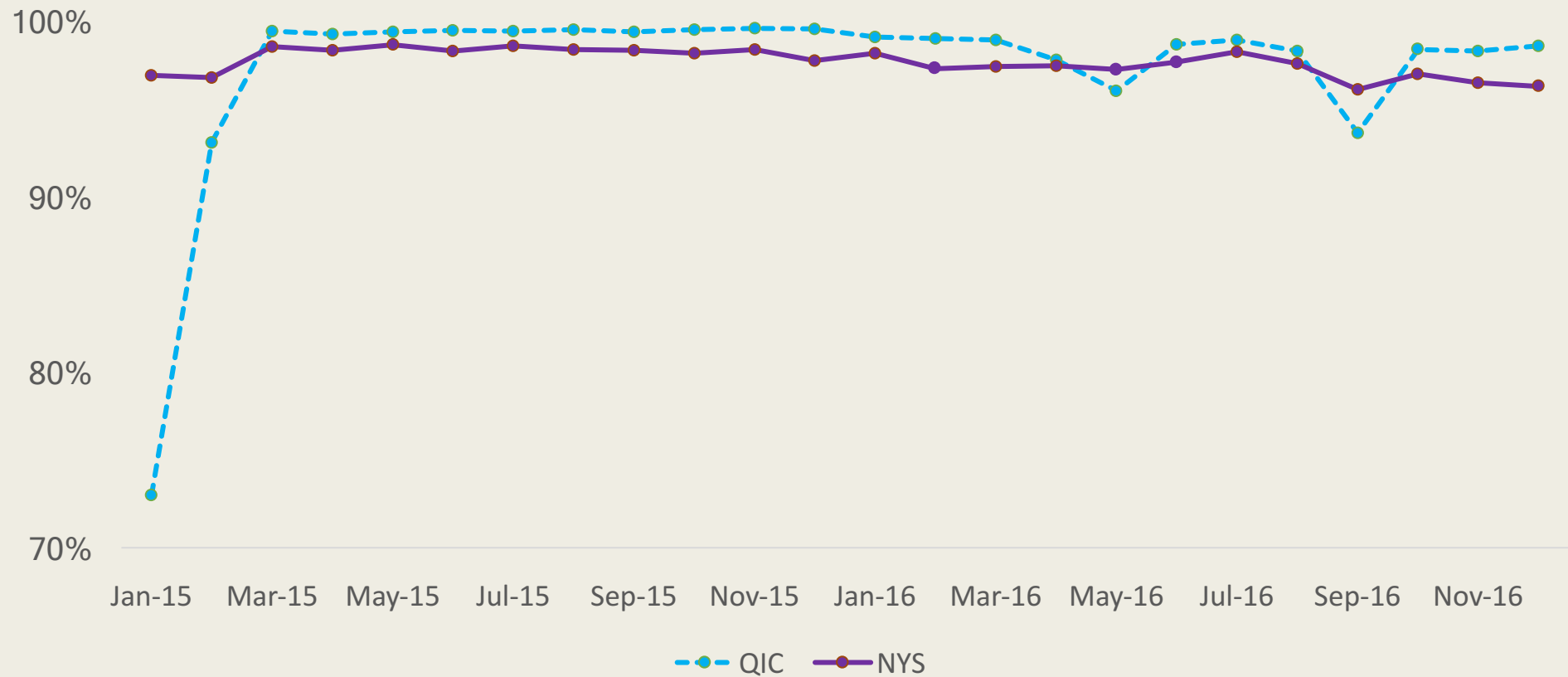


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# Phase 1 Results



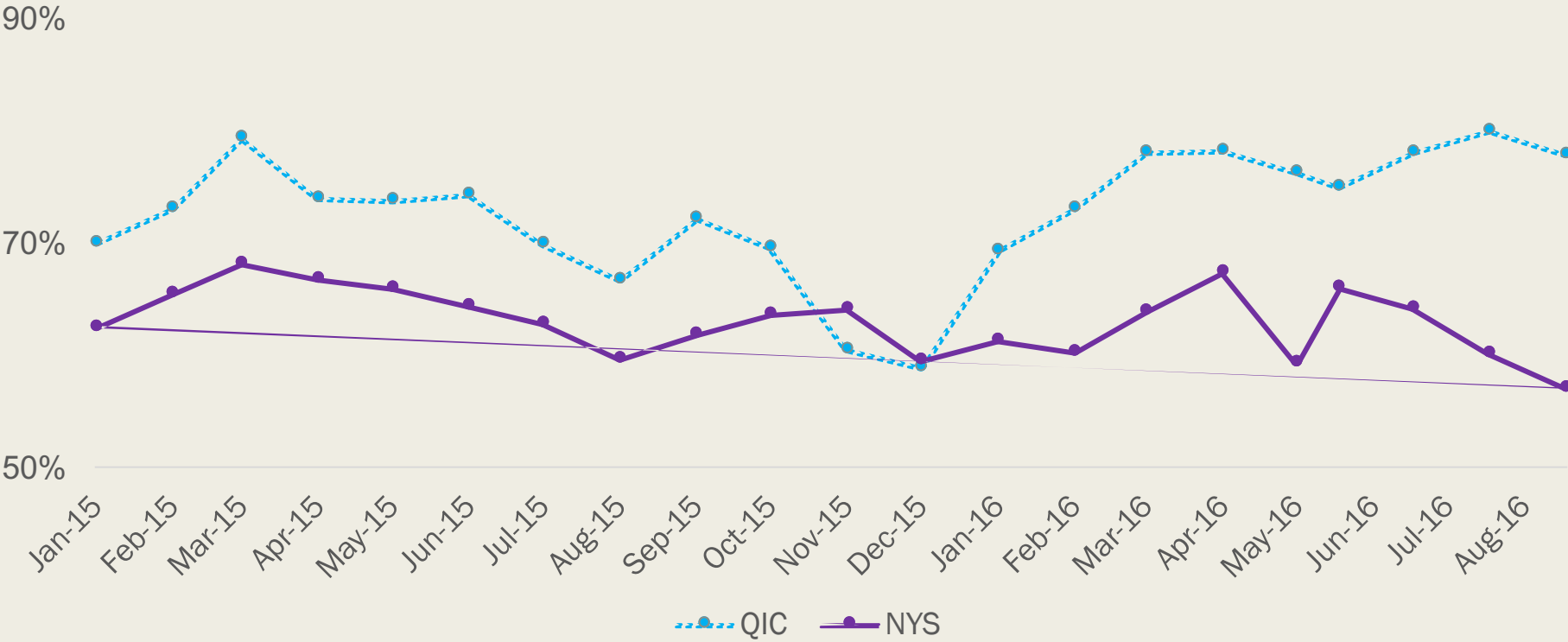
Percent of Infants with Initial Hearing Screening Disposition  
January 2015 - December 2016



# Phase 2 Results



Percent of Infants with Follow-up Hearing Screening Disposition  
January 2015 - December 2016



# Challenges/Lessons Learned

## Challenges

- Obtaining Executive Level Support at hospital
- Teamwork and collaboration across departments
- Dedicated work to understand the NYSDOH reporting requirements
- Discover the documentation process at hospitals
- Special situations
  - ✓ *Infants in the NICU*
  - ✓ *Infants who transfer to other hospitals*
- *Identifying Referral Providers not documented in EHDI-IS*

## Lessons Learned

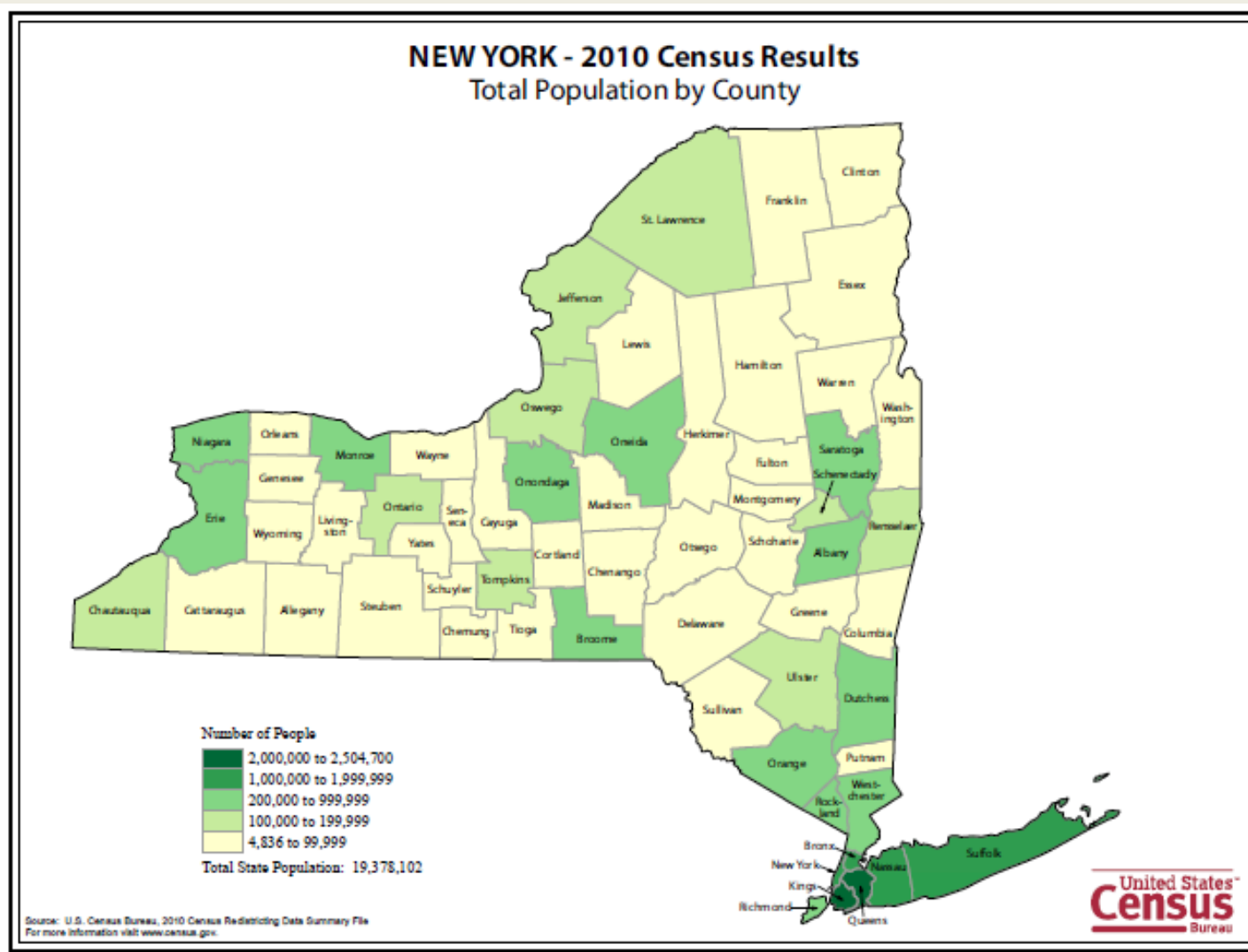
- Keep number of hospitals in QIC to a manageable number (16 was good for NYS)
- Communication and Feedback to hospitals is crucial to engagement
  - ✓ Coaching calls
  - ✓ In-person Sessions
  - ✓ Monthly data reports
- Engage experts such as NICHQ
- Enhance EHDI-IS to include transfers and referral providers
- Hospitals that built an informed team committed to this project achieved early and sustained success.



# Learning Community 2017-2018

## Buffalo Region

- 13 Birthing Facilities
- 16 Pediatric Audiologists
- 2 Family Support Organization  
Regional Offices
- AAP Chapter Champion
- University Center of Excellence in  
Development  
Disabilities (UCEDD)
- Erie County Local Early  
Intervention  
Coordinating Council (LEICC)
- 1 School for the Deaf
- 8 Early Intervention County  
Officials
- 7 Early Intervention Providers
- ~800 Pediatricians
- >3,000 Family Practice  
Physicians
- Early Head Start



# Maryland

Tanya D. Green, M.S., CCC-A

Program Chief, Maryland Early Hearing Detection and Intervention

Office for Genetics and People with Special Health Care Needs

Maryland Department of Health and Mental Hygiene

Prevention and Health Promotion Administration



# INTRODUCTION

**Maryland EHDI (MD EHDI) Program's plan for development and implementation of Learning Communities as required by the current HRSA grant (17-059):**

## **Beginning Stages and Plan**

- Build upon prior successes in quality improvement
- Include network of partners and collaborators at the state and regional levels
- Work to improve the leadership and collaborative infrastructure for EHDI system improvements in order to achieve timely identification and EI referral/enrollment of infants
- Work to improve family engagement and leadership in the system of care

# MISSION AND VISION

## MISSION

The mission of the Prevention and Health Promotion Administration is to protect, promote and improve the health and well-being of all Marylanders and their families through provision of public health leadership and through community-based public health efforts in partnership with local health departments, providers, community based organizations, and public and private sector agencies, giving special attention to at-risk and vulnerable populations.

## VISION

The Prevention and Health Promotion Administration envisions a future in which all Marylanders and their families enjoy optimal health and well-being.



# Who

## Project Team Leaders

- MD EHDI Project Director: Tanya Green, Maryland Department of Health and Mental Hygiene
- PPMD Project Director: Rene Averitt-Sanzone, Executive Director, Parents' Place of Maryland
- Family Engagement Coordinator: Cheri Dowling, PPMD
- Learning Community Coordinator: Stacy Taylor, PPMD
- Content Expert: Debbie Badawi, MD, University of Maryland (UMD) Division of Behavioral & Developmental Pediatrics and MD EHDI AAP Chapter Champion

## Partnerships

Collaborative relationships already existed among the partners in this project.

- Maryland EHDI Program
- Parents' Place of Maryland (PPMD), the statewide F2F
- University of Maryland, School of Medicine

## Partnerships

*Learning Community members will strengthen bonds and expand their reach to improve service delivery in a way that will reduce barriers to screening, diagnosis, and referral, increase access to medical homes, and engage families in the EHDI process to improve outcomes for Maryland babies who are identified as deaf or hard of hearing.*

# Who

## Learning Community Members

*Learning community members were selected based on HRSA FOA guidance, their position, experience in engaging with the populations to be served, and/or their prior experience working with learning communities. Learning community members are being selected from some of the following organizations:*

- The Maryland EHDI Program
- The Parents' Place of Maryland
- University of Maryland (UMD) Division of Behavioral & Developmental Pediatrics
- Maryland's Title V-CYSHCN program
- The state chapter of the American Academy of Pediatrics
- The state LEND Program
- State/community agencies
- Private/public providers
- Public education agencies including early intervention
- The *Maryland Parent Connections* parent to parent mentor program
- Paid parent partners who will provide resource navigation to families of children who are deaf or hard of hearing

# What

The focus of the learning community is to engage health care professionals, families, and other stakeholders.

Partners will work with the Maryland EHDI Program on Quality Improvement strategies that will allow all participants to effectively contribute to and participate in the EHDI system to improve outcomes for Maryland babies who are identified as deaf or hard of hearing.

# What

- Develop curriculum and timelines for the Learning Community
- Develop data collection tools and systems to evaluate behavioral change among learning community participants
- Obtain feedback on materials
- Obtain CEUs for participants in the learning community
- Recruit 5 primary care practices per cohort (2 cohorts) for the learning community
- Recruit community stakeholders and families of children who are deaf and/or hard of hearing to participate in the learning community
- Recruit and train Parent Partners to be paired with primary care practices
- Share goals of the project with learning community partners
- Provide technical assistance to partners who need to improve in their area of the 1-3-6 EHDI process
- Report learning communities' progress to HRSA

# How

- Learning Community structure
- Frequency of meetings
- Assigned meeting facilitator
- EHDI Coordinator involvement in the Learning Community
- Family engagement strategies
- Family involvement in the Learning Community
- Provider engagement and involvement

# Next Steps & Lessons Learned

Lessons Learned/Shared Experiences from participants in multiple, previous learning collaboratives with focus on patients with epilepsy and/or autism:

- Take advantage of **relationships** that are already in place.
  - *Be careful not to reinvent the wheel by trying to form new partnerships.*
- Be **detailed** in your work.
- **Document** your steps so you can duplicate them.
- Be extremely **organized**.
- “A level of trust and good working relationships are imperative, particularly when working with parents of children who have special health care needs.” Stacy Taylor

## Special Thanks

*A special thanks goes to Josie Thomas, retiring executive director of the Parents' Place of Maryland, Debbie Badawi, M.D., Stacy Taylor and the many others who worked extensively on the Learning Collaborative that served as the strong foundation for this current project and who contributed to this presentation.*



# NEBRASKA

## Nebraska Early Hearing Detection & Intervention Program Tele-Audiology Learning Community

### NE-EHDI Team:

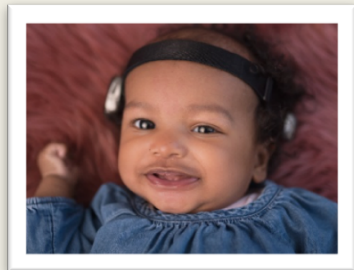
Brenda Coufal, Program Manager

Jim Beavers, Business Analyst

MeLissa Butler, Community Health Educator Senior

Gabby Tachenko, Audiology Student/Community Health Educator (part-time)

Shelli Janning, Guide By Your Side/Community Outreach Coordinator (part-time)



# Leader & Members of the Learning Community

## LEADER - NE-EHDI

## MEMBERS -

### ***Western Nebraska:***

- Educational Service Unit (ESU) #13
- Audiology Clinic in western Nebraska
- Parents
- NE-Liaison – Deaf & Hard of Hearing – ESU #9

**(Why Involved:** Know the people, understand the geographical area, and need.)

### ***Audiology & Hospital Partners:***

- Boys Town National Research Hospital, Omaha NE
- Children's Hospital and Medical Center, Omaha NE
- Barkley Speech Language and Hearing Clinic, Lincoln NE

**(Why Involved:** Know what is needed to conduct audiology services and will connect with the site in Scottsbluff, NE to conduct the diagnostic evaluation.)



## Members cont...



### ***EHDI Consultants:***

- Minnesota EHDI
- North Carolina EHDI

**(Why Involved:** Already have tele-audiology established in their state so they can share their process and lessons learned.)

### ***Newborn Screening & Genetics Program:***

- Program Manager

**(Why Involved:** Interest in the program and shares expertise.)

# Focus of Learning Community

Due to data, and feedback received from families and early education providers in the area, a learning community was formed to address the need for pediatric audiology services.

- Historical data shows that 56% of infants within 200 miles of the Scottsbluff area are over 90 days for confirmatory diagnosis compared to 38% elsewhere in the state due to the lack of pediatric diagnostic facilities in western Nebraska.
- By December 31, 2017, NE-EHDI will implement tele-audiology services at Scottsbluff (western Nebraska) to improve timeliness and accessibility for pediatric audiology diagnostic evaluations.
- By December 31, 2018, the percentage of infants who receive diagnostic evaluations over 90 days will decrease from 56% to 38% that receive evaluations at the tele-audiology site.

# Measurements

- Track % of infants over 90 days for confirmatory diagnosis who live within 200 miles of Scottsbluff, Nebraska.
- Track # of days to tele-audiology evaluation for infants who live within 200 miles of Scottsbluff, Nebraska.
- Track % of infants needing diagnostic evaluation within 200 miles of Scottsbluff, Nebraska compared to the % of infants receiving tele-audiology evaluation by three months of age.

# Successes

- Established a Learning Community work group & have engaged members.
- Acquired interest for the spoke site in western Nebraska.
- Active involvement of the Pediatric Audiology Specialists.
- Found possible funding opportunities through USDA & HRSA for spoke site.
- Other State EHDI Programs with Tele-audiology programs have shared existing work plans and models.
- NE-EHDI has accurate & complete data to support the need and to monitor progress.

# Challenges & How Are We Addressing Them

- Finding a pediatric primary care physician to be a member.
- Securing funds for the project.
- Identifying the spoke site and remote end technician.
- Finding a detailed job description for the remote end technician.
- Defining established IT tele-health availability at hub and spoke sites and knowing what is needed to modify for tele-audiology.

# How is the Learning Community Structured?

- **How often do you meet?**
  - Every other month, or as needed
- **Who facilitates the meeting?**
  - MeLissa Butler, NE-EHDI Community Health Educator Senior
- **Are tasks shared across members?**
  - Yes, members volunteer based on their area of expertise.



# How are Families involved?

- **What strategies did you implement to engage families to participate in the learning community?**
  - Parents of late identified children have been recruited to share their experiences and input on issues related to late identification and delayed enrollment in early intervention services. They serve on the committee in an effort to make changes that will prevent this from happening to other children.
  - **How do you keep them engaged?**
    - Ask their opinions frequently throughout the project.
    - Ask if they want to review documents/processes.
  - **How does the work from the learning community impact families?**
- Tele-audiology services will give families in western Nebraska access to the same quality of pediatric audiology care that families have access to in the metro areas of Nebraska.

# How are Providers Involved?

- **How are you involving providers?**
  - There are several Audiologists located at the hub sites that have been actively involved with the project and will be reviewing all the processes.
  - The Audiologist in western Nebraska is helping us connect with a spoke site in Scottsbluff.
- **What strategies did you implement to engage providers?**
  - Specific questions are asked during the work group meetings that are needed to move the project forward and allows them to share their expertise.
  - They are asked to attend other meetings when their expertise is needed and they work on tasks outside of the work group meetings.
- **How do you keep them engaged?**
  - Ask for their expertise feedback through every step of the project.

# Strategies

NE-EHDI is in the beginning stages of the Tele-Audiology Project so **no strategies have been tested through PDSA cycles at this time.**

## **Strategies we plan to test:**

- 1.Utilize a work plan for tele-audiology processes and procedures.
- 2.Utilize a training model for personnel.
- 3.Provide educational materials for parents following the diagnostic appointment.
- 4.Promote availability of tele-audiology services in western Nebraska.
- 5.Review quarterly rates for diagnostic evaluation compared to the goal of diagnosis by three months of age.
- 6.Survey parents to provide feedback regarding quality of tele-audiology services, family-centered care and counseling.
- 7.Survey audiologists and tele-audiology technicians regarding what is successful and what needs improved.

# Lessons Learned

**NE-EHDI is in the initiation phase of this project so we will have many more lessons learned.**

- Working with other programs with tele-audiology has been extremely informative regarding what steps and processes are needed for the project, and their lessons learned.
- Tele-audiology is more of a public service than an opportunity for the spoke site to make money.
- It is a smoother transition to implement tele-audiology if a spoke site is selected that already conducts other telehealth services.
- It will be the responsibility of the spoke and hub sites to train staff, decide what equipment to purchase, and the billing process.

## Next Steps

- Confirm the spoke site in Scottsbluff, Nebraska.
- Continue to explore funding opportunities.
- Continue to work with IT experts.
- Develop a Work Plan and Evaluation Plan with the input of the members.
- Develop a Training Model with the input of the members.
- Complete PDSA cycles to evaluate the success of the project.

### **What advice do you have for your peers that are just starting out with their learning community?**

- Identify a learning community that helps you achieve your 1-3-6 goals.
- Pace yourself!
- Be realistic with expectations and goals.

# Questions

