Parent views on loss to newborn hearing screening follow-up and strategies to engage families in the diagnostic process

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Outline of Presentation

- Challenge of Loss to Follow-Up (LTFU)
- Participatory Action Research Model
- Stakeholder and Family Focus Groups
- WIC-EHDI Rescreening Intervention Study
- Lessons Learned & Keys to Success
- COACHing for diagnostic success

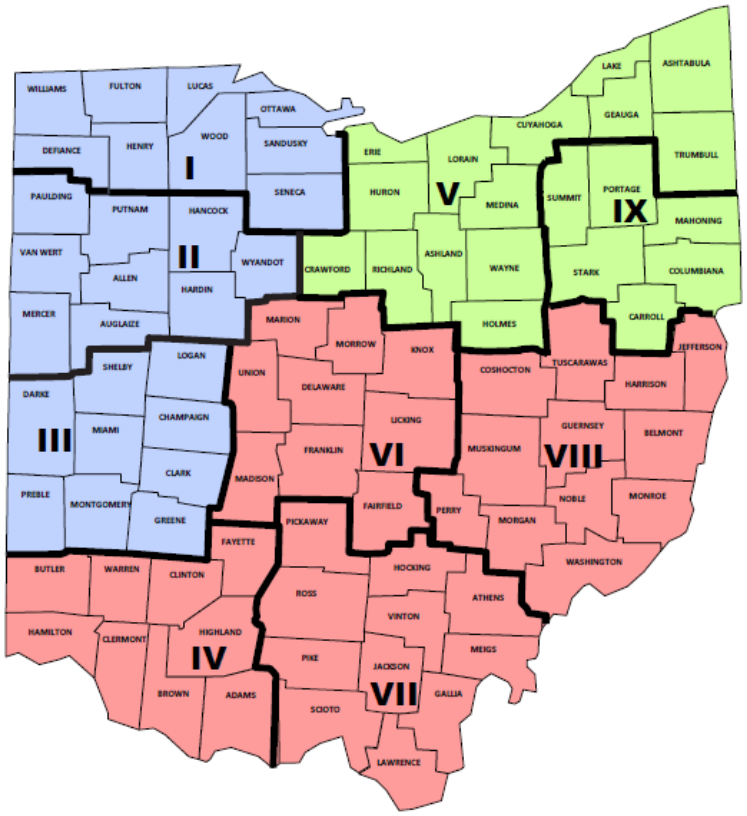
Overview and Rationale

- Congenital hearing loss is the 2nd most common birth anomaly and the most common reason for *preventable* developmental disability
- Newborn Hearing Screening (NHS) now reaches 99% of all Ohio infants, and 98% of all infants in the US (CDC, 2014)
- Unfortunately, less than 50% of infants who do not pass hearing screening receive timely diagnosis and intervention
- Lack of awareness, poor communication, barriers to care and myths about effectiveness newborn hearing screening contribute to poorer follow-up
- The WIC program provides services to >50% of Ohio families and offers a promising solution to these problems

Collaborators

- Reena Kothari, Naomi Halverson, Allyson and Anna Starr, Ohio Department of Health
- Cindy Meale, Butler County WIC
- Betsy Buchanan, Hamilton County WIC
- Wendy Steuerwald, Audiology, CCHMC
- Scott Wexelblatt, MD, Pediatrics, CCHMC
- Gina Hounam, Audiology, Nationwide Children's Hospital

Ohio NHS and EHDI Regional Infant Hearing Program (RIHP) - 2012 Data



- 139,628 Births
- 137,711 Screened (99%)
- 3945 Non Pass (3%)
- 2334 Normal Hearing (59%)
- 213 Hearing Loss (5%)
- 1398 No Diagnosis (35%)
- 1254 Lost to Follow-up (32%)

Annual CDC EHDI data

National 1-3-6 Goalposts
CDC 2013 Data

- Screened by 1 month: 96%
- Diagnosed by 3 months: 71%
- Intervention by 6 months: 68%

- Lost to follow-up at diagnosis: 34%
- Seen but no diagnosis: 42%
- Diagnosed but no doc. intervention: 34%

Participatory Action Research Project with LEND Program

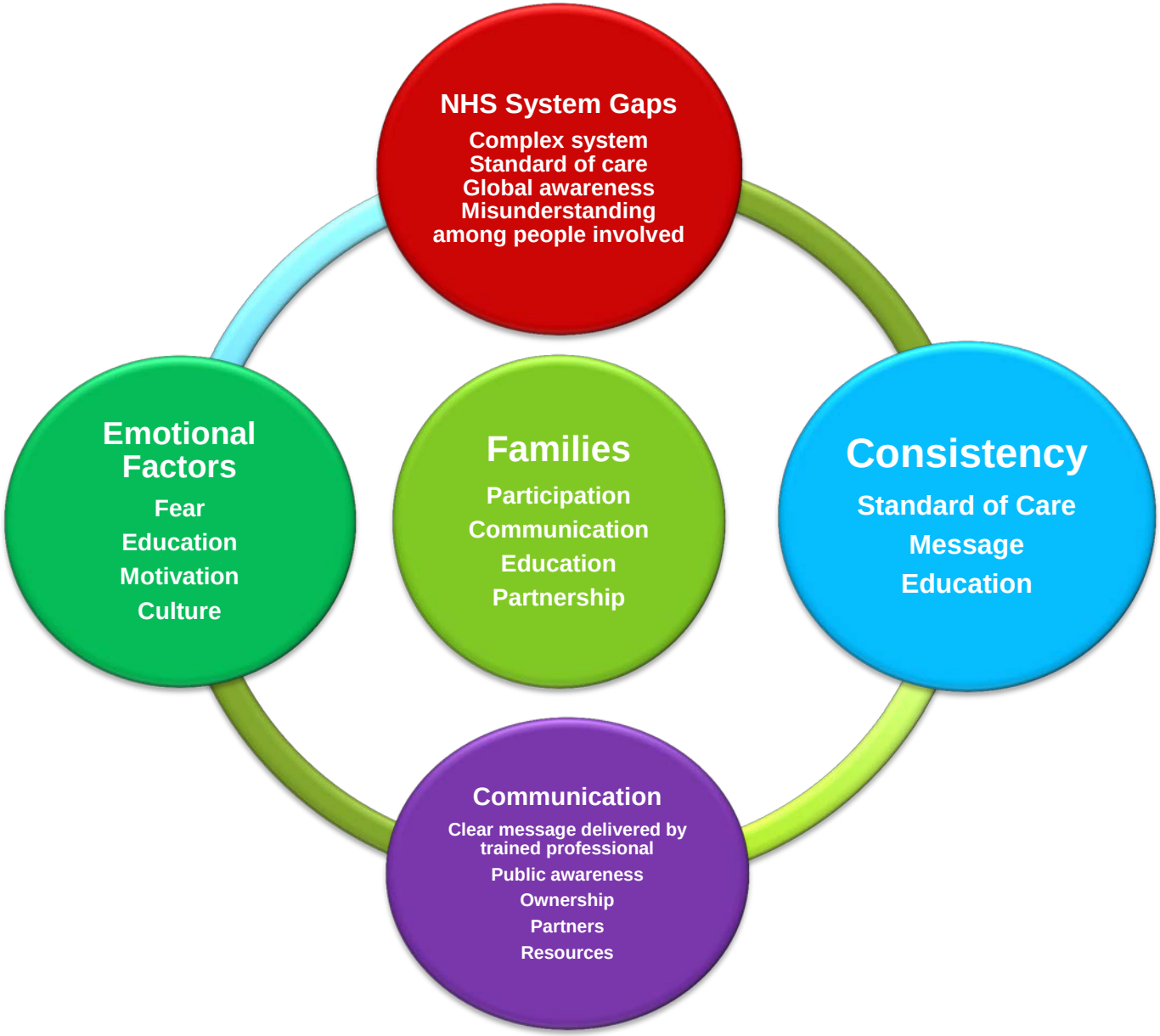
- 30+ stakeholders provided information about NHS system in Cincinnati area
- LEND fellows, Parents, audiologists, physicians, speech-language pathologists, and birth hospital screeners
- Policy partners:
    - Part C Regional Infant Hearing Program and Help me Grow
    - Ohio Department of Health
    - Women, Infant and Children (WIC) program, Hamilton County
    - Ohio Valley Voices – Oral school for Deaf children
    - St. Rita School for the Deaf

Group Level Assessment

Group Level Assessment (GLA)

- **Step One: Climate Setting**
- **Step Two: Generating**
- **Step Three: Appreciating**
- **Step Four: Reflecting**
- **Step Five: Understanding**
- **Step Six: Selecting**
- **Step Seven: Action**

Major Themes



Family Focus Group

- Butler County WIC Program in Hamilton, Ohio
- Invited all WIC participants and staff
- Regional Infant Hearing Program families
- Lunch and small gifts provided for children
- Facilitator: Lisa Vaughn, PhD, Social Psychology
- One to one activities
- Survey, Tell us Your Story, Barriers, In a Perfect World, Education and Q/A

“Tell us your story”
Family Focus Group

Reasons for Incomplete Follow-up

- Socioeconomic: Transportation, insurance, language, convenience
- Education: Understanding reasons for a failed screen and what to do, lack of support by other health providers to follow-up
- Systems: Poor integration of screening, diagnostic and intervention systems
- Variable hospital protocols: Refer rate 1% up to 15% depending on protocol and training
- Documentation: Follow-up may occur, but not be reported to state
- Significance of Result: Downplayed (may be just fluid, temporary, tests may be inaccurate)

Why WIC?

- WIC provides lactation and nutrition support to eligible lower income mothers and their children under age 5 years.
- >50% of newborns are eligible for WIC services, located close to home
- Factors associated with poorer follow-up are addressed by WIC
- Socioeconomic disparities associated with higher risk of hearing loss

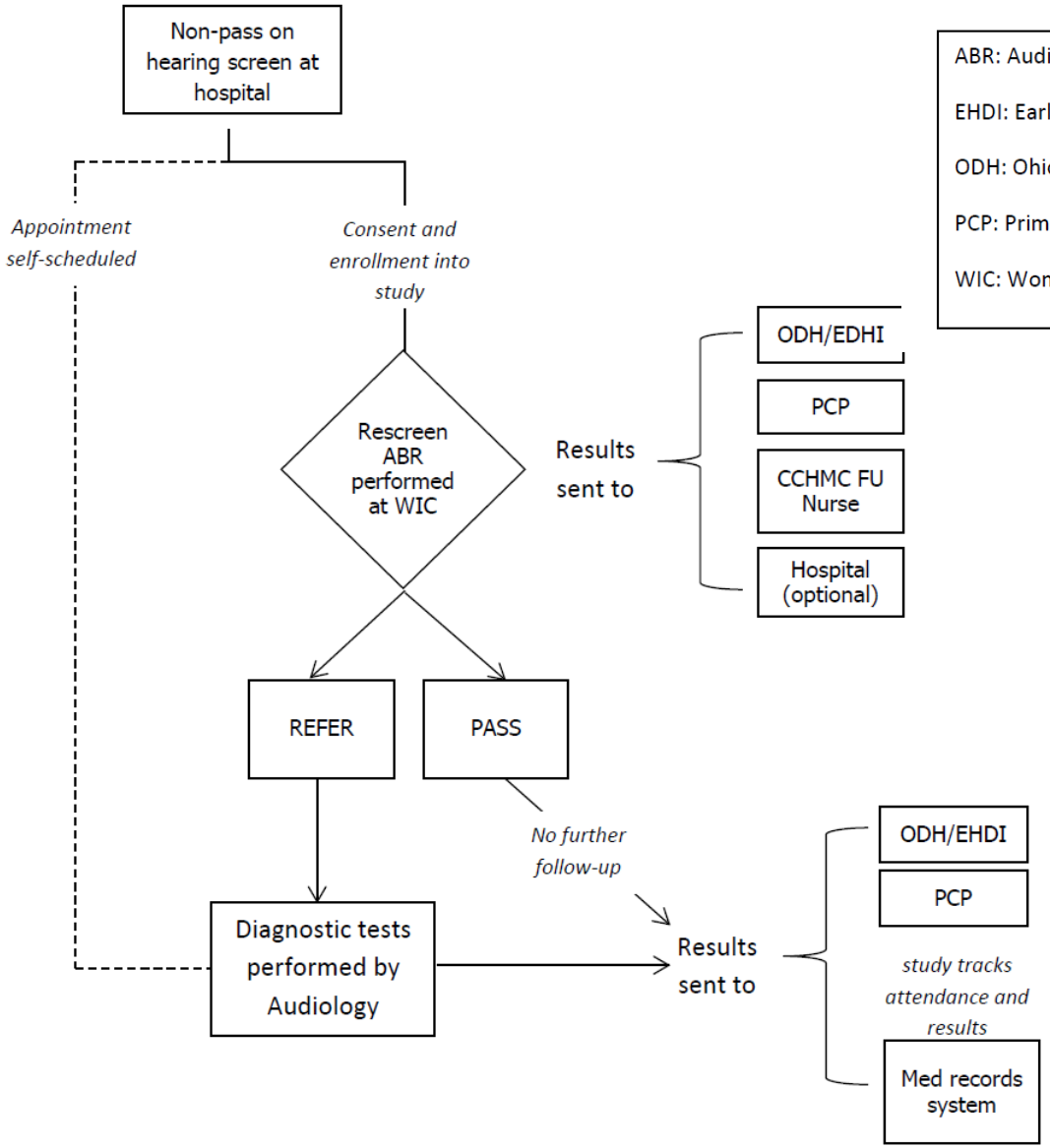
Specific Aim(s)

- Primary Aim:
  - Reduce LTFU for infants referred on newborn screening
- Secondary Aim:
  - Shorten time to first follow-up hearing test
  - Decrease “no-show” rate for hearing confirmation
- Balancing Measure:
  - No increase in time to hearing diagnosis

A-ABR Testing in WIC Clinics

- Addresses all forms of congenital hearing loss
- Trained technician can use – automatic interpretation
- While nursing or bottle feeding
- Infant in natural sleep
- No need for sedation
- Successful up to 5 mos old

Study Design and Methods



ABR: Auditory brain stem response

EHDI: Early Hearing Detection and Intervention Program

ODH: Ohio Department of Health

PCP: Primary Care Provider

WIC: Women, Infant, Children program

Case – Baby A

- Study received UNHS referral from birth hospital
- Sent study recruitment letter and followed up with phone call Mom had already made an appointment for diagnostic test. Neither mom nor baby were WIC participants, but were eligible. Suggested WIC services and supplied phone number
- One month later mom called back to say she had joined WIC and wanted to have baby rescreened as part of the study
- She had been unable to attend the audiology appointment, citing being too overwhelmed with having a newborn
- Consented, enrolled and rescreened infant the next day (at just under two months). Result: unilateral REFER on AABR
- Scheduled infant with Diagnostic Audiology within two weeks
- Infant diagnosed with moderate to severe conductive hearing loss in refer ear

Study Facilities

- **Birth Hospitals - Intervention**
  - Ft. Hamilton Hospital, Hamilton OH: ~650 births/year
  - Mercy Hospital, Fairfield, OH: ~2200 births/year
  - Good Samaritan Hospital, Cincinnati, OH: ~ 6500 births/year
  - University Hospital, Cincinnati, OH: ~ 2300 births/year
- **Birth Hospitals – Control**
  - Bethesda North, Cincinnati, OH: ~ 4200 births/year
  - Christ Hospital, Cincinnati, OH: ~ 3100 births/year
- **WIC Offices**
  - Butler County: 3 offices 5,900 caseload
  - Hamilton County: 10 offices 12,000 caseload

Outcome Measure(s)

- Percent followed up under re-screening intervention
  - WIC enrollees compared to non-WIC at same hospitals
  - Compared to control hospitals
- Percent follow-up for diagnostic testing
- Age at AABR re-screening and diagnostic test
- Age at confirmatory test
- Goal is to meet the 1-3-6 JCIH guidelines, Rescreening by 30 days

Collaboration with Ohio Department of Health

- Provided data on follow-up rates through state database
- ODH data crucial to determine if we are having a significant impact in LTFU rates and time to intervention
- Collaboration with EHDI program key to understanding system and gaps

Demographics

- African-American 38%, White 45%, Other 6%, Multiracial 11%
- Hispanic 20%
- No insurance 10%
- Mom in school 16%
- < High school 25%, GED 1%, High school 35%, Some college 32%, College 7%
- Barriers reported 17%, mostly transportation and work or school schedule

NOMBRE: _____

FECHA: _____

EXAMINADOR/A: _____

Resultados del examen del oído de su bebé

☐ **PASÓ**

Su bebé ha pasado el nuevo examen del oído (ABR) y no necesitará ninguna prueba adicional. Es una buena idea poner atención al sentido del oído de su bebé mientras crece.

☐ **REFERENCIA**

Su bebé no pasó el nuevo examen del oído (ABR) y necesitará más pruebas de diagnóstico para saber por qué no pasó ninguno de los exámenes. Por favor haga una cita con un audiólogo/a que tenga experiencia con bebés (vea el volante).

Nuestro equipo

Nuestros investigadores principales son Lisa Hunter, PhD y Scott Wexelblatt, MD. Nuestra asistente es Laura Rolfes.

Contáctenos

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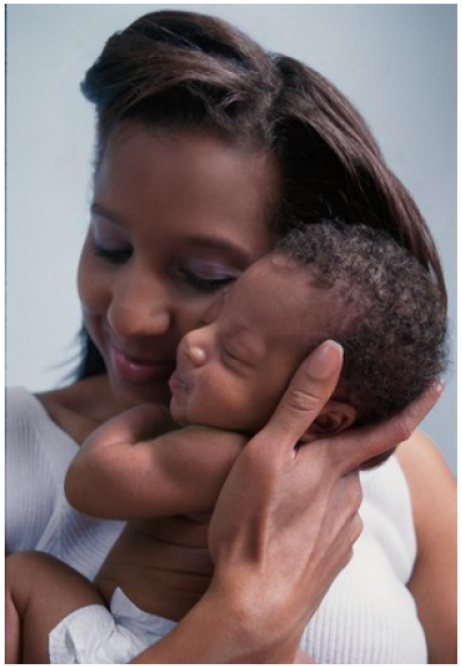
¡Para oírte mejor!
903 NW Washington Blvd.
Hamilton, OH 45013
Recruitment Brochure, Version 1

3333 Burnet Avenue | Cincinnati, OH | 45229-3039



¡Para oírte mejor!

Estudio de investigación patrocinado por el Hospital de Niños de Cincinnati

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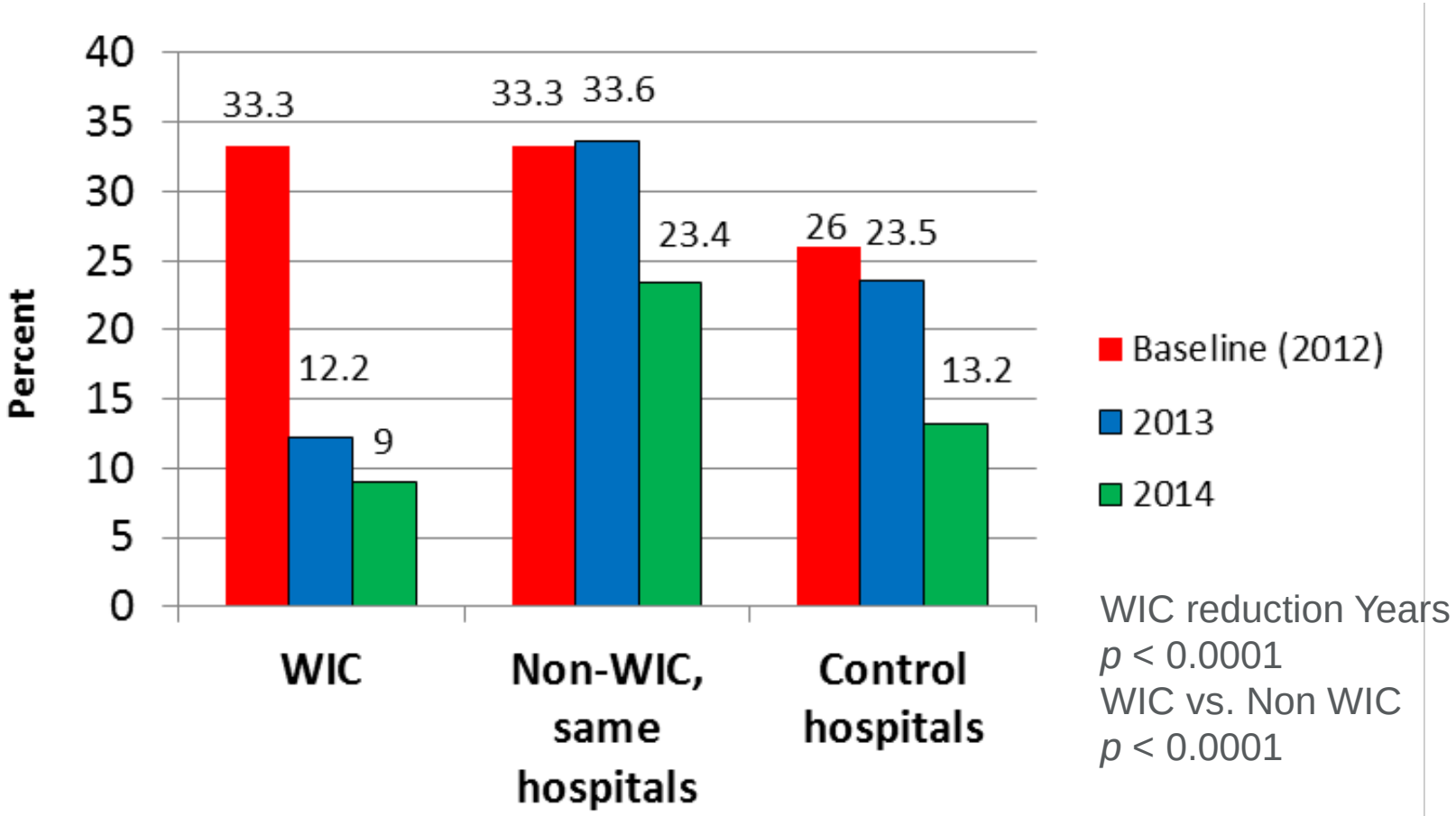
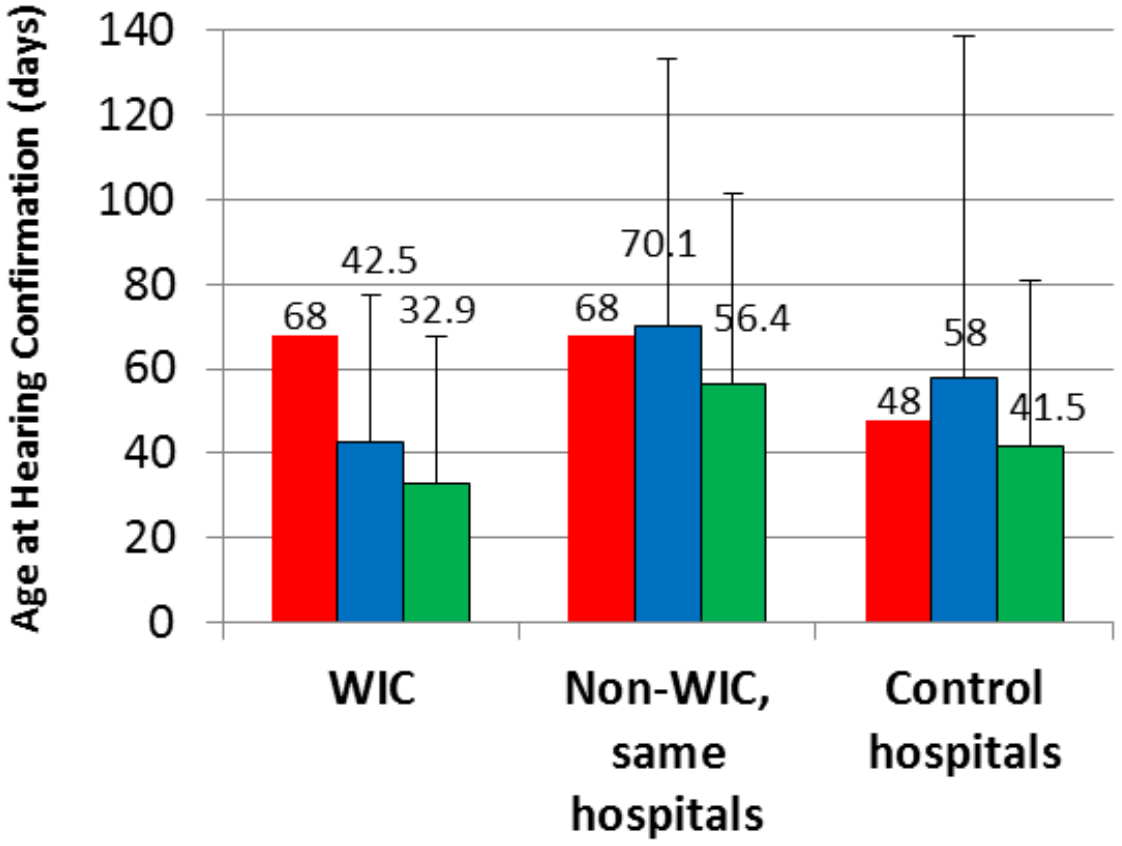
Loss to Follow-up Results



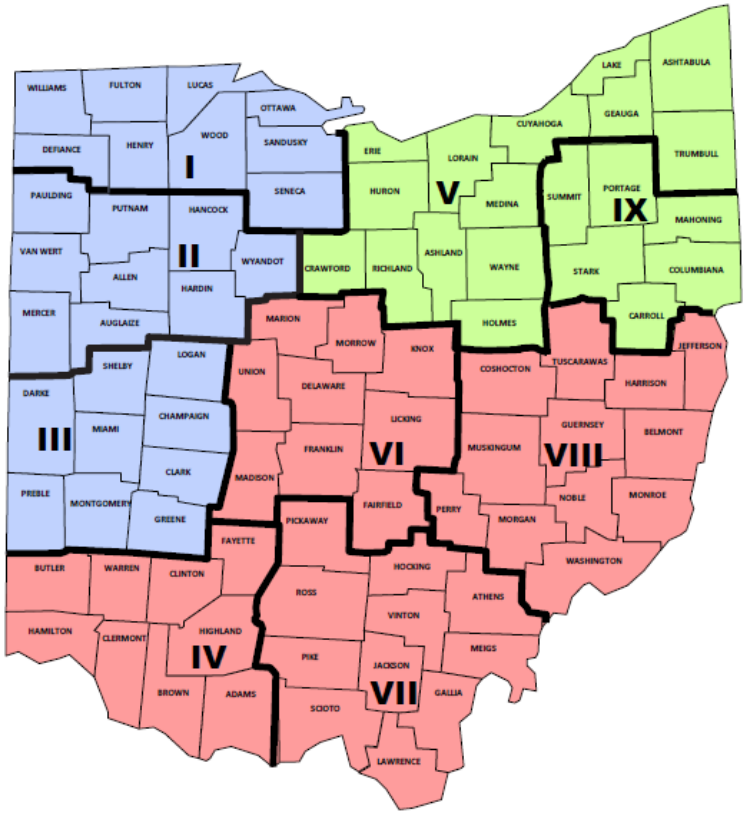
WIC reduction Years
$p < 0.0001$
WIC vs. Non WIC
$p < 0.0001$

Age at Hearing Confirmation



WIC vs. non-WIC, $p<.0001$
WIC vs. control, $p=0.0007$

Ohio NHS and EHDI Regional Infant Hearing Program (RIHP) - 2014 Data



- 140,561 Births
- 136,625 Screened (97%)
- 3962 Non Pass (3%)
- 2607 Normal Hearing (66%)
- 198 Hearing Loss (5%)
- 1149 No Diagnosis (29%)
- 991 Lost to Follow-up (25%)

Annual CDC Data

Rescreening & Diagnostic Results

- 128 infants enrolled for rescreening.
- 12 infants referred from rescreening for diagnostic testing (9.4%)
- 100% show rate at first diagnostic appointment, compared to 67% show rate for diagnostic ABRs for non-WIC study
- 10 of 12 had hearing loss at diagnostic visit, most were conductive and required multiple visits to resolve
- Age at final confirmation for WIC participants was earlier compared to non-WIC infants

Lessons Learned

- Automated ABR Methodology
  - Useful for older babies and in office
  - Does not require a sound booth for reliable results
  - Is very portable
- Study Awareness Increased Enrollment
  - By being aware of study criteria and asking the right questions, WIC staff can help qualify participants
  - By connecting with the hearing screening coordinators at the birth hospitals, we can receive referrals on a timely basis
- Transportation System, bureaucratic barriers

Case – Baby B

- Study received referral from WIC office
- Rescreened infant at ~ 2 weeks of age
- Referred bilaterally on A-ABR
- Scheduled visit with CCHMC Aud by 5 weeks of age
- Fitted for HA by 4 months
- Mother expressed greatly reduced stress since testing was first done in familiar setting

Feedback from Parents

- Often report transportation, schedule and language barriers to obtaining rescreening or diagnostic testing
- Very appreciative of follow-up close to home
- Receptive to education regarding infant's hearing health
- "If you had not offered to come here to perform this test, I doubt I would have ever had it done."
- Father of baby who referred on rescreen stated that even though they had failed to have rescreen performed until 3 mo, "they want the best for their baby girl"

Benefits to WIC and Audiology

- WIC staff have reported a positive effect on show rates by co-scheduling appointments
- Viewed as valuable service for families at WIC
- Decreases diagnostic burden on audiology, possibly decreasing backlog
- Increases awareness of NHS system thorough partnership with WIC

Benefits to Families

- No cost
- Convenient
- Close
- Comfortable
- Compliance
- Relief of anxiety
- Assistance in obtaining diagnostic testing

Keys to Success

- It takes teamwork across many agencies to find and recover LTFU babies
  - Hospital screening program
  - CCHMC neonatology network
  - WIC program staff
  - Audiology services
  - Ohio Department of Health
  - Parents – willingness to participate
- Working with outside hospitals and agencies takes extra time and effort
- Reaching families is a challenge
- No-shows and cancellations not a problem

Remaining Questions

- How can we make this attractive to spread to other regions of the state and nationally?
- How do we interpret changing data in non-intervention group?
- How can we make the project sustainable and cost-effective?

Next Steps

- To impact whole system, need hospitals, WIC, Audiology, Physicians, ODH, working together
- Action groups formed to work on most-needed gaps
- Partnership at state level between WIC and ODH to share data and develop stepwise approach
- Exploring funding mechanisms to enlarge study

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Influence of the WIC Program on Loss to Follow-Up for Newborn Hearing Screening

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[1]Cincinnati Children's Hospital Medical Center

[2]Ohio Department of Health

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- Families of Participants and Stakeholders
- Place Award from Cincinnati Children's Hospital
- Centers for Disease Control – Disability Research Center Development Grant
- Cincinnati Center for Translational Science and Technology
- LEND-AUCD and MCH Training Grant

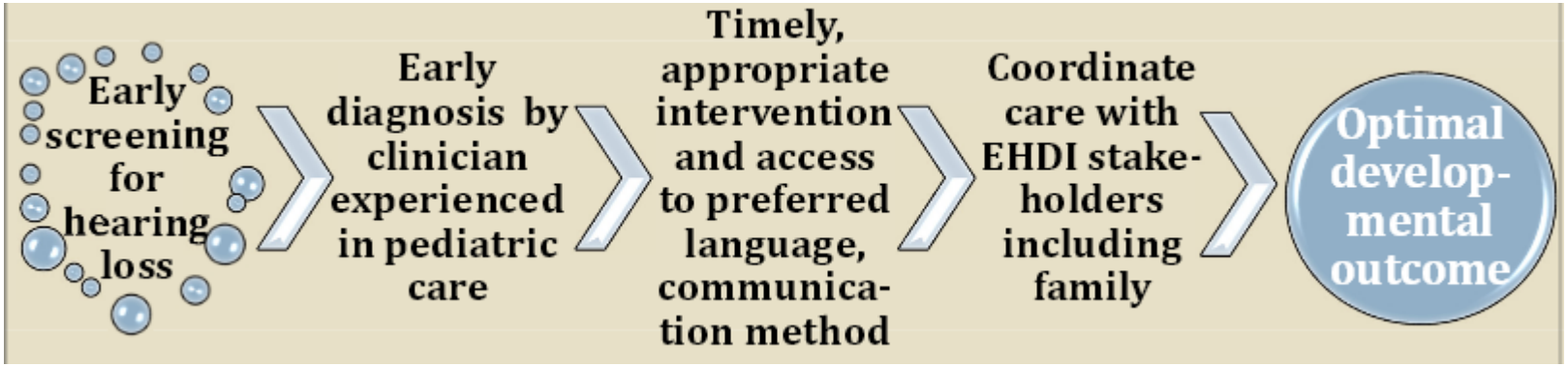
COACHing to improve NHS Outcomes:

Coalition of Ohio Audiologists and Childrens' Hospitals

Who we are, how we got here…

- 2014 EHDI Meeting – Jacksonville, Fl

- **<u>Recurring themes:</u>**
  - Building connections within the community
  - Concept of the Medical Home
  - Partnerships with state stakeholders



Perrin, James M. (2014) Expanding the Medical Home: From Concept to Care Delivery (PowerPoint Slides). Retrieved from http://www.infanthearing.org/meeting/ehdi2014/docs/1430JamesPerrin_WEB_ONLY.pdf

Recurrent Themes

- Standardized Protocols
- Screening/Re-screening Protocols
- Training, Licensure, Certification
- Messaging
- Lost to Follow-up
- Audiology Directory of providers

Why are Guidelines needed in Ohio?

- To achieve best outcomes for infants with PHL
- National guidelines and many studies (JCIH) have shown that early, accurate, high quality, integrated audiologic care is critical.
- Audiologic practice and evidence evolves rapidly - difficult to keep current
- Audiologic practices are highly variable from one setting to another
- *Specific, helpful* guidelines can improve consistency and outcomes

Stakeholder Engagement Process

2014	2015	2016	2017
June ’14- Initial Collaboration meeting September ‘14- Call to Action letter October ’14- 1st Collaboration meeting with Children’s Hospital Audiologists	Feb ‘15-OAC Open Forum March ’15- OSHLA presentation June ‘15-2nd Collaboration meeting August ‘15- UNHS Subcommittee Meeting September ‘15- EHDI abstract Dec ‘15-refine testing protocols	February ‘16- Peer review March ‘16- EHDI Conference presentation May ‘16 - Additional revisions August ’16- UNHS Subcommittee Meeting Oct’16- OSSPEAC Conference	June ‘17 Online and Onsite Training & Statewide Implementation of Protocol

Overview of Protocol

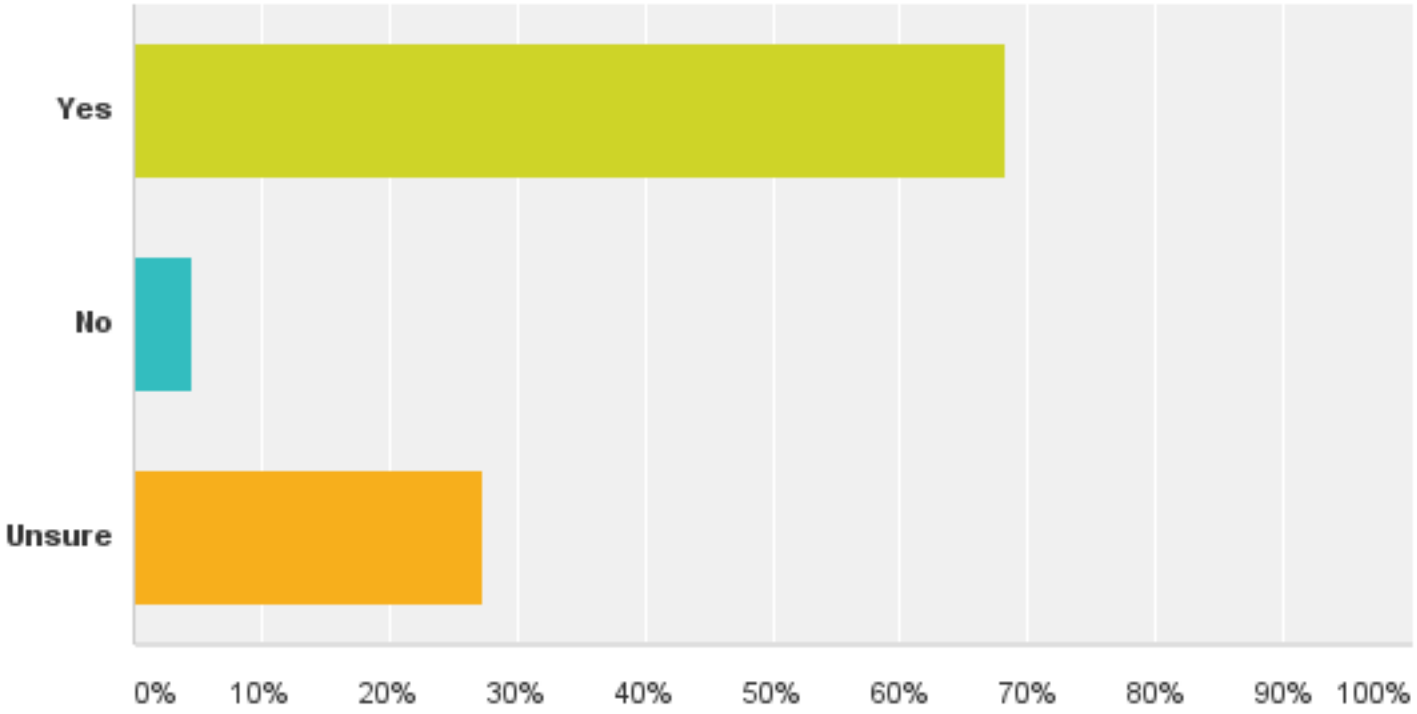
I. Introduction
II. Acronyms
III. Qualified Personnel
IV. Safety and Health Precautions
V. Test Environment
VI. Procedures
VII. Equipment
VIII. Important Points and Tips
IX. Case History
X. Otoscopic examination
XI. Immittance
XII. Diagnostic OAE Evaluation
XIII. Diagnostic Threshold Auditory Brainstem Response (ABR) Protocol
XIV. Follow-up and Intervention protocol

Follow-up and Intervention protocol

1. Complete Diagnostic Assessment
2. Initiation of Intervention
3. Counseling
4. Follow-up recommendations for newly identified children with *sensorineural* hearing loss or *ANSD*
5. Follow-up recommendations for conductive hearing loss
6. Follow-up recommendations for normal ABR with risk factors (JCIH, 2007
7. Documentation
8. Confirmation of Hearing Loss
9. Periodicity Schedule for Evaluation
10. Referrals
11. Sharing information with Families
12. Diagnostic follow up reporting
13. Acknowledgements
14. Peer review
15. References

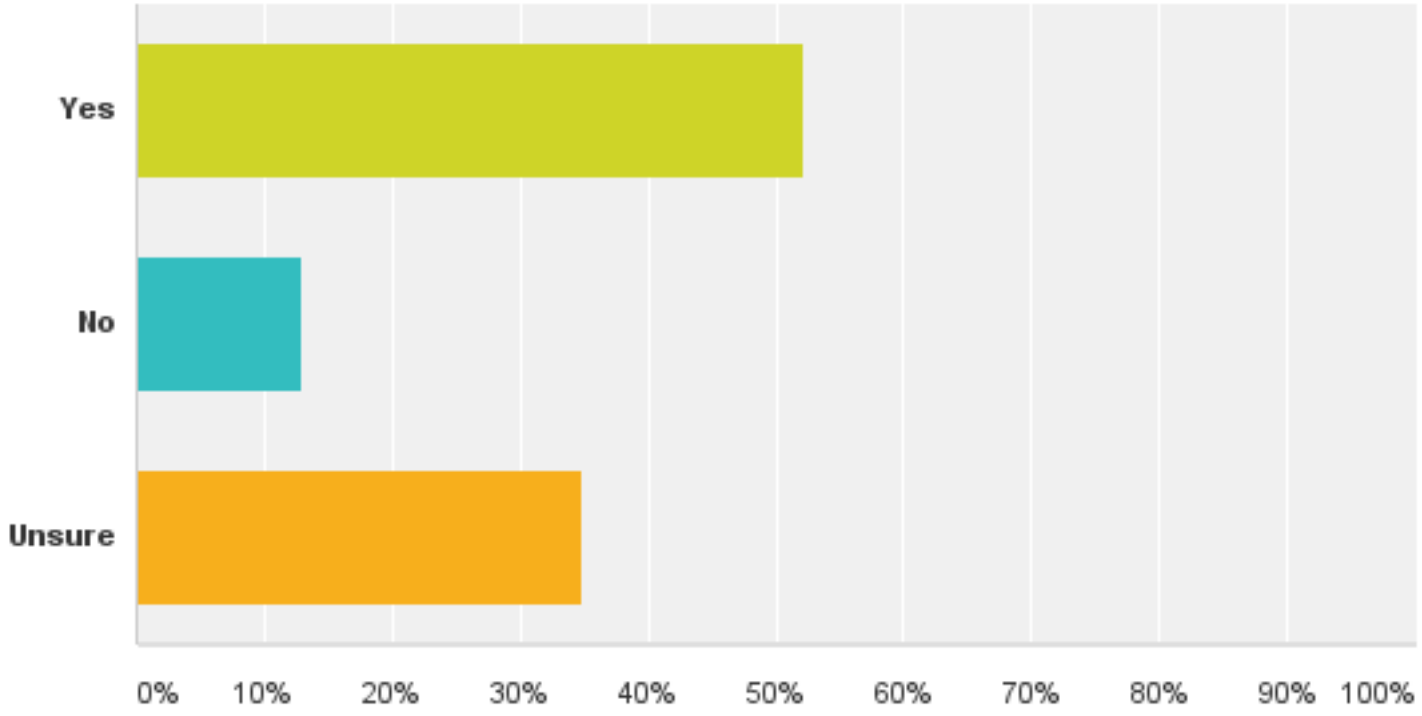
Q8 After reading Recommended Protocols for Diagnostic Audiological Assessment Follow-up to Newborn Screening in Ohio, do you think that following this protocol would result in more complete test results?

Answered: 22 Skipped: 1

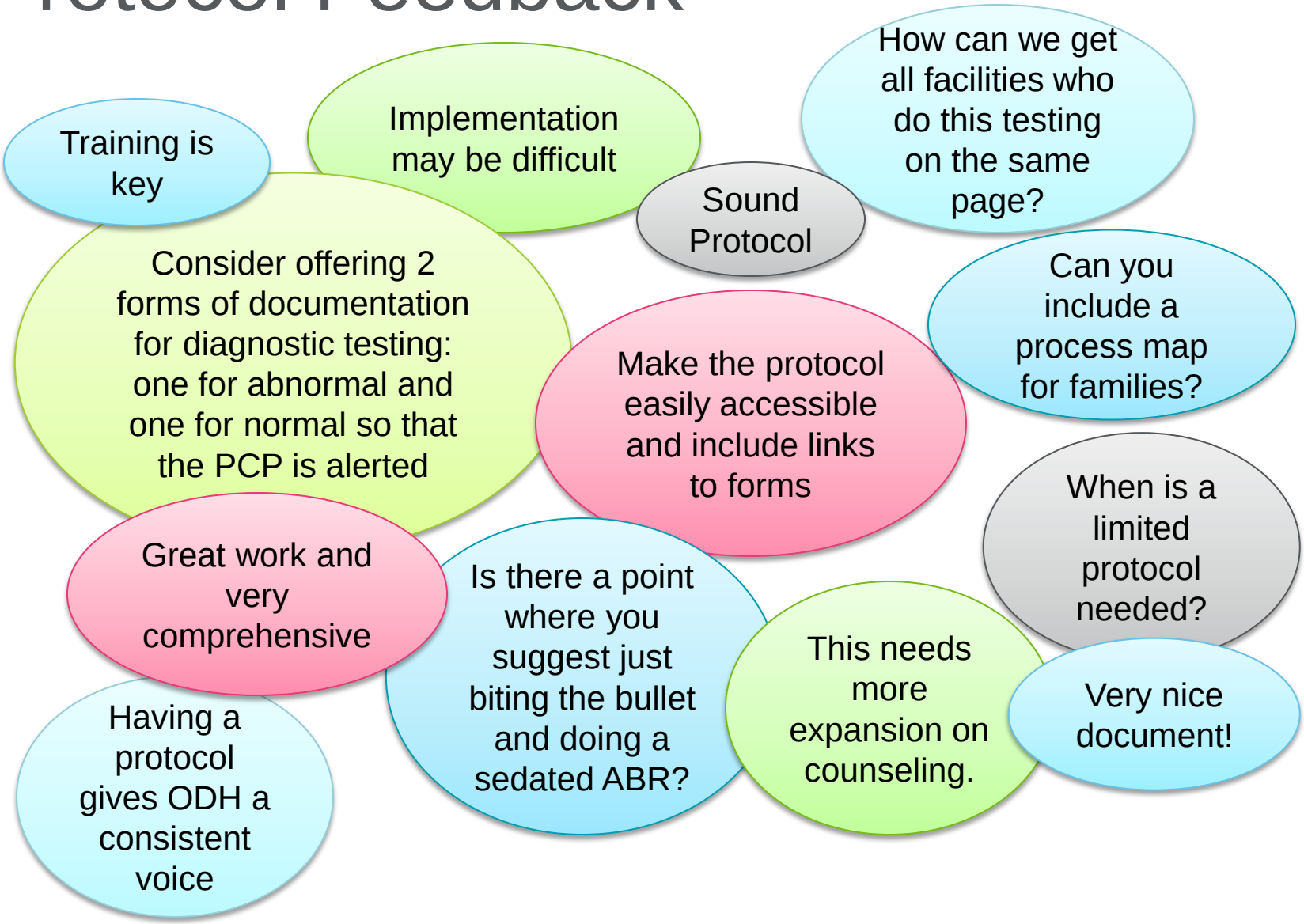


Q10 Do you think this protocol could help reduce the age of identification of infants with hearing loss in Ohio?

Answered: 23 Skipped: 0



Protocol Feedback



COACH Partners

- Akron Children's Hospital
- Cleveland Clinic Special Maternal Unit
- Columbus Speech & Hearing Center
- Cincinnati Children's Hospital Medical Center
- Cleveland Hearing & Speech Center
- Dayton Children's Hospital
- Galion Community Hospital
- Knox Community
- MD School for the Deaf
- Nationwide Children's
- ODH- Infant Hearing Supervisor
- Ohio Board of Speech Language Pathology and Audiology
- OSU AuD student
- St. Elizabeth Boardman Hospital
- Summa Health Systems
- Summit County ESC
- The Christ Hospital
- Toledo Hospital and Toledo Children's Hospital
- UC AuD student
- University Hospitals Case Medical Center-Rainbow Babies and Children
- Wright Patterson Air Force Base


Action is the foundational key to all success.
Pablo Picasso
JohnMaxwellTeam.com

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