

Collaboration Between WIC and EHDI to Improve Follow-Up of Newborn Hearing Screening in Greater Cincinnati



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Disclosure Statement

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- Neither we nor any member of our immediate families have a financial relationship or interest (currently or within the past 12 months) with any entity producing, marketing, re-selling, or distributing health goods or services consumed by, or used on, patients.
- We do not intend to discuss an unapproved/ investigative use of a commercial product/device.

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 - Place Award from Cincinnati Children's Hospital
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- Families of Participants and Stakeholders
- Collaborators:
 - Dr. Daniel Choo, EHDI Advisor
 - Reena Kothari, Ohio Department of Health
 - Cindy Meale, Butler County WIC
 - Betsy Buchanan, Hamilton County WIC

Outline of Presentation

- Challenge of Loss to Follow-Up (LTFU)
- Place Award study in Butler County
- CDC study in Hamilton County
- Lessons Learned
- Keys to Success
- Participatory Action Research Model
- Stakeholder Focus Groups

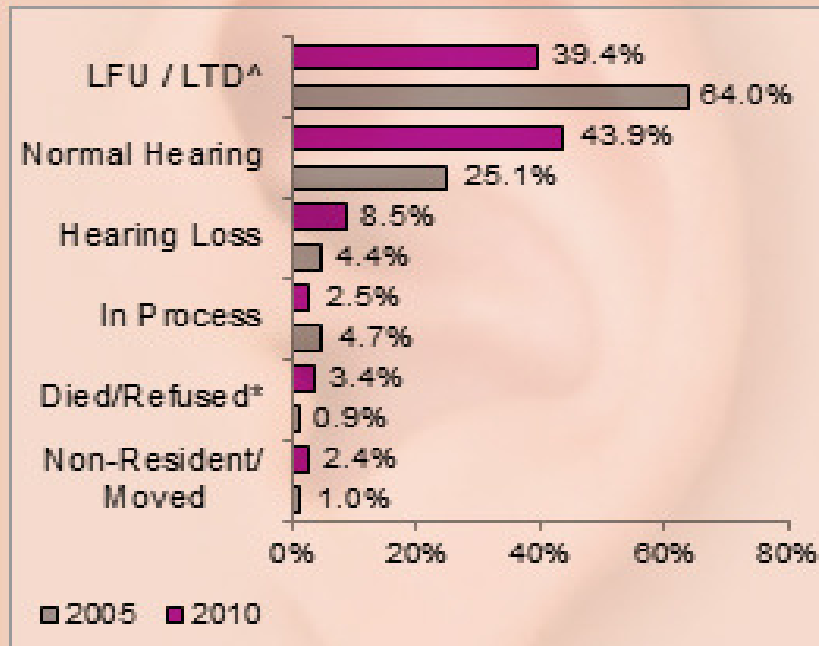
Loss To Follow-up in the U.S.

- Centers for Disease Control and Prevention (CDC) data from 2011 indicated 35% of children in the US with failed newborn hearing screening were lost to follow-up or lost to documentation for diagnosis.
- Range of LTFU is 3% to 83% across 50 states.
- States with the most well-developed EHDI programs report 2.5:1000 with permanent hearing loss but many states report far fewer because of loss to follow-up.
- *26% of infants with documented hearing loss could not be confirmed as having intervention services.*

Progress on Loss to Follow-up and Diagnosis of PHL

<http://www.cdc.gov/features/dsinfanthearingloss/index.html>

**Status of Babies that Did Not Pass Final Hearing Screening
U.S., 2005 and 2010**



[^]Loss to Follow-up (LFU) / Loss to Documentation (LTD)

^{*}Infant died or Parents refused follow-up testing

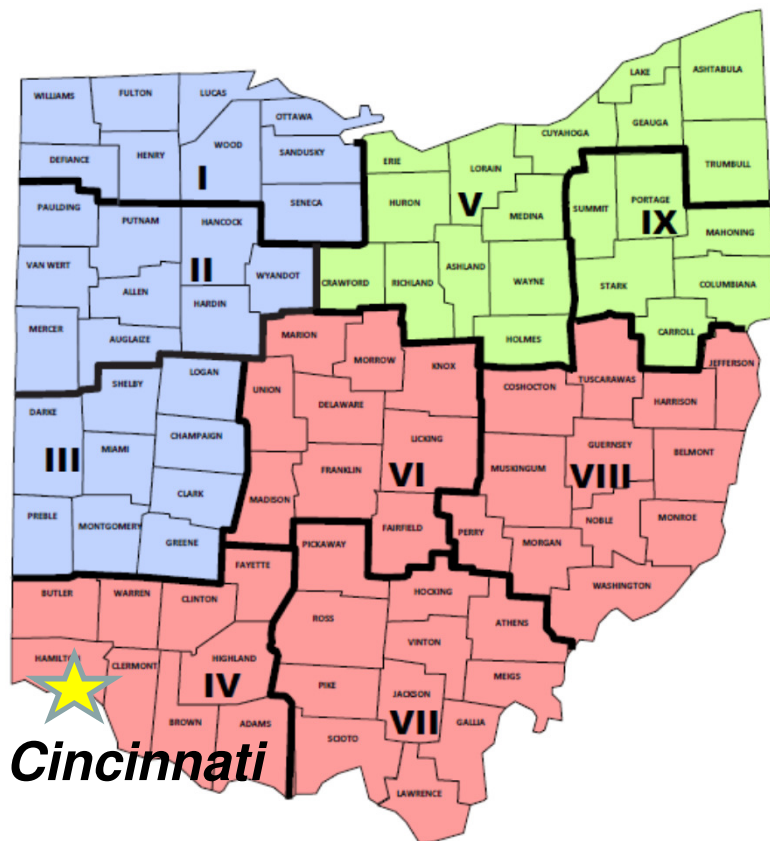
- By 2010, LFU/LTD among babies not passing the screening had decreased to approximately 39.4%.
- In 2010, over 4,900 babies were diagnosed with hearing loss, nearly double the number reported in 2005.

Universal Newborn Hearing Screening (UNHS) In Ohio

<http://www.helpmegrow.ohio.gov>

- Ohio mandated universal newborn hearing screening in 2002; full implementation was in 2004
- 135 birthing hospitals in Ohio, 140K births
- 98.6% of all Ohio infants are now screened at birth (ODH, 2012)
- Prevalence of hearing loss = 1.5 per thousand

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



Cincinnati

Courtesy of Reena
Kothari, AuD
Ohio Department of
Health NHSP

139,628 Births
137,711 Screened (98.6%)
3945 Non Pass
(2.9%)
2334 Normal Hearing
(59.2%)
213 Hearing Loss
(5.4%)
1254 Lost to Follow-up
(31.8%)
144 In Process
(3.7%)



Two-Stage Screening Test Performance Based on Ohio Data (2012)

False Positive Rate = $\frac{\text{Number passed diagnostic}}{\text{Number screened}}$

False Positive Rate = 2.6%

Positive Predictive Value = $\frac{\text{Number passed diagnostic}}{\text{Number Referred}}$

Positive Predictive Value = 8.4%



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 refer rates:** From 1% 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)

WIC-EHDI Collaboration Study

– Primary Aim:

- Reduce loss to follow-up rate for infants failing the newborn screening at the birth hospital and requiring rescreening

– Secondary Aim:

- Shorten the length of time to diagnosis and subsequent intervention for those diagnosed with PHL.
- *JCIH 1/3/6 Guidelines – 1 month to rescreening - 3 months to diagnosis - 6 months to intervention*

Why Women Infant Children (WIC)?

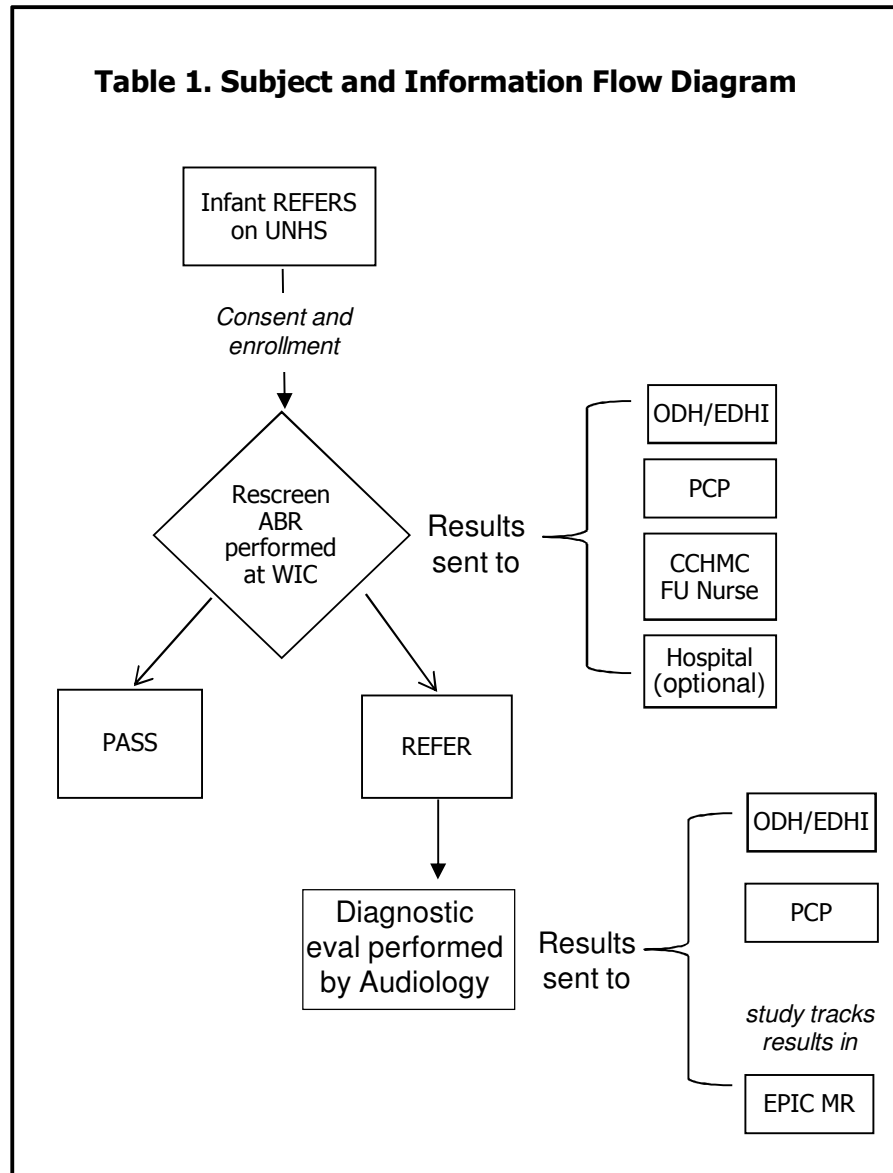
- WIC provides lactation and nutrition support to eligible lower income mothers and their children under age 5 years.
- Approx. 50% of all newborns are eligible for WIC services, located close to home
- Factors that are associated with poorer follow-up are addressed by WIC (transportation, convenience, cost, familiarity)
- Lower socioeconomic strata has higher incidence of hearing loss

Study Facilities

- Birth Hospitals – Butler County
 - Ft. Hamilton Hospital in Hamilton OH: ~650 births/year
 - Mercy Hospital in Fairfield, OH: ~2200 births/year
 - At 2% referral rate, expect 57 referrals per year total, 50% WIC eligible = 28 per year.
 - *Good Samaritan Hospital in Cincinnati's birth rate is ~ 6500/year*
- WIC Offices
 - Butler County WIC West: 330 total caseload (women, infants children)
 - Butler County WIC Bever Pavilion: 5440 total caseload

Process of Re-screening for Intervention Group

Table 1. Subject and Information Flow Diagram



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.

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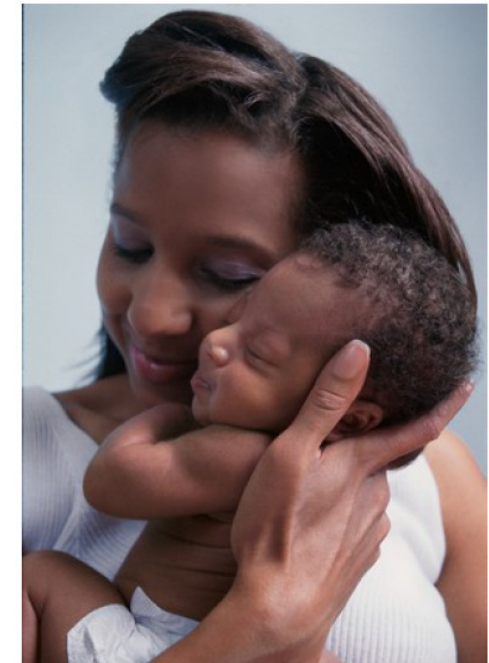
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¡Para oírte mejor!
903 NW Washington Blvd.
Hamilton, OH 45013
Recruitment Brochure, Version 1



3333 Burnet Avenue | Cincinnati, OH | 45229-3039



¡Para oírte mejor!

Estudio de investigación patrocinado por el Hospital de Niños de Cincinnati



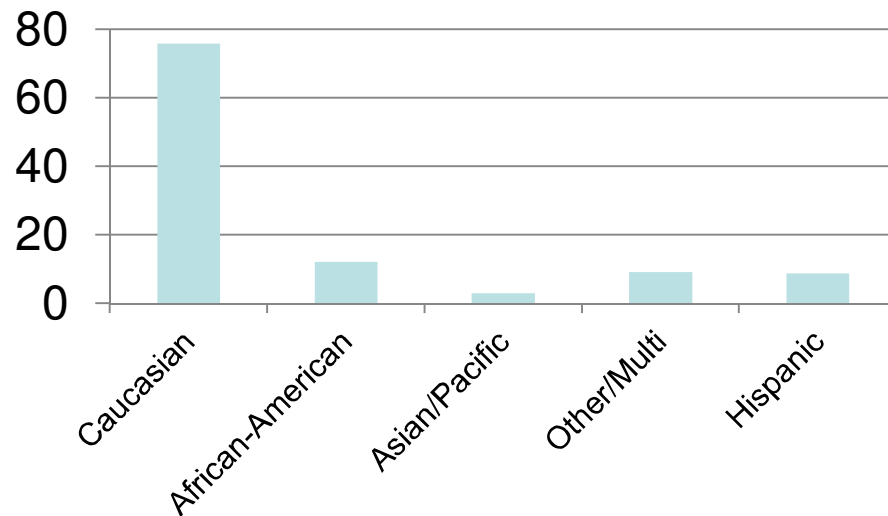
A-ABR Testing in WIC Clinics



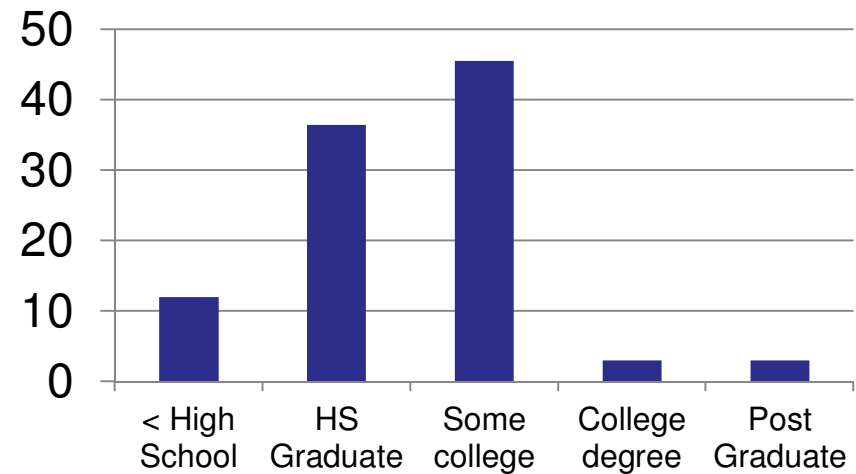
- Testing in Mom's arms
- Trained technician can use – automatic interpretation
- While nursing or bottle feeding
- Infant in natural sleep
- No need for sedation
- Successful in our experience up to 5 months old

Results – 33 infants enrolled

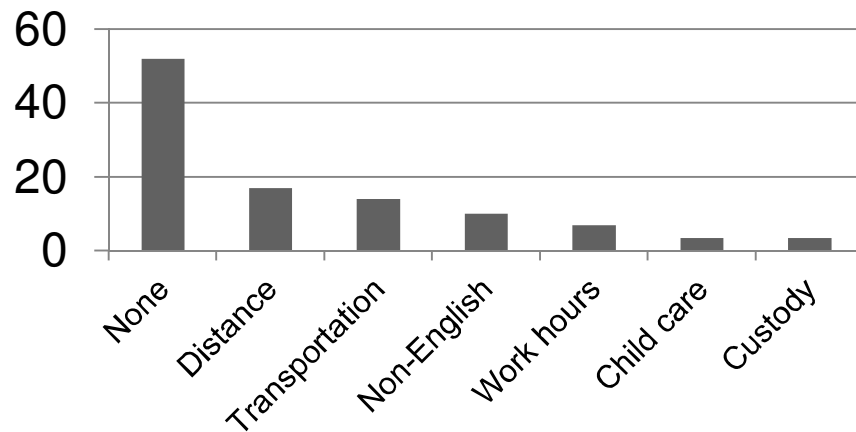
Race & Ethnicity



Mom's Education

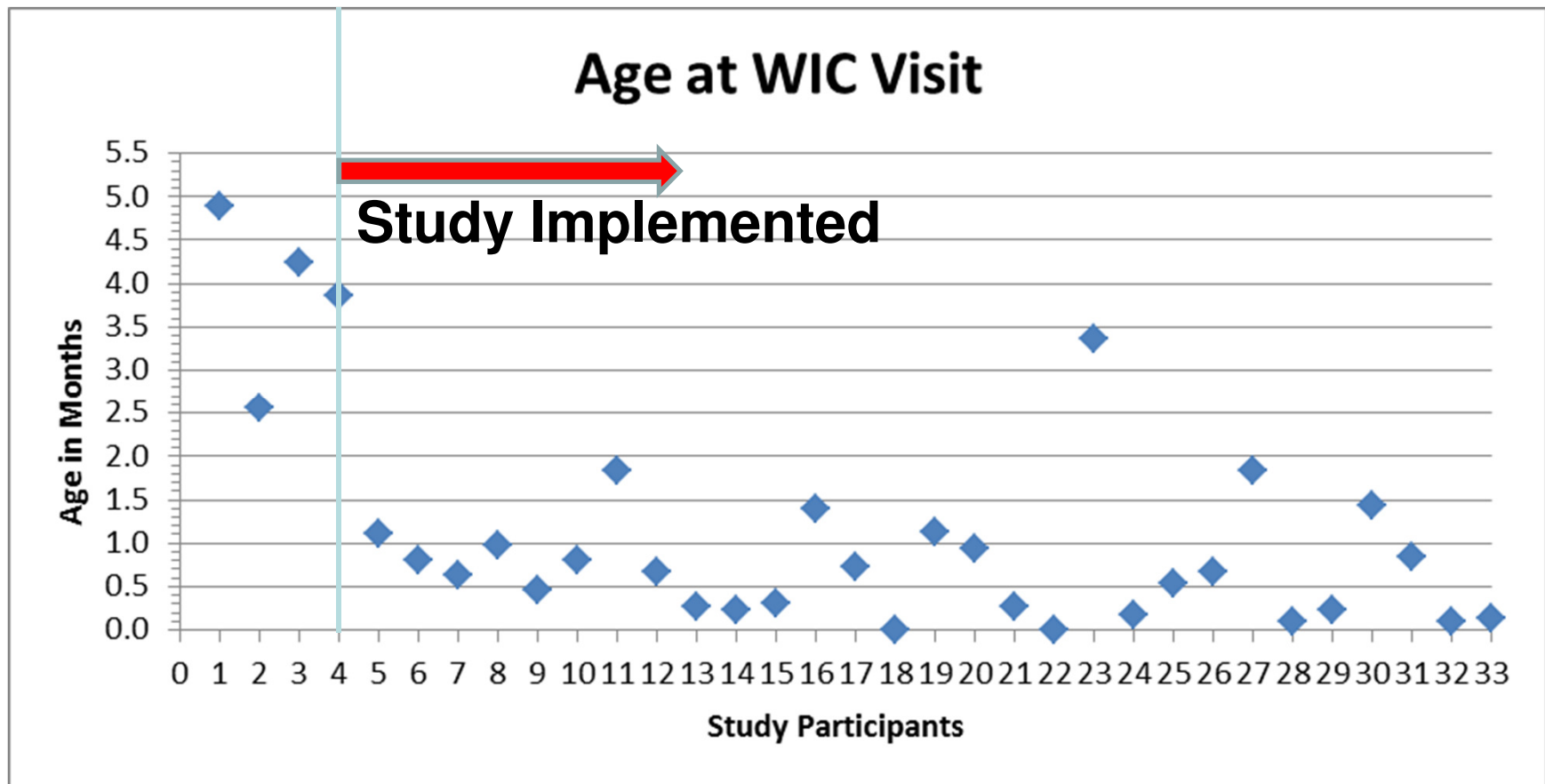


Barriers Reported



Public Insurance: 94%
Hearing Risk Factors: 15%
Mom in School: 15%

Age at follow-up improved from 3.7 m before program to 0.7 m after program



Loss to Follow-up Comparisons

- Eligible WIC Referrals = 33/36 (92% follow-up)
- Diagnostic Follow-up – 5/5 (100% follow-up)
- Could not be contacted or moved = 3/36 (8%)
- No refusals (0%)

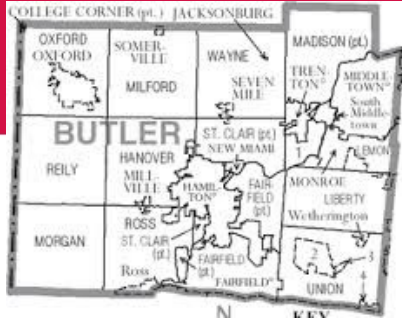
- Cincinnati Area Loss to Follow-up Baseline Data (2010):
 - Hospital 1: 45%
 - Hospital 2: 50%
 - Hospital 3: 33%
 - Hospital 4: 64%

Tracking of Infants who Failed Re-screen

| <i>Age at WIC rescreen</i> | <i>Attended Diagnostic Eval?</i> | <i>Age at Diagnostic Eval</i> | <i>Age at 2nd Diagnostic Eval</i> | <i>Additional Visit Required?</i> | <i>Diagnosis</i> |
|----------------------------|----------------------------------|-------------------------------|-----------------------------------|-----------------------------------|--|
| 12 weeks | yes | 19 weeks | 5.5 mo | Yes, completed | Normal hearing bilaterally |
| 4 weeks | yes | 5 weeks | 2 mo | Yes, completed | Normal hearing bilaterally |
| 1 week | yes | 4 weeks | 2 mo | Yes, completed | Normal hearing bilaterally |
| 1 week | yes | 4 weeks | 2 mo | Yes, completed | Normal hearing bilaterally |
| 3 weeks | yes | 5 weeks | 4 mo | Yes, completed | Mild to mod conductive in right. Mixed hearing loss left |

Centers for Disease Control Grant, Funded September 1, 2013-2015

- Targeted to Hamilton County WIC
- Modeled after current WIC re-screening project in Butler County.
- Hamilton County has the largest number of referred newborn screening cases reported to the Ohio Department of Health and represents a needy demographic.
- Our hypothesis is that the WIC hearing re-screen program will significantly decrease the time between the hospital hearing screening and diagnostic evaluation.
- We will also ascertain the time to intervention for any children identified with hearing loss by following children after diagnosis to track time to enrollment in early intervention.



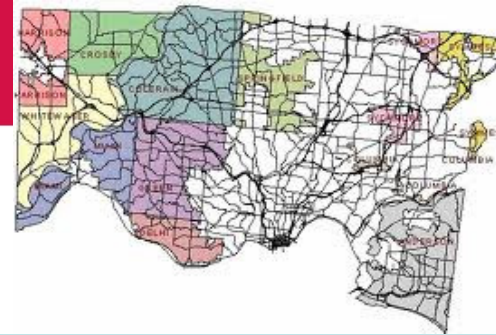
Butler County

Target Hospitals

- Mercy Hospital of Fairfield
- Ft. Hamilton Hospital

WIC Offices

- Bever Pavilion
- West



Hamilton County

Target Hospitals

- Good Samaritan Hospital
- University Hospital

WIC Offices

- Roselawn, pilot
- Four others



Hamilton County Intervention and Comparison Hospitals

| Hospitals | Annual Deliveries | Refer Rate (%) | NHS Referrals (N) | LTFU rate (%) | Medicaid/WIC (%) | Study eligible referrals (N) |
|---------------------------|-------------------|----------------|-------------------|---------------|------------------|------------------------------|
| Comparison 1 | 3055 | 11.3% | 337 | 45% | ≅50% | 168 |
| Intervention 1 | 2298 | 10.6% | 274 | 50% | ≅80% | 219 |
| Comparison 2 | 4141 | 3.0% | 133 | 33% | ≅50% | 67 |
| Intervention 2 | 6385 | 2.2% | 174 | 64% | ≅80% | 139 |
| Total Comparison | 7196 | 6.5% | 470 | 41.7% | ≅50% | 235 |
| Total Intervention | 8643 | 5.2% | 448 | 55.4% | ≅80% | 160 |

Target WIC Locations to Offer Re-Screening

| Hamilton County WIC Program Locations | Infant Caseload | Total Clients | Miles from Hospital | Infant Mortality Rate |
|---------------------------------------|-----------------|---------------|---------------------|-----------------------|
| Elm St | 594 | 2209 | 3 | 24.7 |
| Cann-Madisonville | 238 | 854 | 8 | 5.3 |
| Children's Hospital | 222 | 1016 | 1 | 17.5 |
| Seven Hills | 1113 | 4140 | 12 | 19.9 |
| Roselawn | 959 | 3478 | 5 | 17.1 |
| TOTAL | 3126 | 11697 | | |

**Infant mortality rate per 1,000 live births.
US = 5.9/1000 for 2013.*

Teamwork: Identifying Study Subjects

Laura Rolfes – Study Coordinator

Hospital Hearing
Screeners



Study Staff

Neonatal FU Team

WIC Staff

Keys to Success: Partnering with WIC



- Often WIC knows about the referral first
- We can rescreen babies at WIC as early as a few days old
- Additional opportunities to combine rescreen with WIC visit
- Combining rescreen/WIC visit = less No Shows
- Dedicated staff, comfortable surroundings, privacy
- Already have available Spanish translators

Barriers to Following Up

- During data collection: Few reported
- In casual conversation: Barriers revealed



Examples

- Some LTFU Risk
- Great LTFU Risk
- Definite LTFU

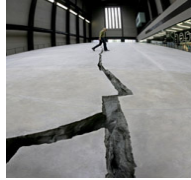
Parents' Reactions

- Appreciation for convenient/free rescreening
- Relieved
 - If baby passes
 - They have fulfilled responsibility
 - Study takes care of paperwork
- Receive help if baby refers on rescreen
 - Rescreen results discussed
 - Appointment made immediately after rescreen referral with parent present
 - Coordinator can explain what will happen at the appointment

100% attendance at follow-up appointments



Direct Impacts of Study

- Prevention of infants from “falling between the cracks” of the newborn hearing screening system. 
- LTFU rate from ~60% in Butler County prior to study initiation to ~10% after
- Significantly shorten time to follow-up for rescreen
- Shorten time to follow-up to diagnostic evaluation

The closer we come to 100% follow-up rate, the better able we are to improve outcomes for all infants with congenital hearing loss.

Indirect Results of Study

- Relief for parents



- of anxiety around possibility of deafness
- for having fulfilled parental responsibility
- can proceed with intervention expeditiously

- Frees space/time in diagnostic system
- Helps WIC extend relationship with clients (i.e. become more of a medical home)

Lessons Learned

- The AABR technology incorporated is easily portable and useful outside of the sound booth.
- Reduction of Loss to Follow-up is a team effort.
- Parents really DO want to follow up.
- Hearing rescreening at WIC appears thus far to be an effective model for decreasing loss to follow-up.

Qualitative Outcomes – Laura Rolfes

- WIC, ODH and hospitals very supportive
- Have pledged support for the expanded project and provided data on follow-up rates through state database
- This data will be crucial to determine if we are having a significant impact in LTFU rates and time to intervention
- Some of the infants found thus far have been >3 months due to “catch up” efforts
- These infants were then resolved and no longer are LTFU.

Participatory Action Research

Sara DiStefano

- Participants included a group of ~30 stakeholders used to gather information about the NHS system in Cincinnati and the surrounding suburbs
- Parents, audiologists, physicians, speech-language pathologists, and birth hospital screeners
- Policy partners attended:
 - Ohio Maternal and Child Health - 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

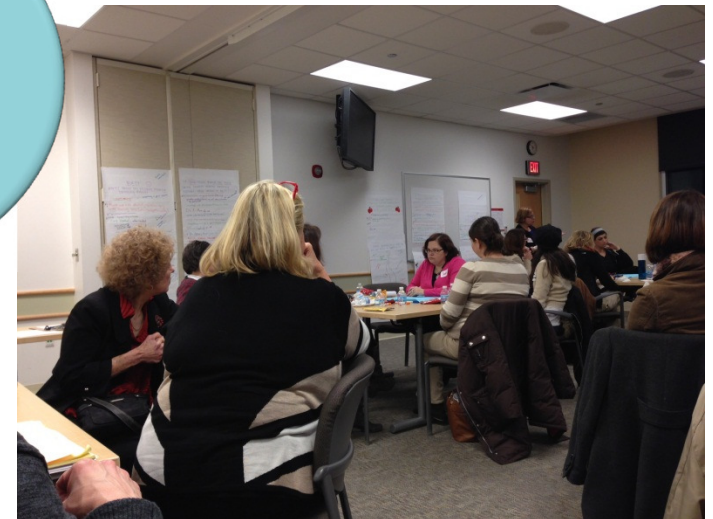
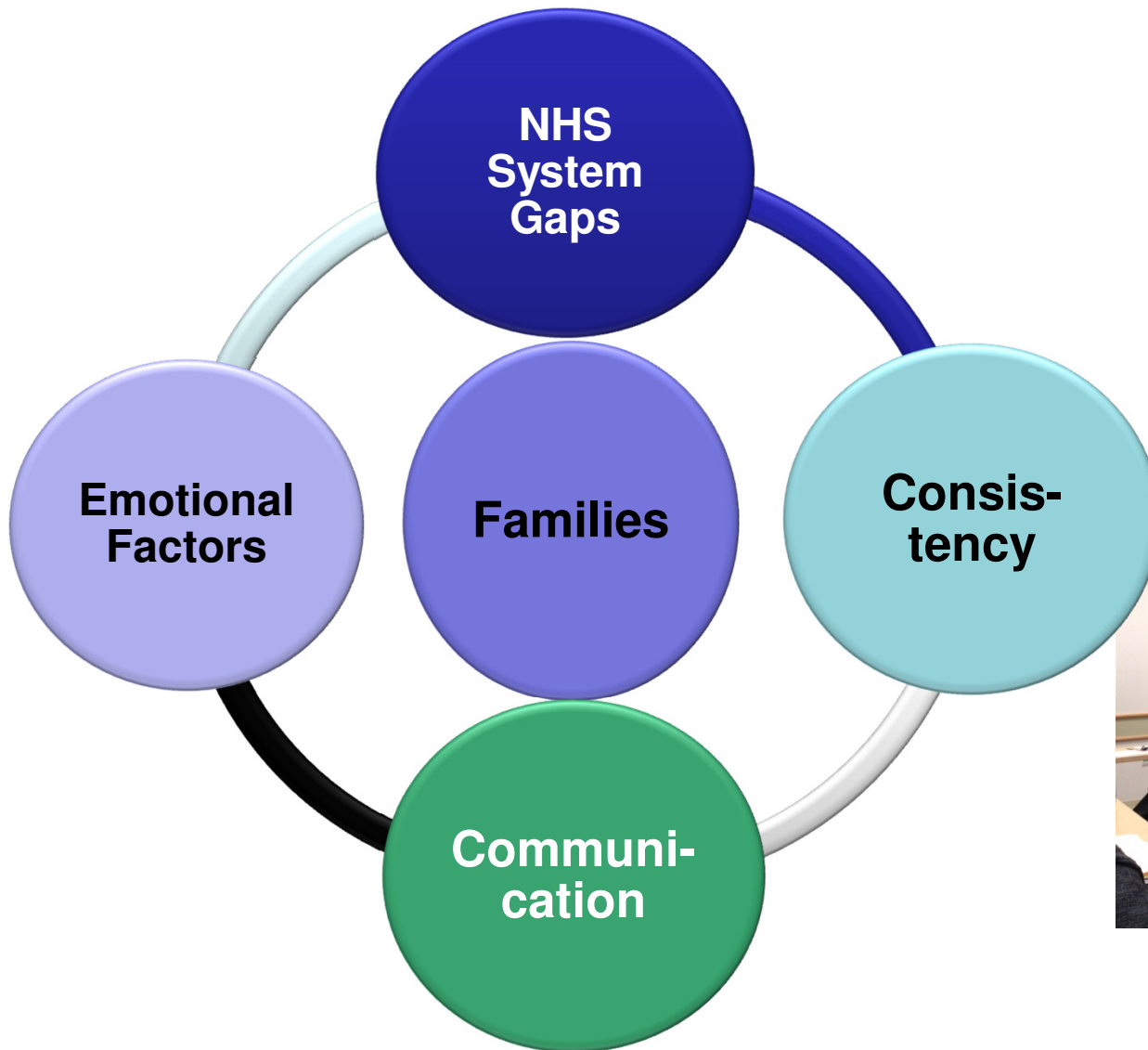
Step Five: Understanding

Step Six: Selecting

Step Seven: Action



Main Themes



Themes

- **NHS is a complex system:** lack of standard of care for follow-up, lack of global awareness, lack of consistency, and lack of communication and understanding among all involved in the process.
- **Emotional Factors:** Fear, Education, Motivation, Culture
- **Communication:** A clearer message needs to be delivered by working together to meet one common goal
 - Public awareness, Ownership, Partners, Resources
- **Families:** Improvement in the NHS process will not be seen without support from families
 - Participation, Communication, Education, Partnership

Next Steps

- Based on the thoughts and ideas generated during the group level assessment, community members, health professionals, and academic partners will continue to come together and collaborate to generate plans and ideas that will help to compensate for the barriers that many individuals face in the NHS process.
- Individual action groups will be developed at a next meeting to begin work on most-needed areas.