

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

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- Neither I nor any member of my immediate family has 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.
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  - 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

# Congenital Hearing Loss (CHL)

- About 1 in 500 babies are born with permanent hearing loss – one of the most common birth defects
- About 8,000 children born in the United States each year with CHL
- Newborn hearing screening has reduced the age of diagnosis from >24 months to about 3 months

# Why is it so important to detect hearing loss at an early age?

- **Developmental Impact:** Infants with CHL do not develop speech and language as their peers do and require hearing aids or cochlear implants
- **Economic Impact:** Costs exceed \$500,000 per child with hearing loss (>40 dB permanent loss without other disabilities)
- **Educational Impact:** Hearing loss interferes with the accurate reception of speech especially under classroom conditions (high background noise, teacher being at a distance)
- **Behavioral Impact:** Similar to spectrum of behaviors reported for cognitive delays, learning disabilities, attention deficits, speech-language disorders



# 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>

- 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%)  
1398 No Diagnosis  
(35.4%)  
1254 Lost to Follow-up  
(31.8%)



# 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 is 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

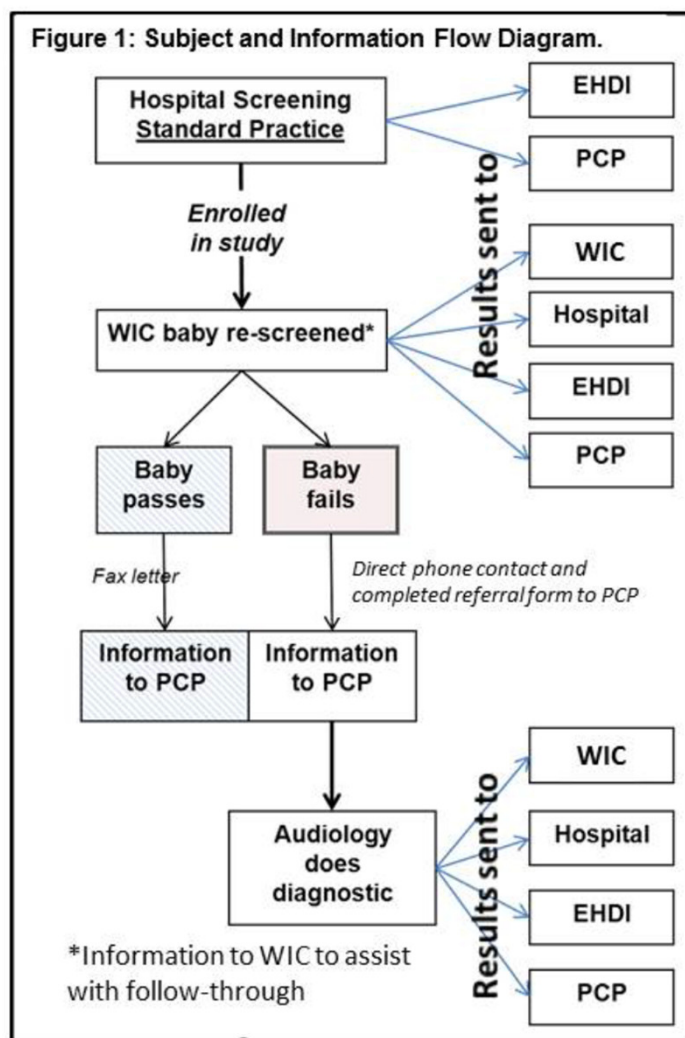


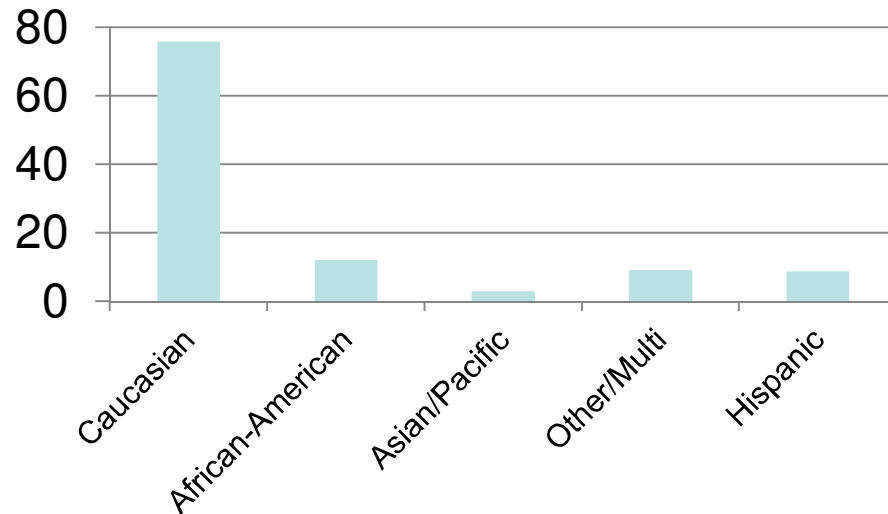
Table 2. Screening and Diagnostic Data
Data Collected
Demographic characteristics
Intervention or Control site
Birth hospital
Hearing re-screen results*
Date of re-screen*
Date of diagnostic assessment*
Diagnostic status*
Hearing loss (Y/N)*
Hearing loss type (sensorineural, conductive, mixed)†
Severity of hearing loss†
Enrollment in early intervention†
Date of EI enrollment†
Type of EI services received†
*For infants who fail hearing re-screen
†For those with diagnosed hearing loss

# A-ABR Testing in WIC Clinics

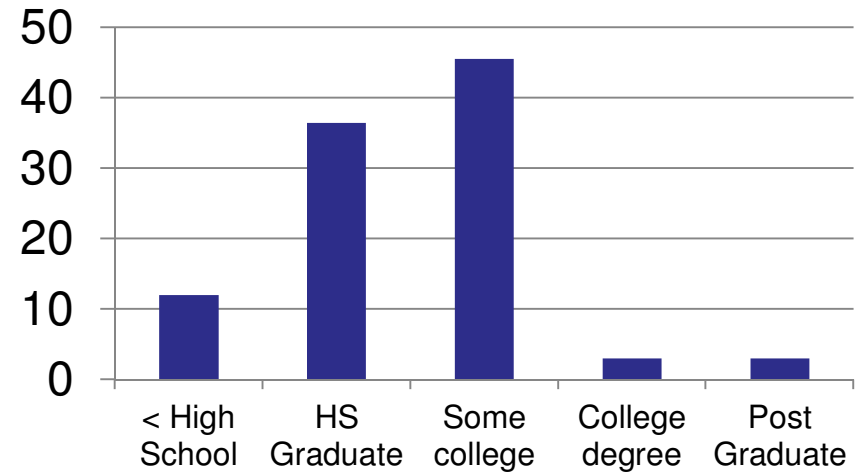
- Testing in Mom's arms
- Trained technician can use – automatic interpretation
- While nursing or bottle feeding
- Infant in natural sleep
- No need for sedation
- Successful in our experience up to 5 months old

# Results – 33 infants enrolled

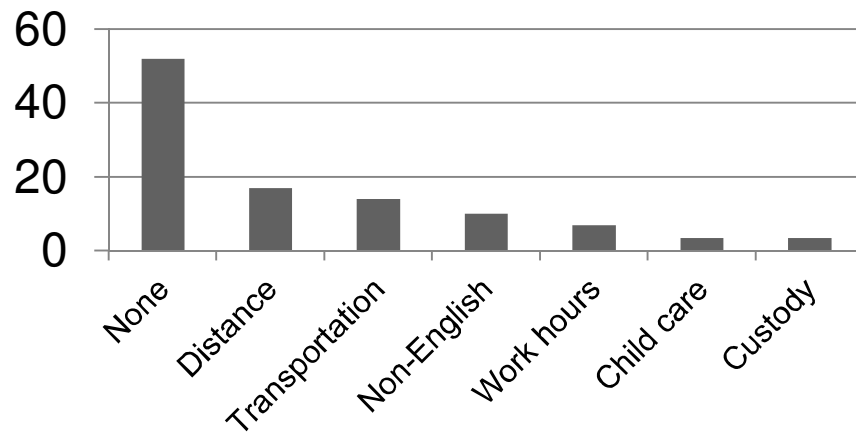
## Race & Ethnicity



## Mom's Education

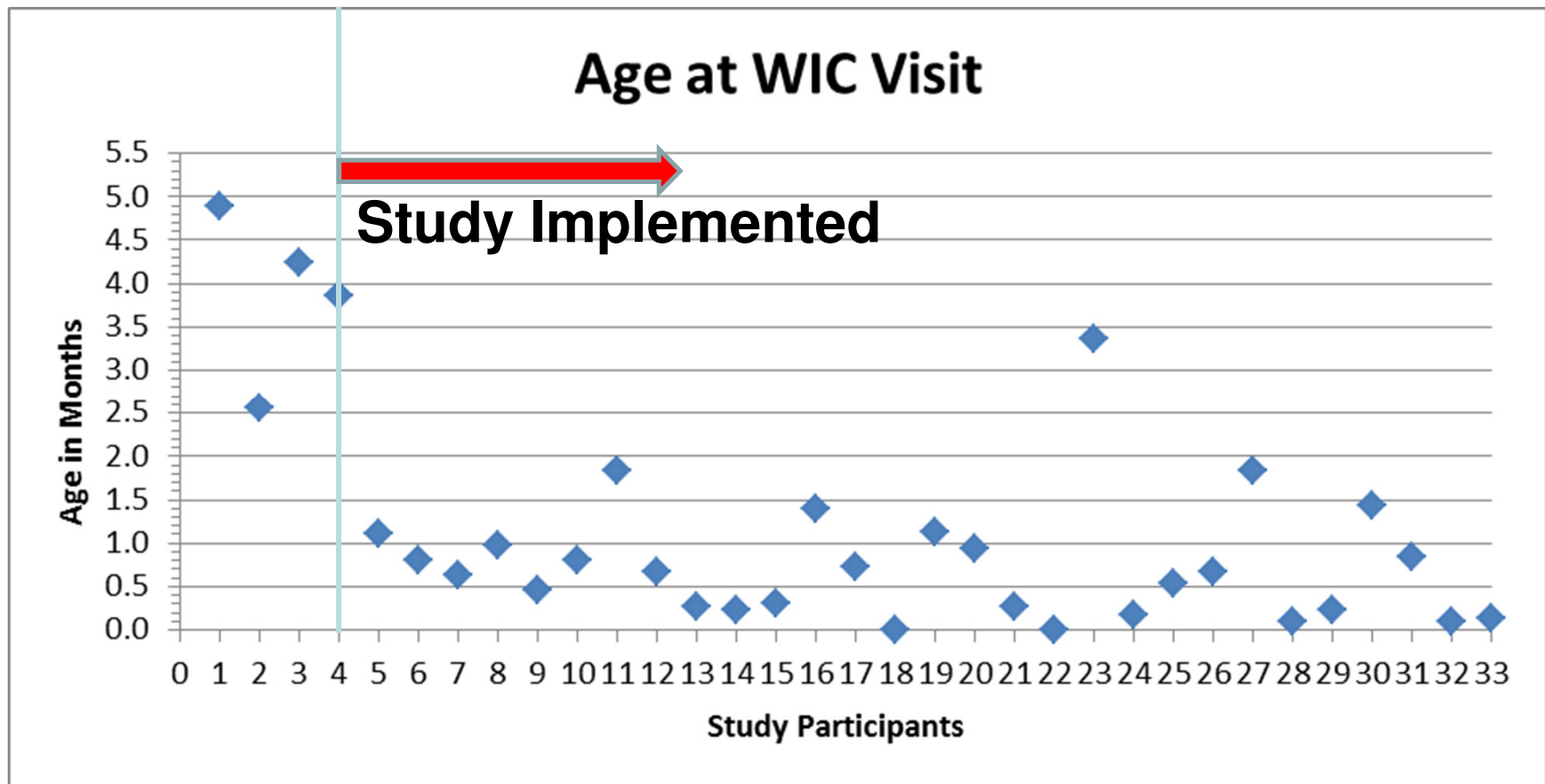


## Barriers Reported



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

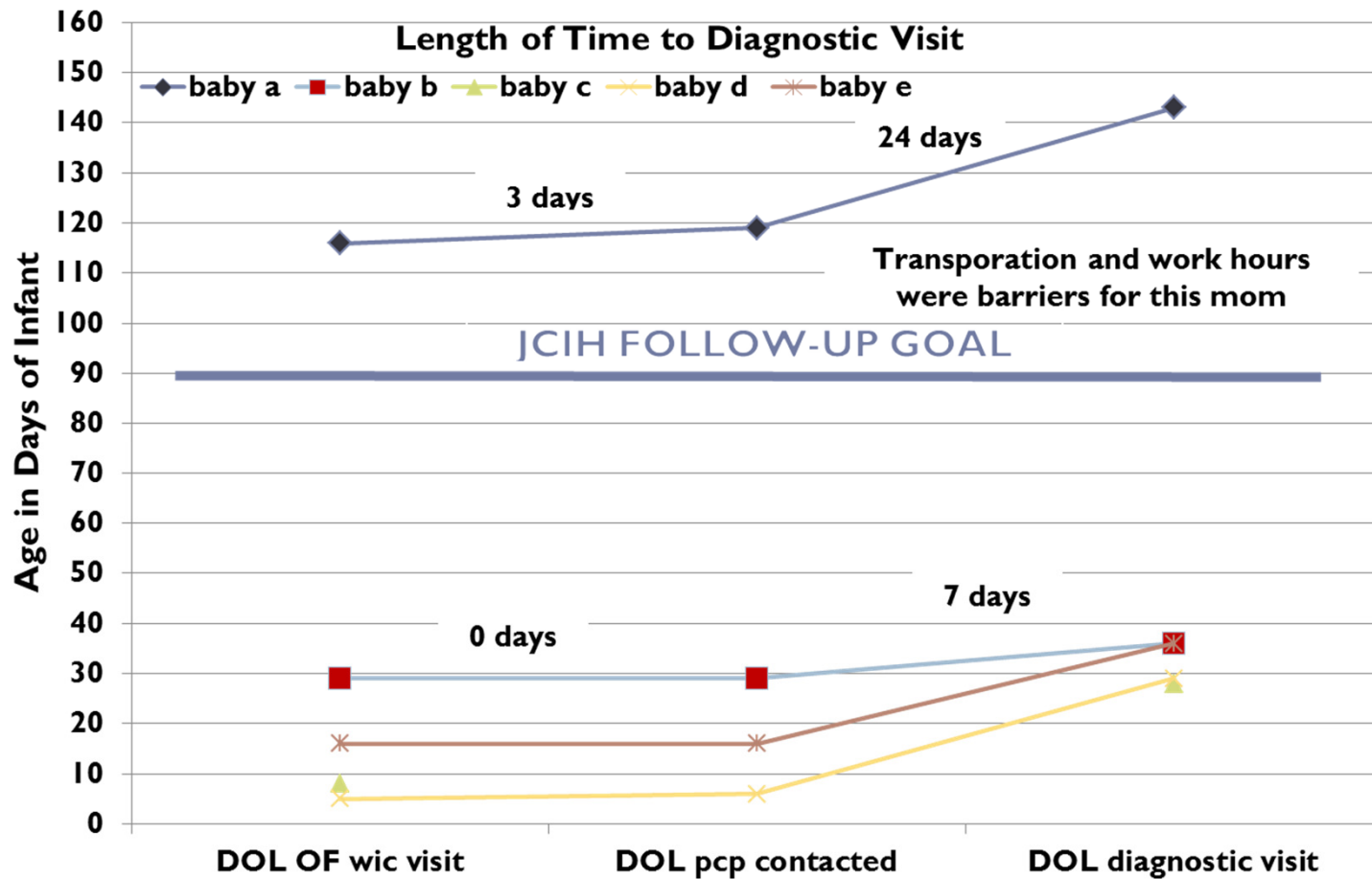
*Age at follow-up improved from 3.7 m before program to 0.7 m after program*



# 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



# 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

# Intervention and Comparison Hospitals

Table 1.1 Hospital	Annual Deliveries	Refer Rate (%)	NHS Referrals (N)	LTFU rate (%)	Medicaid/WIC (%)	Study eligible referrals (N)
<b>Comparison 1: Christ Hospital</b>	3055	11.3%	337	45%	≈50%	168
<b>Intervention 1: University Hospital</b>	2298	10.6%	274	50%	≈80%	219
<b>Comparison 2: Bethesda North</b>	4141	3.0%	133	33%	≈50%	67
<b>Intervention 2: Good Samaritan Hospital</b>	6385	2.2%	174	64%	≈80%	139
<b>Total Comparison</b>	7196	6.5%	470	41.7%	≈50%	235
<b>Total Intervention</b>	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
<b>TOTAL</b>	<b>3126</b>	<b>11697</b>		

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

# Positive Outcomes

- 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.

# Lessons Learned

- Innovative ABR Methodology
  - Useful for older babies and in office
  - Does not require a sound booth for reliable results
  - Is very portable
  - Can be run by a trained health professional
- Study Awareness Increases 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

# Quotes from Parents

- Families' Reactions
  - Often report 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”
  - One family cited language barrier as perceived barrier to follow-up

# Benefits to Study Subjects

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

# Teamwork: Identification of Study Subjects

- CCHMC Perinatal Follow-up Nurses
- Hearing Screen Coordinators at birth hospitals
- WIC Staff



# Keys to Success

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



# Participatory Action Research

- 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

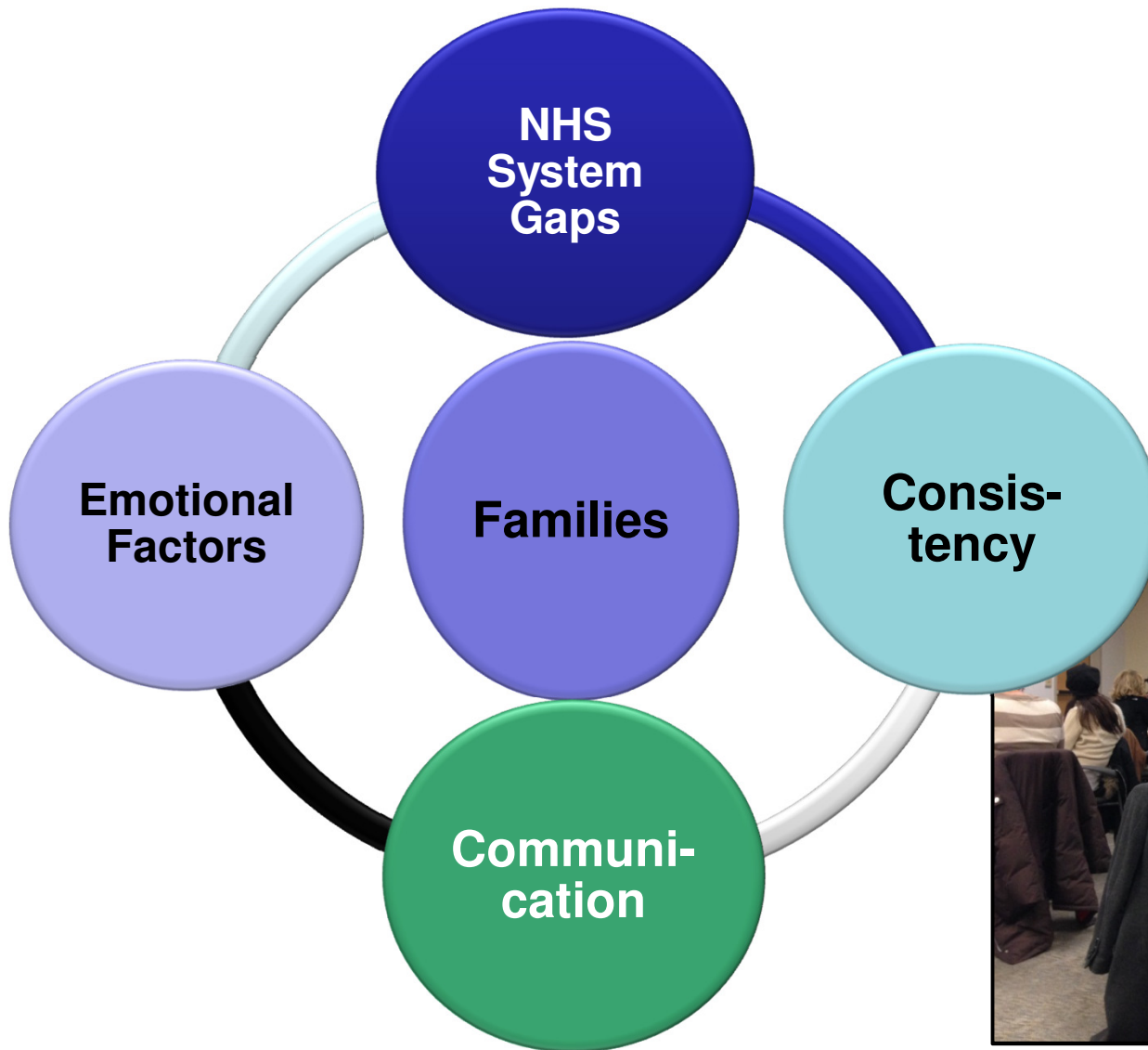
Step Five: Understanding

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, communication gaps between all parts, inconsistent messages, high cost to society, lack of consistency in the process and lack of understanding among all people involved in the process, need for consistency among all professionals involved in the newborn hearing screening process
- **Emotional Factors:** We need to take into consideration the various emotional aspects of the newborn hearing screening for the families involved in the process.
- Fear, Education, Motivation, Culture
- **Families:** Improvement in the NHS process will not be seen without support from families
- Participation, Communication, Education, Partnership
- **Communication:** A clearer message needs to be delivered by working together to meet one common goal
- Public awareness, Ownership, Partners, Resources

# 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.