Participatory Action Research With the Women, Infant and Children (WIC) Program for Improving Loss to Follow-up in Newborn Hearing Screening

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Introduction

• Overall goal is to take action to reduce loss to follow-up
  – Collaboration Between Women, Infant, and Children (WIC) and EHDI to Improve Follow-up of Newborn Hearing Screening in Greater Cincinnati

• Group Level Assessment (GLA)- serves to help gather information on ways newborn hearing screening could be improved
Loss to Follow-up: National

- Centers for Disease Control and Prevention (CDC), 2012-32% of children in the US with failed newborn hearing screening were lost to follow-up/lost to documentation for diagnosis.
- Range of loss to follow-up (LTFU) is 3% to 83% across 50 states.
- States with most well-developed EHDI programs report 2.5:1000 with permanent hearing loss; 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.
Loss to Follow-up: Ohio (2012)

<table>
<thead>
<tr>
<th></th>
<th>Total Number</th>
<th>Percentage</th>
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</thead>
<tbody>
<tr>
<td>Births</td>
<td>139,628</td>
<td></td>
</tr>
<tr>
<td>Screened</td>
<td>137,711</td>
<td>99%</td>
</tr>
<tr>
<td>Non-Pass</td>
<td>3945</td>
<td>3%</td>
</tr>
<tr>
<td>Normal Hearing</td>
<td>2334</td>
<td>59%</td>
</tr>
<tr>
<td>Hearing Loss</td>
<td>213</td>
<td>5%</td>
</tr>
<tr>
<td>No Diagnosis</td>
<td>1398</td>
<td>35%</td>
</tr>
<tr>
<td>Lost to Follow-Up</td>
<td>1254</td>
<td>32%</td>
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Courtesy of Reena Kothari, AuD
Ohio Department of Health NHSP
Improving the System – WIC Study

Rescreening Intervention at Mother’s WIC location Care Coordination

Primary Aim
– Reduce LTFU for infants referred on newborn screening

Secondary Aim
– Shorten time to first follow-up hearing test
Why WIC?

• Provides lactation/nutrition support to eligible mothers and children under 5 years
• Approx. 50% of all newborns are eligible for WIC services
• Presence of WIC offices is large, usually close for families
• Factors affecting follow-up are addressed by screening at WIC
Structure

• Study involved 2 counties in Cincinnati Area
• Newborn hearing screening referral rates measured at total of 4 hospitals
• Re-screenings completed at 4 WIC offices
• Total of 109 infants enrolled
• Compared before and after loss to follow-up rates
Infant Refers Birth Hospital

Appt. Self Scheduled

Enroll in Study

Rescreen at WIC

REFER

PASS

Diagnostic Evaluation

Hearing Confirmation, Intervention if needed

www.Vivosonic.com
Aurix©
Loss to Follow-up Rates Comparison (As of 2/26/15)

• Eligible WIC Referrals = 260
• Re-screened at WIC = 109
• Seen/scheduled for audiology = 98
• Could not be contacted = 15
• In Process/Scheduled = 35
• Refused = 3
• Loss to follow-up = 18/260 = 6.9%
Loss to Follow-up Results

Loss to Follow-up reduced from baseline of 33% to 5% in same hospitals, a reduction of 85%.

2013
$p = 0.0015$

2014
$p < 0.0001$
Age at follow-up reduced from baseline of 117 to 25 days in same hospitals, a reduction of 79%.
Re-screening Results

• Of the 109 babies that were rescreened, 10 did not pass
  – 2 cases of permanent hearing loss diagnosed
  – 5 fluctuating conductive losses
How Do We Impact All Babies Beyond WIC?

- Action groups needed to develop strategies for most-needed areas
- Working on partnership at state level between WIC and ODH to share data
Participatory Action Research (PAR)/Group Level Assessment

• Based on:
  – Reflection, Data Collection, Action

• Aims:
  – improve health, reduce health inequities

• Achieved by:
  – involving people who take actions to improve their own health

• “The reflective process is directly linked to action. The process (PAR) should be empowering and lead to people having increased control over their lives.”

• Participants invited to be in the PAR study should represent the groups who are to be impacted by the research and/or who need the results.

Who is Considered a Stakeholder?

• ANYONE that may be directly or indirectly involved in the issue you have chosen to investigate

• Families, providers, legislators, state/national organizations, counselors, patients…
Basic Fundamentals of GLA

7 specific steps designed to involve all stakeholders interactively

- Step 1: Climate Setting
- Step 2: Generating
- Step 3: Appreciating
- Step 4: Reflecting
- Step 5: Understanding
- Step 6: Selecting
- Step 7: Action
Why GLA?

- Valid data in short period of time
- Involves large groups
- Interactive, participatory process
- Draws from many different, relevant individuals (stakeholders)
- Participant driven, no hierarchy
- Useful in just about any context
Why GLA?

Limitations of Traditional Quantitative Research

- Primarily based on the condition, disease or biological process
- Usually doesn’t consider needs, viewpoints and goals
  - People with the condition
  - Clinicians treating the patient
### General Overview of Stakeholder Meetings

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<tr>
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<th>1st</th>
<th>2nd</th>
<th>3rd</th>
<th>4th</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Date</strong></td>
<td>2-12-14</td>
<td>11-5-14</td>
<td>2-5-15</td>
<td>4-9-15</td>
</tr>
<tr>
<td><strong># of participants</strong></td>
<td>34</td>
<td>30</td>
<td>15</td>
<td></td>
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</table>
| **Goals/main objective** | GLA – collect ideas and opinions regarding LTFU rates.  
- Identify barriers to follow up  
- Determine gaps/weaknesses in the system | Filtered/streamlined the data gathered from last mtg. and expanded on them | Come up with specific action ideas/concepts on how to improve LTFU rates |
Stakeholders Who Have Attended

- Ohio Maternal and Child Health
- Regional Infant Hearing Program
- Help Me Grow
- Ohio Dept of Health
- WIC program- Hamilton Co.
- Ohio Valley Voices
- St. Rita School for the Deaf
- Parents
- Birth hospital screeners
- Physicians
- SLPs
- Audiologists
- Hands and Voices
Themes that Emerged through PAR

- Theme 1- Newborn Hearing Screening System Gaps
- Theme 2- Consistency of System
- Theme 3- Family-Centered Approach
- Theme 4- Communication
- Theme 5- Emotional Factors
Barriers Identified By Stakeholders

- Maternal education level (most significant factor)
- Otitis media at the time of follow-up
- Degree of hearing loss (mild or unilateral)
- Transportation
- Third party payers
- Limited access to providers
- Comorbid diagnoses
- Appointment wait times/scheduling issues in general
- Pediatrician and midwives’ knowledge regarding the process
Stakeholders Meeting – Nov. 5, 2014

• “Pass the Buck”
  – 5 Charts (Consistency, NHS Gaps, Families, Communication, Emotional Factors)

  – Each chart has 4 quadrants (Resources, Opportunities, Barriers, Random thoughts)

  – Groups move quickly through the stations jotting down ideas
Results - Consistency

- “Distributed materials to families in an inconsistent fashion”
- “Message at hospital”
- “State system structure – too many, implemented differently”
- “Wish for one statewide system”
- “Consistent diagnostic protocol”
Results – NHS Gaps

- “Should develop a uniform statement to parents with babies who failed screening test that will be used by ALL professionals (RN, MD, AuD)”

- “Streamlined paperwork → information sent to ODH”
Results – Families

- “Connect more families together early on and for shared experiences”

- “Lack of information and different emotional responses”

- “Cultural/Religious beliefs”

- “Web supports (social media, organizations)”

- “Links to Hands & Voices, Alexander Graham Bell Assoc. for Head and Hard of Hearing, American Assoc. of the Deaf, etc.”
Results – Communication

- “Language/cultural barriers (build communities to decrease these barriers)”

- “Good phone numbers for families and how to contact providers”

- “Using technology to access families living away from services”

- “Be sensitive about health literacy and know parent’s language/reading level”

- “Incorporate awareness through birthing classes, prenatal clinics, WIC, pediatric offices”
Results – Emotional Factors

- “Maternal depression/exhaustion”

- “In denial, advice of relatives/friends, beliefs – minimizing severity”

- “Frustration in navigating the system (overwhelming/intimidating)”

- “Would be great to have a “guide”/support system by your side”

- “Realize the different cultural needs (urban vs. rural)”
Action Summit

- Discussed plan of action
  - Action Summits: small action plan groups
    - Come up with project/s to address problems identified from the meeting → positive changes in the follow up process

- Schedule next stakeholder’s meeting (2-5-15)
- Continued facilitation to create action groups to work on specific goals
- Create a plan to support stakeholders in process of implementing action plan
Stakeholders Meeting – Feb. 5, 2015

• Broke into small groups
  – Asked each group to come up with a specific action project/idea (1-3)
    • Concept
    • How to execute
    • Resources needed
    • Potential barrier

• Report back to the whole group
## Results

<table>
<thead>
<tr>
<th>Concept</th>
<th>Flag Alert in EHR</th>
<th>Education for NBH Screeners</th>
<th>Hearing Screen Mobile Van</th>
</tr>
</thead>
<tbody>
<tr>
<td>Description</td>
<td>Alert physicians when f/u has not occurred for failed screening</td>
<td>Standardized education method for screeners (quality, conveying test results)</td>
<td>Van that goes around town (targeting PCP offices) and offer screening/rescreening</td>
</tr>
</tbody>
</table>
| Barriers: | - Working with staff or IT  
- Slow down clinic flow | - Motivation  
- Buy-in  
- Cost | - Intake process  
- Requires infrastructure, cost |
| Resources: | Help from ODH | Grant application |
## Results

<table>
<thead>
<tr>
<th>Concept</th>
<th>Universal Tool for Screeners/AuD/RN/MD</th>
<th>Informational Video</th>
<th>F/U appointment scheduled prior to discharge</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Description</strong></td>
<td>Provide consistent message to parents about NBHS and results</td>
<td>Video to be shown in hospitals (patients’ rooms) about NBHS</td>
<td>To ensure follow up</td>
</tr>
</tbody>
</table>
| **Barriers:** | - Staff turnover  
- Different backgrounds and training | - Cost | - Absence of law mandating this |
| **Resources:** | ODH | | Utilize case coordinator to facilitate implementation |
Next Steps

• Compiled and forwarded all ideas of the group via email to everyone for review, suggestions and feedback
• Next proposed stakeholders’ meeting: April 9, 2015
• Stakeholders will decide on a project to carry forward
Challenges

• Coordination of stakeholders’ schedules
• Location of meetings
• Large group
• Weather issues
Ultimate Goal

• To create work groups that will continue to meet even after the GLA/PAR phase is over
• To continue to brainstorm ideas and form them into realistic plans to reduce loss to follow-up for NBHS
• Sustainability!
Funding/Acknowledgements

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- Cindy Meale, Butler County WIC
- Betsy Buchanan, Hamilton County WIC
- Families of Participants and Stakeholders
Questions?

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