Participatory Action Research: Improving Follow Up Rates of Newborn Hearing Screening in Greater Cincinnati Area

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Background

Newborn hearing screening (NHS) is a multifaceted system of education, screening, diagnosis, referral, treatment, care management, and ongoing evaluation of the effectiveness of all components. Successful newborn screening systems rely on the collection, sharing and integration of data among the family, clinical care providers, and public health programs.

Although universal NHS has dramatically reduced the number of late-identified hearing loss in children, there are still barriers that prevent the timely follow-up of all babies. Current national average for loss to follow up is 32% of those babies referred on the NHS.

Goals and Objectives

1. Determine gaps or weaknesses in the NHS system that contribute to loss to follow up.

2. To use participatory action research (PAR) [Fig.1] to generate qualitative data about health beliefs and behaviors regarding utilization of NHS systems.

3. Develop specific, sustainable projects to decrease loss to follow up rates in NHS at birth hospitals and requiring screening.

Methods

- Participants included a group of ~30 stakeholders [Fig.2] to gather information about the NHS system in Cincinnati and the surrounding suburbs.
  - 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
  - Hands and Voices

- Participants met together and broke into small groups where they provided ideas on the different issues impacting NHS and shared it to the whole group.

Data collection

- Descriptive, qualitative data about barriers to follow up were collected using a Group Level Assessment (GLA) model during our Stakeholders’ Meeting.
  - Prompt boards [Fig.4] were utilized during the meeting to capture participants’ ideas.

- Small groups were created and participants came up with specific action plans [Table 1] on how to improve follow up rates.

Results

- “Distributed materials to families in an inconsistent fashion”
  - “Should develop a uniform statement to parents with babies who failed screening test that will be used by ALL professionals (RN, MD, AuD)”
  - “Lack of information and different emotional responses”
  - “Language/cultural barriers (build communities to decrease these barriers)”
  - “In denial, advice of relatives/friends, beliefs – minimizing severity”

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<table>
<thead>
<tr>
<th>Concept</th>
<th>Flag Alert in EHR</th>
<th>Education for NBH Screening</th>
<th>Hearing Screen Mobile Van</th>
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</thead>
<tbody>
<tr>
<td>Description</td>
<td>Alert physicians when flu 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 SCP* offices) and offers screening/hearing</td>
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<tr>
<td>Barriers</td>
<td>Working staff or IT</td>
<td>Motivation</td>
<td>Intake process</td>
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<tr>
<td>Resources</td>
<td>Help from ODH</td>
<td>Cost</td>
<td></td>
</tr>
</tbody>
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NHS.

References


2. 2012 CDC ETDI Hearing Screening & Follow-up Survey (www.cdc.gov/ncbddd/hearingloss/ehdi-data.html)


Next Steps

- Continue meeting with stakeholders to carry out action plans that are sustainable to effectively reduce loss to follow up rates in NHS.

- Create work groups that will continue to meet even after the GLA/PAR phase is over.

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