Your Role in Outcome Evaluation: Why Good Data Matters

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Discussion Topics

• Federal Requirements
  – Outcomes
  – Findings

• State Requirements
  – Roles & Responsibilities
  – Quality Indicators
  – Reporting & Outcomes Analysis

• Take Home Messages
Federal Cooperative Agreement

- **Goal A:** Maintenance of the AzEHDI database to identify, match, collect, and report standardized data that is unduplicated and individually identifiable for every occurrent birth through screening, diagnosis and intervention.
- **Goal B:** Improve and develop reporting systems to ensure accurate tracking and surveillance of unduplicated identifiable data from multiple sources that is consistent with national standards and trends.
- **Goal C:** Work to develop a plan by year 4 of the Cooperative Agreement to enhance the fully developed EHDI-IS to exchange data accurately, effectively, securely, and consistently between the EHDI-IS and the EHR Systems to reduce duplicate data entry and reduce loss to follow-up.
### Occurrent Births

<table>
<thead>
<tr>
<th>Category</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Screened</td>
<td>86,055</td>
<td>99 %</td>
</tr>
<tr>
<td>Not Screened</td>
<td>1,024</td>
<td>1 %</td>
</tr>
<tr>
<td>Deceased</td>
<td>355</td>
<td></td>
</tr>
<tr>
<td>Declined</td>
<td>170</td>
<td></td>
</tr>
<tr>
<td><strong>Unknown</strong></td>
<td>441</td>
<td></td>
</tr>
<tr>
<td>Others (combined)</td>
<td>58</td>
<td></td>
</tr>
<tr>
<td><strong>Passed (IP + OP)</strong></td>
<td>85,222</td>
<td>99 %</td>
</tr>
<tr>
<td><strong>Not Pass</strong></td>
<td>833</td>
<td>1 %</td>
</tr>
</tbody>
</table>

### Diagnostics

<table>
<thead>
<tr>
<th>Category</th>
<th>Count</th>
<th>Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not Pass</td>
<td>833</td>
<td></td>
</tr>
<tr>
<td>Confirmed Normal Hearing</td>
<td>248</td>
<td></td>
</tr>
<tr>
<td>Confirmed Hearing Loss</td>
<td>156</td>
<td></td>
</tr>
<tr>
<td>No Documented Diagnosis</td>
<td>429</td>
<td></td>
</tr>
</tbody>
</table>

### Early Intervention

<table>
<thead>
<tr>
<th>Category</th>
<th>Count</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hearing Loss</td>
<td>156</td>
<td></td>
</tr>
<tr>
<td>Unilateral</td>
<td>76</td>
<td></td>
</tr>
<tr>
<td>Bilateral</td>
<td>80+</td>
<td></td>
</tr>
<tr>
<td>Intervention in AzEIP</td>
<td>60</td>
<td></td>
</tr>
</tbody>
</table>
Of 15 babies identified with hearing loss who **passed** an inpatient or outpatient screen...

11 had Bilateral Loss
4 had Unilateral Loss
When a hearing test is performed on a newborn, the initial hearing test results and any subsequent hearing test results must be reported to the department of health services as prescribed by department rules.

The newborn screening program shall establish and maintain a central database of newborns and infants who are tested for hearing loss and congenital disorders that includes information required in rule.

If tests conducted pursuant to this section indicate that a newborn or infant may have a hearing loss or a congenital disorder, the screening program shall provide follow-up services to encourage the child's family to access evaluation services, specialty care and early intervention services.
Office of Newborn Screening Responsibilities

The Director shall...

- Establish a program to ensure the tests are conducted in an effective and efficient manner

- Provide education to the general public, medical community, parents & professionals

- Maintain a centralized database — Hi*Track

- Be responsible for Follow-up Services to encourage families to access evaluation services, specialty care and EI

- Establish an Advisory Committee with an Audiologist and Otologist—Lylis and Dr Fucci

Health and Wellness for all Arizonans
Submitter Responsibilities

If you’re screening, reporting is mandatory

- Devise a system for reporting, thereby making it easy to comply
- Develop or revise reporting SOPs & guidelines to current circumstances
- Identify areas to improve in data collection
- Be prepared with “emergency” protocols in order to meet requirements
Reporting Requirements

- Name, DOB, Gender, MR #
- Birth order
- Mom’s first/last name
- Submitter name—Hospital
- Name of Provider
- Date of Test
- Contact Person info
- Screening stage
- Race, Ethnicity
- Equipment used
- Results for BOTH ears

R9-13-207

Timing

At a minimum...
Each week by the 6th day of the subsequent week

UPLOADING DAILY IS GREAT!!
Hearing Quality Indicators

- Pass and Refer rates
- Not screened
  - Missed
  - Refused
- OP return rate
- Timely Submission
- Number Screened

What’s Next?

What is Measurable?

- Pass and Refer rates
- Not screened
- OP return rate
- Timely Submission
- Number Screened

What’s Next?
Take Home Message: What does it all mean at your facility?

• Both the Federal & AZ requirements need accurate, timely hearing data to make decisions

• Data has to be patient-level for the best measurement of outcomes

• Look for the “Winnable Battles” within LTFU, i.e. no info & missing

The power is with you!
Questions?

Thank you!!