Children labeled medically complex enrolled in Early Intervention

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Background

• Approximately 40% of children with hearing loss have additional developmental concerns

• This high rate may be due to an increasing ability to support children born extremely prematurely and reliance on life-saving supports for medically complex children

• These children are increasingly served by early intervention (EI)
State System

- Regionalized tracking of children not passing UNHS is paired with the Early Intervention System (Regional Infant Hearing Programs)

- This system also collects child data about hearing loss and other issues
Annually in Ohio:

- Approximately 150,000 births per year
- Approximately 6000 non-pass UNHS
- Approximately 450 expected to be born with some degree of hearing loss
Regional Infant Hearing Programs

Coordinates tracking and follow-along for newborns identified through Ohio’s newborn hearing screening program

Assures that all families enrolled in the program receive Part C core services

Provide Early Intervention specific to hearing loss Provides services at no cost to the families

Have strong community linkages
SKI*HI Curriculum

- The Parent Advisors are SKI*HI trained

- SKI*HI: specialized curriculum offering nonbiased information on communication choices, ongoing home and family centered support for infants and children with deafness or hearing loss

http://www.skihi.org/ (Utah State University)
Objectives

• To compare medically complex children who are Deaf/hard of hearing (HOH) to children without medical complexities enrolled in EI in one state between years 2003-2006

• To understand language growth in the population of children enrolled in early intervention services for Deaf/hoh described as medically complex
Methods

• Children with permanent HL

• Enrolled in RIHP EI program 2003-06

• SKI*HI Language Development Scale
  – At least every 6 months
  – Provides units for specific ages
  – Language quotient (LQ) was created by dividing the actual score (unit completed) with the unit that signifies the appropriate language skills for the child’s current age
Medically Complex

• Determined by Regional Infant Hearing Program Parent mentors

• Typically children with medical diagnoses such as
  – seizures
  – tracheostomy
  – G-tube
  – children with some syndromes likely represented in this group as well
Methods

- Children with complex medical condition (n=177) were compared to children without medical complexities (n=328*) regarding HL characteristics

- Analysis of language among MC children
  - Changes in language units (representing gains in language skills)
  - Language quotients over time (representing language levels relative to age of child)

- Baseline language levels by early EI enrollment (<6 mos of age) late EI enrollment (>6 months)

- Change of language over 1st 12 mos of EI

*Am Ann Deaf, Winter 2011
Decreasing ages over time

Age in Months

0 3 6 9 12 15 18

Medically Complex
Not Medically Complex

Age of Identification Age of Enrollment
Type and Level of HL

Percent of Children

Medically Complex (n=177)
Not Medically Complex (N=328)
<table>
<thead>
<tr>
<th></th>
<th>Medically Complex</th>
<th>Not Complex</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N=177</td>
<td>n=328</td>
</tr>
<tr>
<td>Median age months at ID</td>
<td>5.5 (2.7-11.4)*</td>
<td>3.4 (1.7-9.2)</td>
</tr>
<tr>
<td>Median age at EI enrollment</td>
<td>8.6 (4.8-15.6)*</td>
<td>6.5 (3.2-15.5)</td>
</tr>
<tr>
<td>% enrolled by 6 months</td>
<td>36%*</td>
<td>49%</td>
</tr>
<tr>
<td>Received amplification</td>
<td>77%</td>
<td>76%</td>
</tr>
<tr>
<td>Median age at amplification</td>
<td>9.5 (6.3-18.2)*</td>
<td>7 (4.2-16.1)</td>
</tr>
<tr>
<td>% of children with severe to profound SNHL receiving CI</td>
<td>28%*</td>
<td>52%</td>
</tr>
</tbody>
</table>

Median with interquartile range reported
*p<0.01 difference between groups
Communication Modality

<table>
<thead>
<tr>
<th>Communication Modality</th>
<th>Medically Complex</th>
<th>Not Medically Complex</th>
</tr>
</thead>
<tbody>
<tr>
<td>Oral</td>
<td>40%</td>
<td>50%</td>
</tr>
<tr>
<td>ASL/Bilingual</td>
<td>10%</td>
<td>60%</td>
</tr>
<tr>
<td>Total Comm</td>
<td>50%</td>
<td>30%</td>
</tr>
<tr>
<td>Other</td>
<td>0%</td>
<td>10%</td>
</tr>
</tbody>
</table>
Medically Complex by enrollment age

- Enrollment <6 months (N=63)
- Enrollment ≥6 months (N=114)
Medically Complex by enrollment age

- Enrolled <6 months
- Enrolled ≥6 months

Percent of Children

SNHL  COND  MIXED  AN  MILD  MOD Sev-Prof  UNI
Bilateral Baseline Language by Enrollment Age

- Age At EI Enrollment
  - <=3 mos
  - 3-6 mos
  - >=6 mos

LDS Language Quotients
- 40
- 50
- 60
- 70
- 80
- 90
- 100
- 110

p=0.2
p=0.003
Adjusted mean baseline quotients

LDS Language Quotients

Receptive

Expressive
Expressive Language Gains

Mild/Moderate Hearing Loss

Duration in Early Intervention

Expressive Language Units

< 6 months age at enrollment
≥ 6 months age at enrollment
Expressive Language Relative to Age
Mild/Moderate Hearing Loss

- < 6 months age at enrollment
- ≥ 6 months age at enrollment
Expressive Language Gains

Unilateral Hearing Loss

Duration in Early Intervention

Expressive Language Units

< 6 months age at enrollment
≥ 6 months age at enrollment
Expressive Language Relative to Age

Unilateral Hearing Loss

Expressive Language Quotient

Duration in Early Intervention

< 6 months age at enrollment

≥ 6 months age at enrollment
Expressive Language Gains

Severe to Profound Hearing loss

< 6 months age at enrollment
≥ 6 months age at enrollment
Expressive Language Relative to Age
Severe to Profound Hearing Loss

Expressive Language Quotient

Duration in Early Intervention

< 6 months age at enrollment
≥ 6 months age at enrollment
Language Outcomes Among MC

- For all degrees of HL, MC entering EI early had significantly higher mean baseline LQ (>20 points, p<0.01) than late entry children

- Children enrolled early with severe/profound HL made significant language gains (β=0.27, p<.0001) in the 1st year, with LQ remaining steady

- Similar gains were seen among those enrolled late (β=0.28, p<.0001), with potential for increase in LQ (β=0.76, p=0.2)

- Children with mild/moderate HL had similar gains (β=0.33, p<.0001), with increasing LQs among late entry group (β=0.86, p=0.01), indicating possible “catch up” to early entry peers
Limitations

- No definition of medically complex
- Language quotients rather than standard scores
- No developmental/cognitive proxy measure in either group
Summary of Findings

• Both groups received amplification at equal rates, however the medically complex were fit with amplification at older ages.

• Despite similar rates of severe-profound SNHL, children who are medically complex were less likely to receive cochlear implants (28% vs 52%).

• Children with medical complexities compared to those with no medical complexities were less likely to meet the 1-3-6 goals regarding identification and enrollment.
Summary of Findings

• MC children who entered EI <6 months of age had significantly higher baseline language than children who entered ≥6 months of age

• Age at EI enrollment seemed to be the most important factor for language in this population of children
Thank you

- Ohio Department of Health
## Among those labeled MC

<table>
<thead>
<tr>
<th></th>
<th>Enrolled &lt; 6 mos (n=63)</th>
<th>Enrolled ≥ 6 mos (N=114)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Median age of ID in mos</strong></td>
<td>2.4 (0-5.5)</td>
<td>8.6 (0-32.3)</td>
</tr>
<tr>
<td><strong>Median age of Enrollment</strong></td>
<td>3.8 (0.8-5.9)</td>
<td>13.4 (6-34.5)</td>
</tr>
<tr>
<td><strong>Type of HL</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SNHL</td>
<td>40 (63.3%)</td>
<td>86 (75.4%)</td>
</tr>
<tr>
<td>Conductive</td>
<td>12 (19%)</td>
<td>8 (7%)</td>
</tr>
<tr>
<td>Mixed</td>
<td>11 (17.5%)</td>
<td>16 (14%)</td>
</tr>
<tr>
<td>AN</td>
<td>0</td>
<td>4 (3.5%)</td>
</tr>
<tr>
<td><strong>Severity of HL</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild</td>
<td>5 (17.9%)</td>
<td>13 (11.4%)</td>
</tr>
<tr>
<td>Moderate</td>
<td>27 (42.9%)</td>
<td>50 (43.9%)</td>
</tr>
<tr>
<td>Severe-Profound</td>
<td>25 (39.7%)</td>
<td>35 (20.7%)</td>
</tr>
<tr>
<td>Unilateral</td>
<td>6 (9.5%)</td>
<td>16 (14%)</td>
</tr>
</tbody>
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