Patient Input for Program Development & Improvement

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Where we began...

2017

- Dr. Francis arrived at Duke from John’s Hopkins
- Commissioned strategic plan
- Conducted an internal/external landscape analysis
Two questions:

1. What barriers to successful outcomes for children who receive cochlear implants exist in North Carolina?

2. What can Duke do to reduce these barriers, improve outcomes and increase opportunities for success?
Gathered input from:

- Duke Medical Center
- EHDI Team
- EI Teachers for DHH
- NC Dept. of Public Educ. DHH
- Parents
- BEGINNINGS
- Private SLPs
- Duke Team
• Time and distance to a CI center is a barrier for many families.

• There is room in NC for another pediatric CI program that compliments established CI centers.

• Need to develop a model of service delivery that is family and community-focused.

• A community-based model requires building trust and relationships throughout the state.

• Parent input to the development process is essential.
Next Steps

• Buy-in from Duke clinical & administrative teams
  • Establish processes and procedures for consistent service delivery
    • Create Parent Advisory Panel to guide and ensure family-centered care
Parent Advisory Panel

- Parents of children currently receiving services at Duke
- Parents of children who formerly received services at Duke
- Parents of children who received services outside of NC
5 questions; included Likert rankings plus opportunity for written comments

1. Overall perception/satisfaction
2. Indication of typical emotional state after appointment
3. Identify best part of program
4. Identify most frustrating part of program
5. Identify most important factor in choosing a pediatric hearing program
Services Received*:
4/5 audiology
2/5 otolaryngology
1/5 speech
N=5

*One parent received services in TX.

• Scheduling & coordination problematic
• Parent education materials insufficient
• Emotional support not provided
• General information vs. child specific information
Face-to-Face Meeting

5 Parents (3 in person; 2 conference call)
Chief of Head & Neck Surgery
Clinical Director Pediatric Audiology
Director of Speech-Language
Strategic Planning Consultant
## What We Learned

<table>
<thead>
<tr>
<th>Parents Told Us:</th>
<th>We Responded:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pediatric clinic is crowded, noisy &amp; not family</td>
<td>Rearranged space with attention to noise reduction, making spaces cozier (e.g., dimmable lights, bassinets, sound buffers, paint)</td>
</tr>
<tr>
<td>friendly</td>
<td></td>
</tr>
<tr>
<td>Parents need easy to understand audiograms</td>
<td>Provide familiar sounds audiogram at time of diagnosis</td>
</tr>
<tr>
<td>Parents do not have enough info about “what to</td>
<td>Created a script for the team that calls parents to remind them of appointments</td>
</tr>
<tr>
<td>expect” when they come for appointments</td>
<td></td>
</tr>
<tr>
<td>Miscommunication among staff causes undue angst</td>
<td>Hired a “Parent Navigator” to serve as point of contact for parents; examining chain of communication to identify ways to reduce miscommunication</td>
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<tr>
<td>for parents and reduces trust</td>
<td>at every stage of the process.</td>
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</tbody>
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<td>Team did not provide enough specific support during diagnostic process</td>
<td>Scheduled a series of trainings for Duke team on various topics of support, e.g., “how to deliver difficult news.”</td>
</tr>
</tbody>
</table>
| Parents need more information and support at the time of diagnosis. | Patient Navigator  
Child Life Specialist  
Parent Liaisons |
Limitations

• All were mothers.
• Participants had availability to participate.
• Did not reflect SES, ethnicity, and geographic diversity.
Summary

1. What barriers to successful outcomes for children who receive cochlear implants exist in North Carolina?

• **Access** to audiological and LSL services where families live.
• **Parent input** is essential to development of program that truly meets their needs.
2. What can Duke do to reduce these barriers, improve outcomes and increase opportunities for success?

Increase community capacity to meet the needs of children and families where they live.
Next Steps

• New parent advisory panel members
• Follow-up interviews by Patient Navigator regarding experience at Center
• Written parent surveys
• Strengthen multidisciplinary program through improved communication and cross training
• Work collaboratively to expand community resources.
Thank you

For additional information please contact
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