

# Family Support Community for Parents of Children with Cochlear Implants

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# Disclosures: Relevant Relationships

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Receives compensation as Programs Leader at Hearing First. In this role, she serves as the Coordinator of the Family-to-Family Support Community

# Qualitative Research Study of 15 Parents

Primary questions for parents following their child's diagnosis

- Where do parents turn for help and information?
- What were the barriers along the way?
- What were the things that helped them move toward LSL?



## Methods and Materials

15 parents of children with hearing loss participated in interviews, video and audio recordings of their day-to-day experiences, in-person focus groups and phone interviews.

**15 Participants**

**48 Questions**

**235 Responses**

**281 Videos**

**235 Audio Recordings**

**85 Photos**

# Results

## Four Key Stages of the Parent Journey

### Receiving the Diagnosis:

The diagnosis is devastating for families who experience feelings of helplessness, guilt, shock, heartbreak, disbelief and denial.



### Seeking Services and Information:

In seeking information, families feel overwhelmed with choices, too much conflicting and inaccurate information, lack of available audiology and LSL services. These barriers can lead to indecision and inaction



### Taking Action:

Families reconcile the diagnosis with their dreams and find appropriate audiology and LSL services to help them reach an LSL outcome for their child's immediate and long term emotional, social and academic success



### Integrating LSL:

Families experience challenges and celebrations throughout the LSL journey but adapt their lives to maintain hearing technology and integrate LSL into all aspects of their lives to facilitate their child's LSL outcome

## Two Groups of Parents Emerged

**Seeking:** Parents early in the journey who are seeking emotional support, services and hope for their child's future

**Supporting:** Parents with experience on the journey who have capacity to support those new to the journey

“I was expecting the city I live in to be able to provide some local support. And I found nothing.”

# The Must-Do List from Supporting Parents

Supporting parents offered the following words of wisdom to seeking parents:

- Speak to other parents immediately
- Find the right professionals
- Not doing the “extra work” is not an option
- Take action right away
- Learn quickly to adjust to a new family dynamic
- Recognize your capacity to be your child’s best teacher

# Online Family-to-Family Support Community

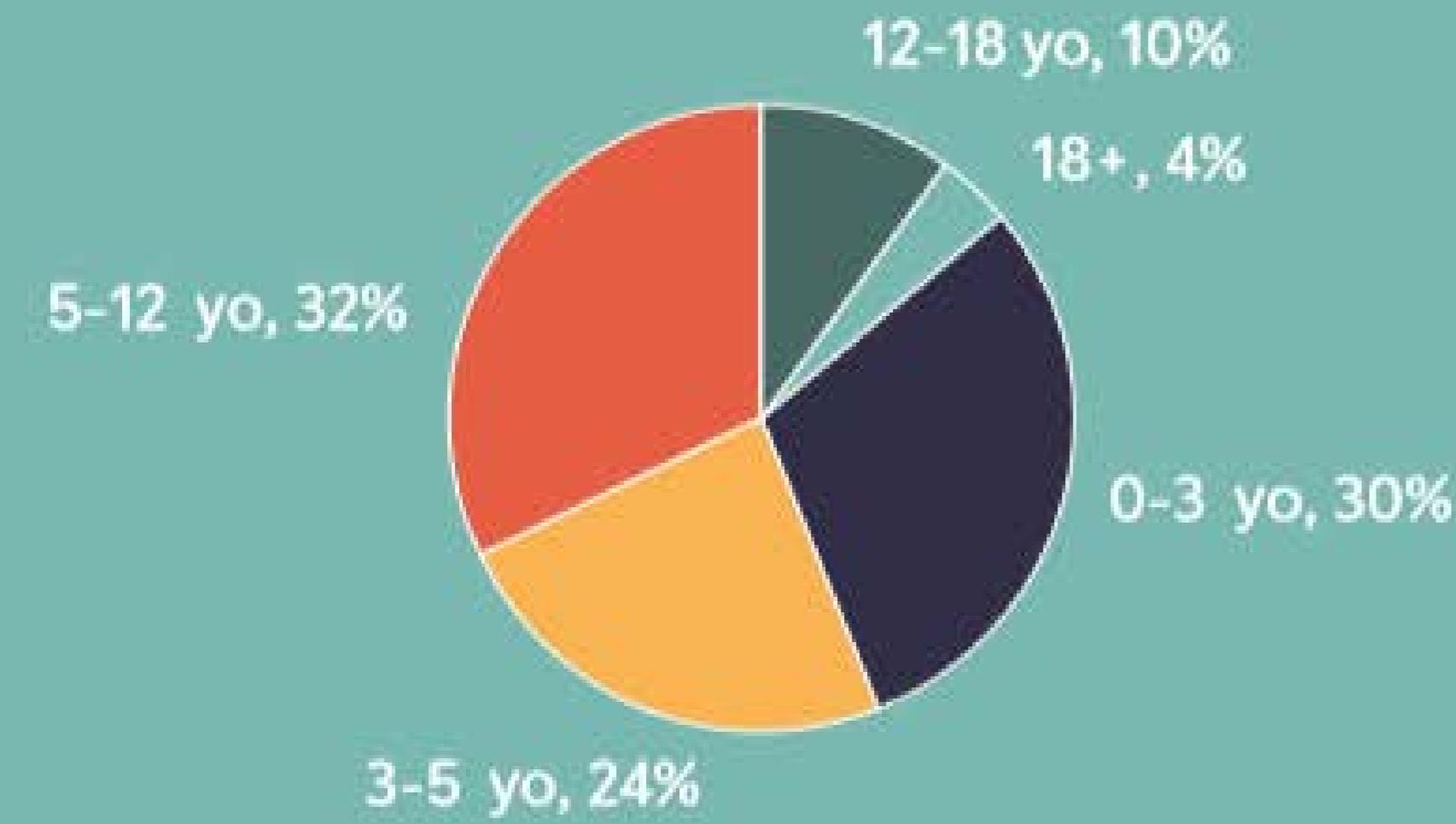
The Family Support Community was designed to offer families an online space to:

- Connect with other families any time
- Gain hope for the future
- Receive accurate information
- Find services
- Ask questions
- Share challenges
- Celebrate successes



# Community Analytics

## Ages of Children Represented in the Community



54% of Community members are in the earliest stages of the CI and LSL journey.

## Community Numbers:



**985** Members



**50** US states



**44** Countries

## How Members are Connecting:

**257** Forum Threads **1,078** Responses

# Family Support Community

## What Families Are Getting From the Community:

- Hope for their child's future
- Finding audiology and LSL services
- Access to structured learning experiences
- Tips for integrating LSL into their day-to-day life
- Connecting with families in their geographic region
- Getting answers to questions specific to their child's diagnosis

## What Families Are Talking About in the Community:

- Deciding on cochlear implants
- Choosing a company for CI
- Tips for CI headpiece
- Sports with cochlear implants
- Air travel with CIs
- Short radio clip about our CI experience
- My son inspires others
- Music with CIs
- How early did your little one get cochlear implants?
- Upcoming CI surgery - what do we expect?

## Hearing First

The Hearing First website is a multimedia digital experience and connection point designed to link families who have chosen listening and spoken language (LSL) for their children with hearing, and the professionals who work with them, with the resources, information, tools, community and learning experiences they need to ensure the children in their lives succeed.



Website



Professional  
Learning  
Community



Family Support  
Community



Coaching  
& Mentoring  
Cohorts



Learning  
Experiences

**Join us at [hearingfirst.org](http://hearingfirst.org) #LearnOutLoud**