

Family Support Community for Parents of Children with Cochlear Implants

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Disclosures: Relevant Relationships

Teresa Caraway, Ph.D., CCC-SLP, LSLS Cert. AVT, CEO
Receives compensation as CEO at Hearing First

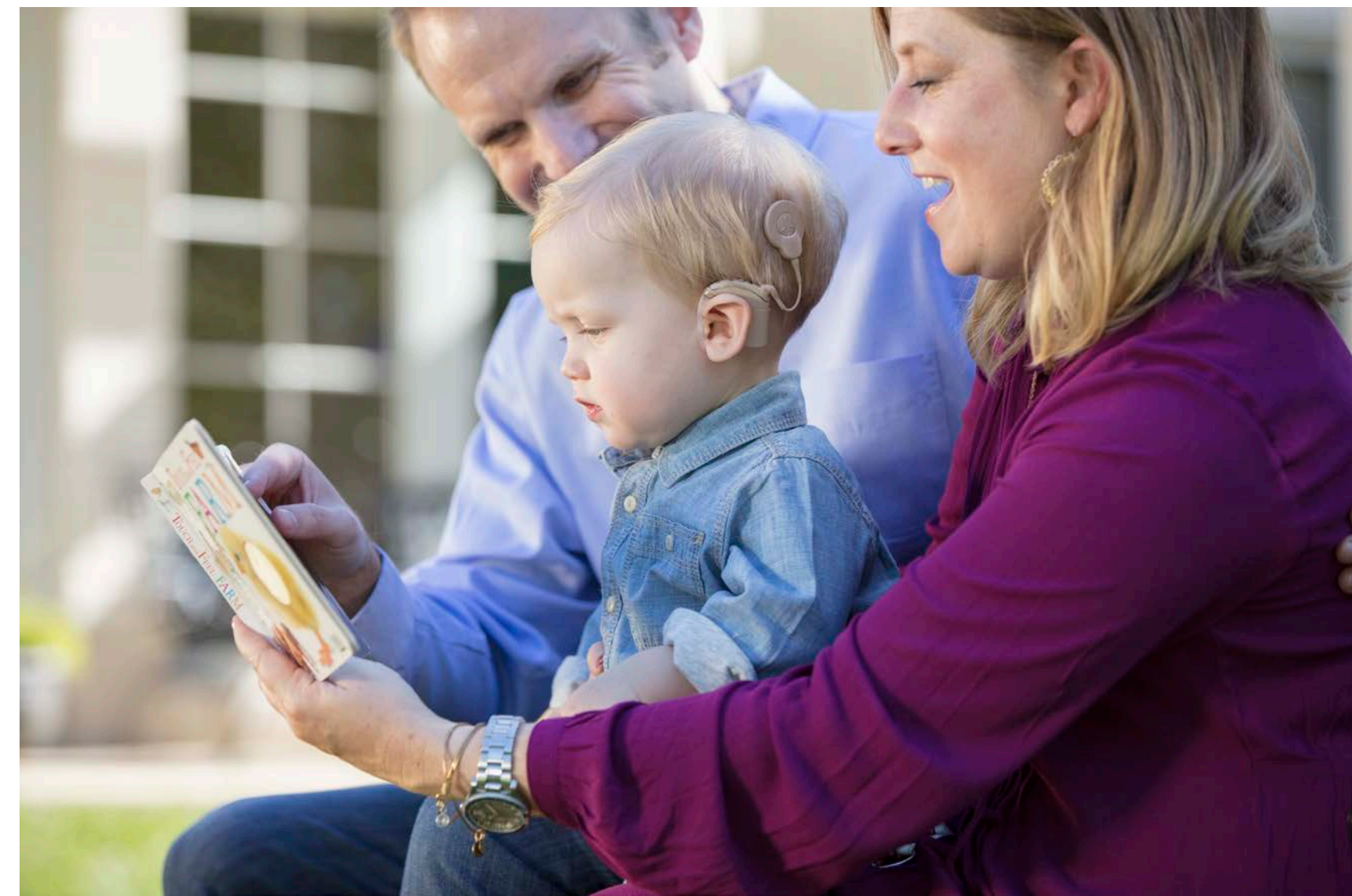
Wendelyn L. DeMoss, M.S. CCC-SLP, LSLS Cert. AVT, Programs Officer
Receives compensation as Programs Officer at Hearing First

Marge Edwards, M.S. CCC-SLP, LSLS Cert. AVT, Programs Leader
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

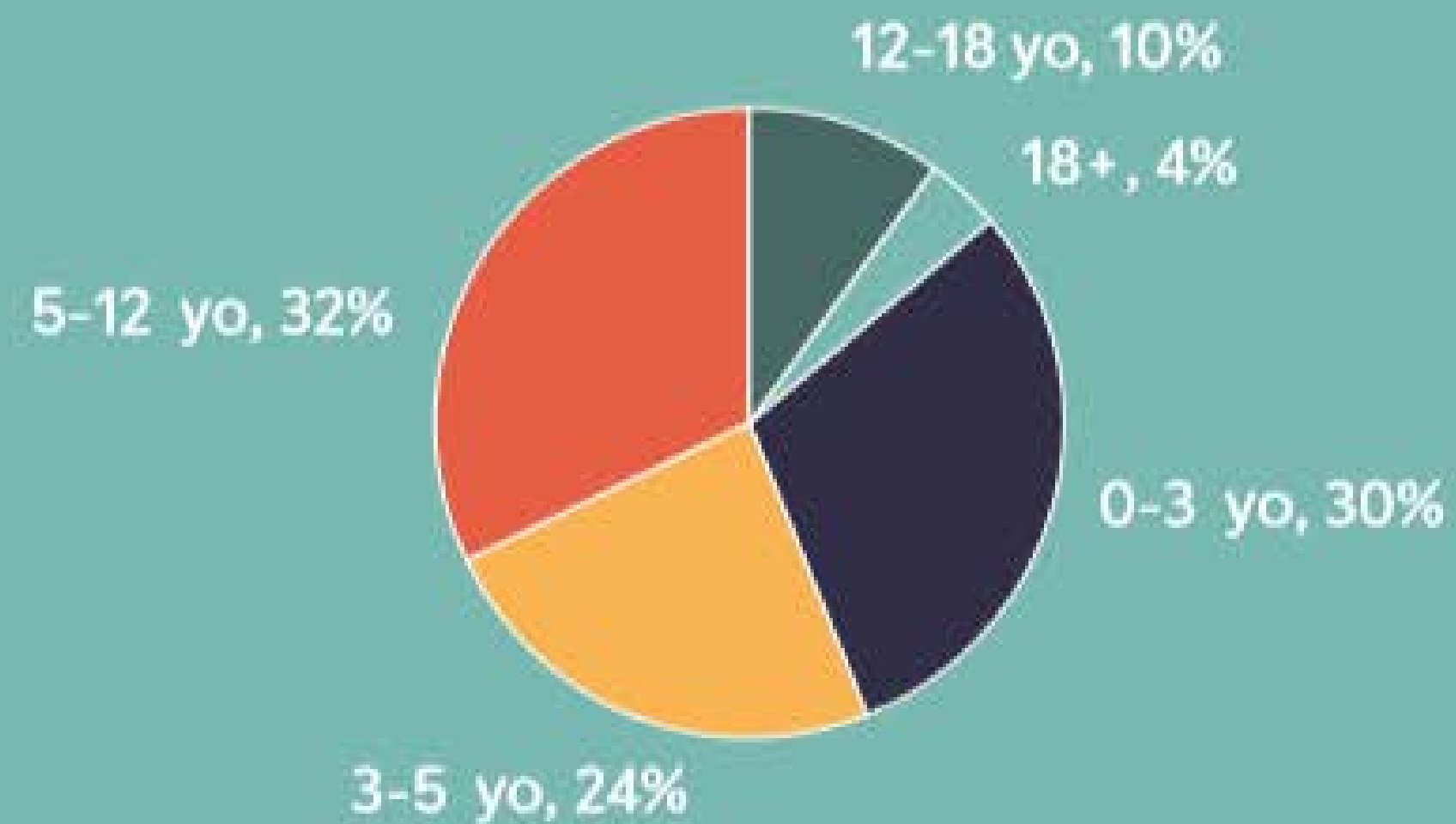
The Family Support Community was designed to offer families an online space to:

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



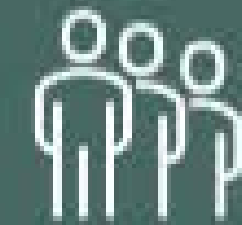
Community Analytics

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 #LearnOutLoud