

For kids with hearing loss, new therapy is an option, but it's scarce

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When Linda Baumgartner was in sixth grade, she played Anne Sullivan - Helen Keller's teacher - in a school play.

"I've always loved the idea of working with children who had hearing loss," Baumgartner said. "And I was interested in how you have to hear in order to be able to talk."

She became a speech-language pathologist and went through six years of training to become an auditory-verbal therapist - a specialist who focuses on developing kids' hearing skills as much as their speech and language.

The auditory-verbal therapy approach is a growing specialty in the field of hearing health and education that's also facing a shortage, said Alexander Graham Bell Association for the Deaf and Hard of Hearing, which certifies therapists like Baumgartner.

The reason: "The number of families seeking a listening and spoken language outcome far exceeds the number of qualified professionals available to meet their needs," according to the association.

In the United States, nearly 5 in 1,000 children between ages 3 and 17 have some hearing loss; 1 in 1,000 babies are diagnosed with hearing loss at birth, according to the Centers for Disease Control and Prevention. Half of the cases have their root in genes and the other half are due to infections, complications or unknown causes.

There's no standard treatment for kids who are born with hearing loss or develop it at a very young age. While some parents choose sign-language-only for their child and support the "deaf culture," others choose [hearing aids](#) or [cochlear implants](#) and follow it up with speech therapy, including auditory-verbal therapy.

"My experience and for a lot of parents is that it's very confusing," said Carolyn Calvo, director of Florida Hands & Voices, a group of parents and professionals who work with kids with hearing loss.

"Every child is different and having a standard is not possible," said Calvo, whose 6-year-old son Benjamin has hearing loss and wears hearing aids. "For me, I really didn't know which therapy would be most beneficial, so I tried to incorporate everything I could to keep all the doors open. I didn't really know. I couldn't get a clear answer."

"It's an invisible disability," said Tanya Williams, facilitator of Hearing Me, a support group for families with children with hearing disabilities at Arnold Palmer Hospital's Howard Phillips Center.

Implants and hearing aids "are only vehicles, but intervention is the key," Debra Knox, a speech-language pathologist at UCF Listening Center.

"You can't have one without another. It's a 24/7 commitment," said Knox, who is finishing her advanced training in becoming an auditory-verbal therapist.

Julie Schipp, who has two kids with hearing loss, said an audiologist told her about auditory-verbal therapy.

"But trying to find an AV therapist in Central Florida is almost impossible. It's hard; there are not a lot of resources," said Schipp, who has been taking her kids to UCF Listening Center to work with Knox.

Hearing sounds - whether it's cooing of an adoring mom or the barking of the family dog - is a neurological process.

"I always tell my students, hearing is not about the ear, it's about the brain," said Dr. Linda Rosa-Lugo, an associate professor in the University of Central Florida's Department of Communication Sciences and Disorders. For kids who are born deaf or with severe hearing loss, the neural pathways that are built in response to sounds are never made. So amplifying sound should be accompanied by training that teaches the brain to analyze and understand the sound that's coming in.

Baumgartner is starting a program at Florida Hospital called Little Hearoes, bringing several services, including cochlear implant mapping, hearing-aid fitting, a loaner-aid program, parent support groups, parent education and auditory-verbal therapy, under the same roof.

And she's not stopping there.

About eight years ago, said Baumgartner, "I was working with a family who was having a hard time making a decision about their child's hearing options. And they asked me when we will have a cure, and I had to say, 'Unfortunately not soon enough for your child.'"

That led her to look into the potential for stem-cell therapy. Along with her husband, a pediatric neurosurgeon at Florida Hospital, she's now running early trials to see if stem cells can improve kids' [hearing loss](#).

That's how 4-year-old Chandler Eichelberger ended up on a Florida Hospital bed recently, playing with his iPad while receiving a bone marrow transplant via a simple IV.

Chandler wears hearing aids and has been receiving auditory-verbal therapy. He is patient No. 2 in Baumgartners' bone marrow stem cell

study, which is at the very early stages and far from a definitive answer or treatment. But that's promising enough for the little boy's parents.

"We wanted to, one, potentially do something that might benefit him, and secondly, advance this field," said his dad, Chad Eichelberger, who had traveled from Tennessee with his wife and son to participate in the trial. "It's just crazy to me that there hasn't been more studies done for something that affects so many kids."

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