


TEACHERS COLLEGE
COLUMBIA UNIVERSITY
A Graduate School of Education, Health & Psychology

"I remember my husband bringing him over. But he was white-noise to the nurse. It was only after the boy had been born that the nurse said, 'You know, this is a hearing aid. It's not like you could see him when he was born, but we're not really equipped for him.' Go figure!"

Berger, Hall, & Hartman 2022

 Clarke Schools
For Hearing and Speech


1

TEACHERS COLLEGE
COLUMBIA UNIVERSITY
A Graduate School of Education, Health & Psychology

The EHDI Experience for Parents of Children with Microtia/Atresia

EHDI March 13-15, 2022
Virtual

Meredith Berger, MEd Teachers College, Columbia University Clarke Schools for Hearing and Speech	@Meredith_berger mb4374@Columbia.edu mberger@clarkeschools.org
DaeShawn Hall, MS Teachers College, Columbia University	@daeshawnhall djh2154@tc.Columbia.edu
Maria Hartman, PhD Teachers College, Columbia University	@TCDeafEd mch33@Columbia.edu

 Clarke Schools
For Hearing and Speech


2

TEACHERS COLLEGE
COLUMBIA UNIVERSITY
A Graduate School of Education, Health & Psychology

Disclosures

Meredith Berger Non-Financial: • Option Schools: Executive Board, Director at Large • Children's Hearing Institute-Medical and Educational Advisory Board • NYS EHDI Advisory Committee • Parent of a child with microtia/atresia, uses Cochlear bahas	Maria Hartman Non-Financial: • Children's Hearing Institute Board Member • St. Francis de Sales School for Deaf Board Member
DaeShawn Hall	None

Berger, Hall, & Hartman 2022

 Clarke Schools
For Hearing and Speech

3

Learning Outcomes

- Examine JCIH recommendations and current research on parent experiences with the UNHS process
- Identify themes of experiences for parents of children with microtia/atresia and determine whether their experiences align with the goals of EHDI
- Develop strategies for supporting families of children with microtia atresia that align with the goals of JCIH and EHDI

TEACHERS COLLEGE
COLUMBIA UNIVERSITY
A Graduate School of Education, Health & Psychology

Berger, Hall, & Hartman 2022

Clarke Schools
For Hearing and Speech

4

What are the experiences, perspectives, challenges, and needs of parents following the birth of a child with microtia/atresia (aural atresia)?



TEACHERS COLLEGE
COLUMBIA UNIVERSITY
A Graduate School of Education, Health & Psychology

Berger, Hall, & Hartman 2022

Clarke Schools
For Hearing and Speech

5



TEACHERS COLLEGE
COLUMBIA UNIVERSITY
A Graduate School of Education, Health & Psychology

Berger, Hall, & Hartman 2022

Clarke Schools
For Hearing and Speech

6

TEACHERS COLLEGE
COLUMBIA UNIVERSITY
A Graduate School of Education, Health & Psychology






Berger, Hall, & Hartman 2022

Clarke Schools
for Hearing and Speech

7

TEACHERS COLLEGE
COLUMBIA UNIVERSITY
A Graduate School of Education, Health & Psychology

2019 JCIH Guidelines

(The Joint Committee on Infant Hearing, 2019)

1:3:6

- 1 All infants-hearing screening no later than one month of age
- 3 Diagnostic audiologic evaluation to confirm the infant's hearing status no later than 3 mo
- 6 Family centered EI services services should begin ASAP and no later than 6 months of age

And:

- Immediate referral to Early Intervention.
- Immediate access to high-quality, well-fitted, and optimized hearing aid technology.
- If the family chooses, fitting of hearing aid amplification no later than four months of age

Clarke Schools
for Hearing and Speech

8

TEACHERS COLLEGE
COLUMBIA UNIVERSITY
A Graduate School of Education, Health & Psychology

JCIH Recommendations-Microtia/Atresia

Timing of Newborn Hearing Screening

Infants with congenital aural atresia in one or both ears or with visible pinna/ear canal deformity such as stenosis or severe malformation should not be screened in either ear but should be referred for diagnostic audiologic evaluation immediately upon discharge. The diagnostic audiologic evaluation can also be accomplished while the infant is in the NICU or other inpatient hospital unit.

Referral to early intervention services

The purpose of early intervention is to achieve optimal child and family outcomes. Hence, the audiologist must make the referral for Part C Early Intervention (IDEA, 2004) services as quickly as possible following confirmation that a child is deaf or hard of hearing. Federal regulations require that this referral be made within seven working days of diagnosis (IDEA, 2004). **In cases of congenital aural atresia, the referral can and should be made by the birth hospital.**

Clarke Schools
for Hearing and Speech

9

TEACHERS COLLEGE
COLUMBIA UNIVERSITY
A Graduate School of Education, Health & Psychology

Children with mild bilateral and unilateral hearing loss: Parents' reflections on experiences and outcomes.

Fitzpatrick, E., Grandpierre, V., Durieux-Smith, A., Gaboury, I., Coyle, D., Na, E., & Sallam, N. (2016). Children With Mild Bilateral and Unilateral Hearing Loss: Parents' Reflections on Experiences and Outcomes. *The Journal of Deaf Studies and Deaf Education*, 21(1), 34-43. <https://doi.org/10.1093/deafed/enu047>

20 parents of children mild bilateral or unilateral

- 4 children had conductive loss.
- Diagnosis process was hard and filled with uncertainty
- Importance of the hearing loss was minimized by professionals
- Uncertainty about need for amplification

 Clarke Schools
for Hearing and Speech

Berger, Hall, & Hartman 2022


10

TEACHERS COLLEGE
COLUMBIA UNIVERSITY
A Graduate School of Education, Health & Psychology

Parental preferences for the first consultation for microtia.

tot Westerflter, C. V. V. H., Stegeman, I., Muradin, M. S., Smit, A. L., & Breugem, C. C. (2018). Parental preferences for the first consultation for microtia. *International journal of pediatric otorhinolaryngology*, 106, 10-15.

- 87 parents
- Survey regarding initial information presented to parents after their child's birth
- 26% received no information after birth
- 60% of parents describe the initial informing consult as "terrible" or "bad"
- 1 parent (.01%) described initial consult as "excellent"

 Clarke Schools
for Hearing and Speech

Berger, Hall, & Hartman 2022


11

TEACHERS COLLEGE
COLUMBIA UNIVERSITY
A Graduate School of Education, Health & Psychology

Microtia: epidemiology and genetics

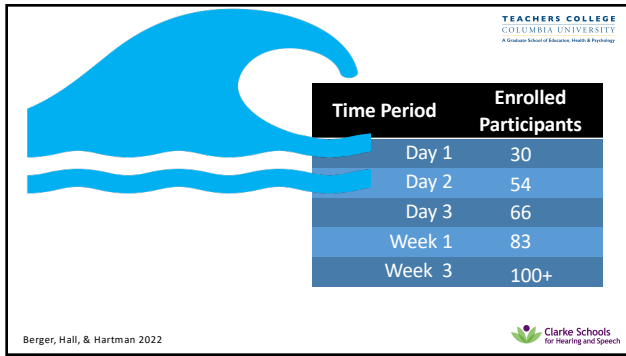
Luquetti, D. V., Heike, C. L., Hing, A. V., Cunningham, M. L., & Cox, T. C. (2012). Microtia: epidemiology and genetics. *American Journal of Medical Genetics Part A*, 158(1), 124-139.

- 0.83 to 17.4 per 10,000 births
- Hispanics, Asians, Native Americans, and Andeans at the higher end
- Black/African descent-least likely
- 20-40% higher in males
- Right ear-60% and unilateral 80-90%
- Vertebral anomalies, macrostomia, oral clefts, facial asymmetry, renal abnormalities, cardiac defects, microphthalmia, holoprosencephaly, and polydactyly—many are associated with Oculo-auriculo-vertebral spectrum (OAVS)

 Clarke Schools
for Hearing and Speech

Berger, Hall, & Hartman 2022

12



13

Study Design

Inclusion criteria:

- Parent of a child/children with microtia/atresia
- Child between 6 months-6 years of age
- Able to complete survey and interview in English

1. Survey-demographic info and other details
2. Semi-structured Interviews

TEACHERS COLLEGE
COLUMBIA UNIVERSITY
A Graduate School of Education, Health & Psychology

Berger, Hall, & Hartman 2022

Clarke Schools
for Hearing and Speech

14

Survey

Parent	Child
<ul style="list-style-type: none"> ➢ Age ➢ Education level ➢ Occupation ➢ Relationship to child 	<ul style="list-style-type: none"> • Languages used in home • Communication Modality • Gender • Race/Ethnicity • UNHS result • Etiology • NICU, medical needs

TEACHERS COLLEGE
COLUMBIA UNIVERSITY
A Graduate School of Education, Health & Psychology

Berger, Hall, & Hartman 2022


Clarke Schools
for Hearing and Speech

15


TEACHERS COLLEGE
COLUMBIA UNIVERSITY
A Graduate School of Education, Health & Psychology

Participants

Initial Survey N=116 Interviews for Current Study N=21



- 18 mothers, 2 both parents
- 95% had “some college” or higher
- 33% ≥ 40 yrs.
- 76% English only homes


Berger, Hall, & Hartman 2022 

16


TEACHERS COLLEGE
COLUMBIA UNIVERSITY
A Graduate School of Education, Health & Psychology

Child characteristics

- Gender
 - Male (n=16)
 - Female (n=5)
- Ear
 - Right (n=15)
 - Left (n=4)
 - Both (n=2)
- Etiology
 - Unknown (n=19) 90%
 - Family History (n=1) 5%
 - Syndrome (n=1). 5%




- Age at ABR
 - ≤3 (n=18) 86%
- Type of Hearing Loss
 - Conductive (n=18)
 - Mixed (n=1)
 - **Not Sure. (n=2)**
- Amplification History
 - Uses (n=17) 64.5%
 - Never Had (n=1) 20%
 - Had but doesn't use (n=3)
- Age when dispensed:
 - 3 weeks-36 months
 - 66% received ≤6 months

Berger, Hall, & Hartman 2022 


17

TEACHERS COLLEGE
COLUMBIA UNIVERSITY
A Graduate School of Education, Health & Psychology

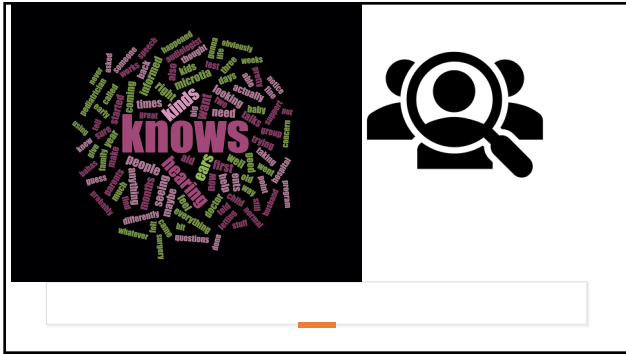
Race/Ethnicity



White/ Caucasian (only)	16
Black/African-American or African and White/Caucasian	0
Asian or Asian bi/multiracial	2
Hispanic/Latino or Hispanic bi/multiracial	2
Asian/Hispanic multiracial	1

Berger, Hall, & Hartman 2022 

18



19

TEACHERS COLLEGE COLUMBIA UNIVERSITY <small>A Graduate School of Education, Health & Psychology</small>	
Initial awareness	Response/reactions of medical professionals in hospital Newborn hearing screening experience Referrals for follow up after leaving hospital
Concerns/Worries	Cause/Blame Immediate Future
Decision Making	Amplification Communication Modality Early Intervention
Supports	Sources of Information What helped Early Intervention
Advice	Professionals Other/new parents

Berger, Hall, & Hartman 2022

20

Knowledge, support and awareness in hospitals

Reactions/responses of medical staff

"I think it was a student or a nurse or someone who wasn't really involved who told us "you'll see he has an ear deformity". After the whole fear of losing him, it was just a little traumatic how they told us but that's how we were informed."

"I think no one in the room really knew what to say or what call it, microtia or anything right then. I think they just you know, noted that his ear didn't look normal and they brought in a NICU doctor...I think that NICU doctor said he thought they'd probably call it microtia"

"When the pediatrician came upstairs. She's looks at her ear canals-and said they're closed, we're going to have an ENT come and take a look. And that was kind of it in like the first like, I don't know, like, the immediate 30 to 40 minutes from when she was born."

Lack of timely and accurate information

"They were saying that before you leave the hospital, an ENT will come and look at her ...we were there for 2 days and no one came. We kept asking & asking- no one ever came."

"we didn't even know the name until like three months later until we got into see the ENT"

Berger, Hall, & Hartman 2022

21

Dr. Google

TEACHERS COLLEGE
COLUMBIA UNIVERSITY
A Graduate School of Education, Health & Psychology

- “The microtia part... I didn't really get anybody to explain that to me. Like this stage three thing. I didn't even find that out until I asked because we googled and I'm like, hey, there's all different kinds on here.”
- “We did our own little Google search- this is probably like this word. I don't know exactly how to say it. You know? And it looks like it's not really very harmful or, or anything. I think this is probably what it is. We got a little google research of our own. But no one said, Oh, this is microtia, this is atresia.
- “it's like a horrible thing to Google something and like the first thing it says, you know, microtia is a congenital birth defect”
- “We kind of just self-diagnosed and figured it out kind of on our own. When we left the hospital, we were pretty confident she had grade three microtia- that was purely on our own researching”



22

Self-blame and concerns for the future

TEACHERS COLLEGE
COLUMBIA UNIVERSITY
A Graduate School of Education, Health & Psychology

This is my fault.

“My first thought was shit, what did I do wrong? It sounds horrible. But your first thought is, should I have eaten that or what did I cause to, you know, do to cause this?”

“You think how did I fail her? She was inside of me, what did I do that caused it? ”

“I was not a drug user. I was not drinking while pregnant...which was helpful when people ask questions for me to say it wasn't my fault, because it's very easy to feel like I did something wrong during pregnancy. And that was not in fact my fault”

Concerns for the Future

“You think, what will her life be down the road? Is this going to be a burden? Is this going to make her peers tease her? You already start thinking of those thoughts”

“Everybody said he's gonna be bullied. And he will have difficulty in school if he has only one ear.”

Berger, Hall, & Hartman 2022



23

Experience with EHDl

TEACHERS COLLEGE
COLUMBIA UNIVERSITY
A Graduate School of Education, Health & Psychology

- “We had a very rough ABR because actually their machine wasn't working. And so we were sitting there watching and not seeing any activity. And we were just crying thinking, Okay, he's, he's deaf. That's just what our life will be we'll deal with it. And it was a young audiologist who I think was newer to the clinic or the hospital. They were both trying to troubleshoot the machine. And it it took them way too long to let us know that what's going on, we just thought he can't hear.”
- “It wasn't until I found the Facebook groups...And then I learned a lot from there. It was very shocking to see all those babies with bahas because I didn't even know that was an option for him.”

Early Intervention

- “I was asking about speech, and the EI official said he's so young, we don't do anything until we know there's problem.”
- The speech therapists were curious, because I was the only one they had. So they were more curious about how does it work kind of questions and more like asking me like a health care provider or pediatrician.”



24

TEACHERS COLLEGE
COLUMBIA UNIVERSITY
A Graduate School of Education, Health & Psychology

References

Fitzpatrick, Elizabeth, et al. "Children with mild bilateral and unilateral hearing loss: Parents' reflections on experiences and outcomes." *Journal of Deaf Studies and Deaf Education* 21.1 (2016): 34-43.

Krishnan, L. A., Lawler, B., & Van Hyfte, S. (2017). Parent educational materials regarding the newborn hearing screening process. *International Journal of Pediatric Otorhinolaryngology*, 95, 34–38. <https://doi.org/10.1016/j.ijporl.2017.03.025>.

Larsen, R., Muñoz, K., DesGeorges, J., Nelson, L., & Kennedy, S. (2012). Early hearing detection and intervention: Parent experiences with the diagnostic hearing assessment. *American Journal of Audiology*.

Luquetti, D. V., Heike, C. L., Hing, A. V., Cunningham, M. L., & Cox, T. C. (2012). Microtia: epidemiology and genetics. *American Journal of Medical Genetics Part A*, 158(1), 124-139.

The Joint Committee on Infant Hearing. (n.d.). Year 2019 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs. *Journal of Early Hearing Detection and Intervention*, 4(2), 1–44. <https://doi.org/10.15142/JFDI-8748>.

Westerflieer, C. V. V. H., Stegeman, I., Muradin, M. S., Smit, A. L., & Breugem, C. C. (2018). Parental preferences for the first consultation for microtia. *International journal of pediatric otarhinolaryngology*, 106, 10-15.

Berger, Hall, & Hartman 2022

 Clarke Schools
for Hearing and Speech
