



Childhood hearing loss detection and intervention systems: A qualitative exploration of African-American and Caucasian parents' experiences and needs



Q & A

INTRODUCTION

Universal newborn hearing screening (UNHS) has been supported as an integral component of early hearing detection and intervention (EHDI) programs which aim to identify and treat childhood hearing loss (HL) early and minimize its negative effects on the child and family. The majority of research has supported UNHS and EHDI services for children with HL. However, there is little literature on the impact of childhood HL detection and intervention on the family. Research by Fitzpatrick, et al. (2008)¹ provided valuable insights into parent needs and experiences with childhood HL. However, this research was conducted for parents in Ontario, Canada, and did not describe some participant variables that might have been relevant to their health experiences. Although there is some research to suggest that variables such as geographic location, race, and socioeconomic status (SES) might impact health experiences and outcomes (U.S. Department of HSS, 2008)², it is not clear how experiences with the EHDI process might differ according to these variables. Thus, it is not certain that the insights obtained by Fitzpatrick, et al. are transferable for families of children diagnosed with HL in other geographic areas with different racial and economic compositions. Our research sought to provide insight into these issues by expanding the investigation of parent experiences to include Caucasian and African American parents of children identified with HL in Memphis, TN within the past 5 years.

Specific objectives for this study were:

1. To understand local parents' experiences and needs surrounding childhood HL.
2. To identify systematic strengths and weaknesses of pediatric hearing-related services in the Memphis community.
3. To explore how geographic, racial, and SES differences might impact parents' experiences with the EHDI process.

PARTICIPANTS

Five families of 6 different children identified with HL in the Memphis metropolitan area within the past 5 years participated in this research. Participant demographics were as follows:

Code Name	Family Composition	Identified Race	Highest Completed Education	Reported Annual Income
MOSD Mom C1	Married mother of 3 year old twins; one son failed UNHS (wears HAs); other son NH	Caucasian	Completed Bachelor's degree	\$100,000 to \$200,000
K AA 1a, AA 1b	Married mother of 3 children; oldest son NH, middle daughter (age 6) identified at pediatrician at age 5, youngest son (age 3) failed UNHS. Both with HL wear HAs	African American	Completed Associate's degree	\$25,000 to \$45,000
Mom C2	Divorced mother of 2 children; older daughter NH, younger son (age 5) failed UNHS, has bilateral CI	Caucasian	Completed high school	\$25,000 to \$45,000
Aunt Uncle AA 2	Aunt and uncle of 4 year old, identified at pediatrician screening at age 2, wears HAs.	African American	Completed high school	\$10,000 to \$25,000
Mother C3	Married mother of 2 children, expecting third child. Older daughter NH, younger daughter with genetic HL failed UNHS	Caucasian	Graduate Degree	\$100,000 - \$200,000

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PROCEDURE

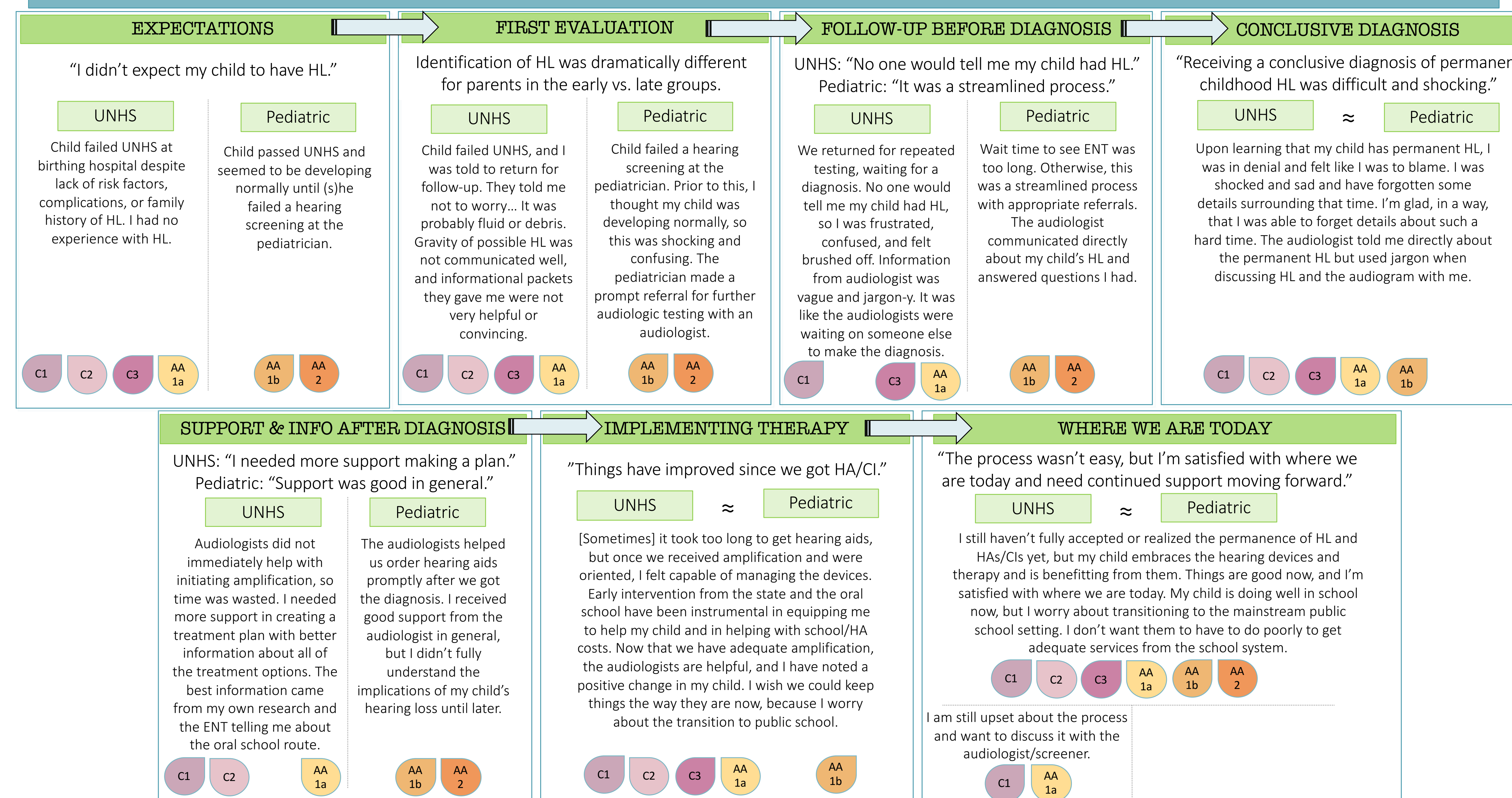
Semi-structured interviews were conducted over a 6-month period. Parents were asked to recall experiences with childhood HL and to identify strengths and weaknesses of the current service model.

Primary interview questions:

1. What was your experience with the HL diagnosis process?
2. What were your needs following diagnosis of your child's HL?
3. If you could redesign the system, what would be the important components you would include?
4. Did you perceive any differences in services and treatment based upon race?

Interviews were transcribed, systematically coded, and categorized according to similarities in meaning. Those categories identified by at least two research participants are summarized for children identified early (< 1 year; "UNHS") and later (> 1 year; "Pediatric").

RESULTS



SUMMARY OF RESULTS: Two distinct experiences emerged when exploring these data. Four of the parent experiences (3 Caucasian and 1 African-American) began with the child failing UNHS. Two of the parent experiences (both African-American) began when the child failed a hearing screening at the pediatrician. Experiences differed drastically between these two phenomena. All 6 children had no previous indications or family history of HL. All parents reported satisfaction with treatment as it stands today and that their children embrace hearing assistive technology and therapy.

Experience 1: Child failed UNHS at birthing hospital

- Learned child failed UNHS and told to return for follow up. Generally did not understand importance of follow-up based on interaction with screener and were told that failed screening was likely due to something other than hearing loss (e.g., fluid, debris in ear canal, etc.)
- Felt brushed off by audiologists who continually rescheduled for retesting and did not communicate directly or clearly with me about my child's hearing loss. Audiologist used complex jargon and seemed to be waiting on someone else to make the diagnostic call. Only some audiologists gave good support and had a plan for initiating treatment (e.g., hearing aids) after diagnosis; most did not seem to have a treatment plan and provided inadequate information. Felt like time was wasted after diagnosis and it took too long to get hearing aids. Early intervention services generally helpful with financial support and information about hearing loss, management strategies, and treatment options.
- Emotions during process: denial, guilt, shock. Frustration and anger directed at audiologists (due to drawn out diagnostic process and minimal helpfulness in quickly initiating hearing aid process) and ENTs (due to timeliness and availability).
- All four children attend local oral school currently. Parents are grateful for services received there but fearful of transition to public schools due to idea that children with hearing loss are sometimes lost in the wind and have to be doing poorly to receive adequate services.

Experience 2: Older child was believed to have normal hearing until failed hearing screening at pediatrician

- Streamlined process with referral to audiologist/ENT and initiation of hearing aid process after failed screening at pediatrician.
- Satisfied with diagnostic and amplification services provided by audiologists.

Q: What were local parents' experiences and needs surrounding childhood hearing loss?

A: Parents needed but did not receive direct and jargon-free communication regarding potential HL and the need for follow-up after failed UNHS. Following failed UNHS, parents needed timely assistance in developing a treatment plan and initiating amplification, but felt brushed off by audiologists. Participants experienced difficulty scheduling ENT appointments quickly and having long wait times, but ENT services were direct and helpful with treatment referrals. Pediatricians seemed to brush off possible HL for those infants who failed UNHS but provided timely and streamlined referrals to ENT and audiology for older children (age 2-5). Early intervention services were reportedly helpful overall.

Q: What strengths and weaknesses of pediatric hearing-related services were identified in the Memphis metropolitan community?

Strengths: (1) streamlined diagnostic and treatment process when identified > 1-2 years of age; (2) permanent HL explained thoroughly after diagnosis; (3) satisfactory amplification, early intervention, and educational services received at local oral school; (4) support from state early intervention services (5) strong audiologic services after hearing aids received and treatment initiated, and (6) direct communication from ENT.

Weaknesses: (1) delayed and vague diagnostic and treatment processes when identified at UNHS; (2) understated importance of follow up and possibility of HL after failed UNHS; (3) audiologists' use of jargon; (4) lengthy wait times to see ENT; (5) lack of pediatrician concern for HL during first 1-2 years of life; (6) cost of services and amplification; (7) inadequate provision of appropriate public school services for children who have HL but perform well.

Q: How did geographic, racial, and SES differences impact parents' experiences with the EHDI process?

A: Racial and SES differences were suspected but not indicated in this small sample. Several concerns regarding insurance were indicated. One mother who used Medicaid believed superior services might have been obtained at a "better" center if she had private insurance. One mother indicated difficulty in affording audiologic services given that the family had private insurance and made "too much" money. Like the Ontario study¹, general dissatisfaction with communication of diagnosis, a lack of support during treatment initiation and resource identification, and an emerging mistrust of hearing health professionals were identified. No noted differences between the Ontario and current studies were presumably related to geographic and racial differences, but it was noted that differences might be found with a sample including participants with lower SES due to Canada's universal healthcare system aiding with hearing aid costs.

DISCUSSION

Our results indicate an urgent need to improve newborn hearing screeners' and audiologists' communication with parents regarding potential for hearing loss, importance of follow-up and clear, jargon-free articulation of diagnosis. Following diagnosis, patients seek greater informational support regarding treatment options and timely initiation of therapy. It is possible that communication weaknesses identified in this study contribute to high loss-to-follow-up for early intervention rates in this region. Development of succinct, thorough, and community-specific informational resources to be delivered to parents at each stage of the hearing loss process (i.e., failed screening, diagnosis of HL, treatment options, etc.) may be helpful in supporting parents in the future.

REFERENCES

- ¹ Fitzpatrick, E., et al. (2008). Parents' needs following identification of childhood hearing loss. *American Journal of Audiology*, 17.
- ² U.S. Department of Health and Human Services. (2008) The Secretary's Advisory Committee on National Health Promotion and Disease Prevention Objectives for 2020. Phase 1 report: Recommendations for the framework and format of Healthy People 2020.