A pilot study identifying relative parental value systems for deaf child developmental domains in the context of Early Hearing Detection and Intervention (EHDI) system narratives

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1. Introduction

- Early decision-making for deaf children's' language and communication choices, such as using American Sign Language (ASL) and/or a spoken language like English, has an ongoing impact on quality-of-life outcomes across the lifespan.
- Factors potentially influencing the EHDI decision-making process for parents are targets for intervention to improve deaf child development.
- **The purpose** of this pilot study is to learn more about the role of relative decision-making values when similar information is framed different ways.

Do priorities of child development domains change based upon early framing of language and communication concern with a hypothetical, recently-identified, deaf newborn?

2. Methods

- Survey-based pilot study using ResearchMatch. Emailed contact list until met 600 complete responses; slightly >300 for each of the two RedCap surveys. Respondents received one of two surveys.
- Survey scenarios offered information presented in either a medical or cultural framework for a hypothetical, recently-identified deaf newborn during hospital newborn hearing screening and follow-up appointment with a pediatric Audiologist.
- Scenario framings were developed in consultation with two experienced clinical audiologists (one white, Deaf woman and the other a hearing, Black woman).
- Standardized demographic data was collected for all respondents, including current parental status and if the respondent had a child with a disability or deaf/hard of hearing child.
- After reading the hypothetical scenario, respondents replied to questions around child developmental domains with forcedranking.
- A self-personality assessment was administered to determine if personality had any association with child development domain prioritization.
- Quantitative data analyses included: logistic and ordered regression, permutation testing, univariate and bivariate analyses and odds-ratio determination.

Medical vs. Cultural frameworks

- Medical and cultural framework scenario framing was intentionally used from the perspective of culturally Deaf adults and Deaf scientific professionals.
- Some clinical phrases were used across both scenarios for accuracy and to reflect current best practices.



Value indicated as most important in rank order by frame							
Value		Medical	Cultural		Adj. Odds		
		(N = 341)	(N = 335)	Р	Ratio ^{a,b}	Р	
Cognitive	Ν	208	181				
	%	61.0	54.0	0.039	1.32	0.039	
Socio-emotional	Ν	67	72				
	%	19.6	21.5	0.316	0.91	0.298	
Language	Ν	48	55				
	%	14.1	16.4	0.225	0.84	0.204	
Physical	Ν	18	27				
	%	5.3	8.1	0.099	0.62	0.058	

^a Odds Ratio = Medical Odds/Cultural Odds ⁹ Adjusted for race (white vs. non-white) and the degree that someone self-reports as being outgoing and social—two factors with marginal evidence of different across groups (p values < 0.2).

Ordered logistic regression of individual ratings for values Value

Learning

Thinking and problem solving

Parent attachment and/or peer relationships

Emotional development and regulation

Communication (self-expression, understanding others)

Literacy (reading, writing) Gross motor skills (walking)

Fine motor skills (finger dexterity)

^a Medical frame versus cultural frame

Adjusted for race (white vs. non-white) and the degree that someone self-reports as being outgoing and social—two factors with marginal evidence of different across groups (p values < 0.2).

Proportional	Р
Odds ^{a, b}	
1.22	0.190
1.43	0.052
0.91	0.292
1.12	0.279
1.17	0.237
1.02	0.439
1.12	0.238
1.22	0.108

hearing screening results with you.

Nurse: I'm sorry, your child failed both the hearing screening and rescreening in both ears. But don't worry too much, it is likely just fluid in the ear. We are referring you and your child to an Audiologist so that it can be determined whether or not your child has a hearing

results.

Audiologist



4. Discussion





Medical

Cultural

Imagine that you are in the hospital and a parent of a newborn baby. The hospital has performed standard newborn screenings, including one that screens your baby's hearing levels. The nurse is now sharing your baby's

Nurse:

Your child was screened and rescreened in both ears. The result of the screening is "refer," which means that testing is needed to determine your child's hearing levels. It may be fluid in the ear, but it's important your child is tested. We are referring you and your child to an Audiologist so that it can be determined whether your child is hearing, deaf, or hard of hearing.

You went to the Audiologist for testing. Below is what the Audiologist communicates with you about your child's

Your child has been diagnosed with bilateral severe to profound hearing loss. Hearing loss in this range is treatable. Your child may be a candidate for cochlear implantation, depending on the results of a medical evaluation. We can initiate the process for hearing aid fitting as soon as your child receives medical clearance for hearing aids. I can give you referrals for ENT physicians today so that we can get the process going for medical clearance for hearing aids. It is important that your child has access to sound and speech in English as soon as possible. There is only a small "window" of opportunity for developing listening skills that they will need for ideal long-term outcomes for speech and spoken language. That is, if you wish for your child to speak and hear normally. Take the next few days to think about what you want, but understand this is an urgent situation. If we do not act quickly, your child's brain will not have the best possible access to sound for future development.

Audiologist:

Your child has been identified as deaf in both ears with hearing levels in the severe to profound range. Around 1-2 out of every 1000 infants born in the U.S. is identified to be deaf or hard of hearing. Deafness itself is not a life-threatening disability, although it can be related to additional disabilities in some cases. Your child may also be a candidate for cochlear implantation, depending on the results of a medical evaluation. We can initiate the process for hearing aid fitting as soon as you are ready, and I will need medical clearance to fit your child with hearing aids if you choose to try hearing aids. In the meantime, it is important that your child has access to language for brain development. American Sign Language can be used to support your child's growth because it is an accessible, visual language.

Now that you have learned about your newborn baby's hearing status, we would like you to consider these attributes of human development in terms of your newborn baby below.

3. Results

Both groups were demographically similar with no significant differences. Overall, participants skewed:

female-identifying

• mean age of 52 years

• High degree of education (Bachelors and Masters degrees). ○ 55% with household incomes greater than \$75,000.

For medically-framed scenario respondents, there was a 32% higher odds (1.32 OR) of prioritizing cognitive development as the most important domain (p=0.039).

For culturally-framed scenario respondents, there was 62% higher odds (1.62 OR) that they would prioritize physical **development** as the most important domain (p=0.058).

• Neither group prioritized the language developmental domain for a deaf child; even those considered highly-educated among the general population may not have full understanding as to how cognition emerges in developing children.

Literature studying parent choice in the context of deaf children and language and communication options stress the parent's goals for their child. This suggests a systemic lack of understanding that a child's developmental outcomes (language) may require different needs and services that could directly contradict a parent's personal wishes for their child.

Findings suggest a greater emphasis on the importance of linguistic access being prioritized to support typical neurocognitive development in deaf children.

Limitations of the study include lack of diversity among survey respondents; findings cannot be generalized to the general population. We also did not ask respondents to self-report upon their own possible disability status.