



A Critical Time for Language: What Families of Deaf Infants Wish They Had Known

Julie Rems-Smario, EdD

Laura T Petersen, MA

Marlon Kuntze, PhD

EHDI 2024

Denver, Colorado

Agenda

Literature review

Methods

Survey Data

Interview Data

Discussion

Limitations

Conclusion/Future Directions

Literature review:

The purpose of informed family choice is

1. To learn about language opportunities
2. To be provided with guidance on making choices
3. To have a literate child

Literature review:

Language decisions are often ultimately influenced by:

1. The manner the information is provided (Crowe et al., 2014)
2. The amount of information received (Scarinci et al., 2018)
3. An internalization of professional's views (Decker et al., 2012)
4. A sense of being overwhelmed (Kurtzer-White et al. 2003)

Briefly, information given is “conflicting, complicated, overwhelming, biased, based on opinion, and limited in scope.”
(Crowe et al., 2014)

Literature review:

Family's initial perception:

1. ASL is foreign and unfamiliar (Young, 2002)
2. Any communication option is probably as good as another
3. The spoken language option is more consoling (helps lessen the feeling of intimidation of raising a deaf child) (Crowe et al., 2014)
4. Spoken language is key to academic achievement and literacy development.

Literature review:

1. The information shared is usually selective
2. Families:
 - May find the task of raising a deaf child more daunting than it needs to be
 - Often don't know there is additional information or perspectives

Literature review:

What families may not have been told:

1. Contingent interactions are key to language development (Hall WC, 2017; Hall ML et al., 2019)
2. Contingent interactions build on the development of infant attention (Masek et al., 2021)
3. Language deprivation compromises long-term development in many areas (Cheng et al., 2019)
4. Well-developed signing skills equates to well-developed general language skills (Allen et al., 2015; Hermans et al. 2008; Mouny et al., 2014)

Questions of the study



How was the journey from hearing screening to school placement for families who chose a school where ASL is the primary language of instruction?

What do families wish they were told and provided when they first learned their child was Deaf?

Methods: 2 Sources of Data

SURVEY:

34 families' survey answers about their initial and current experiences with medical and early intervention providers

INTERVIEWS: Four parents of deaf children, aged six or younger, with different hearing levels.

Focus of the Survey

Family Demographics

Initial Resources Received

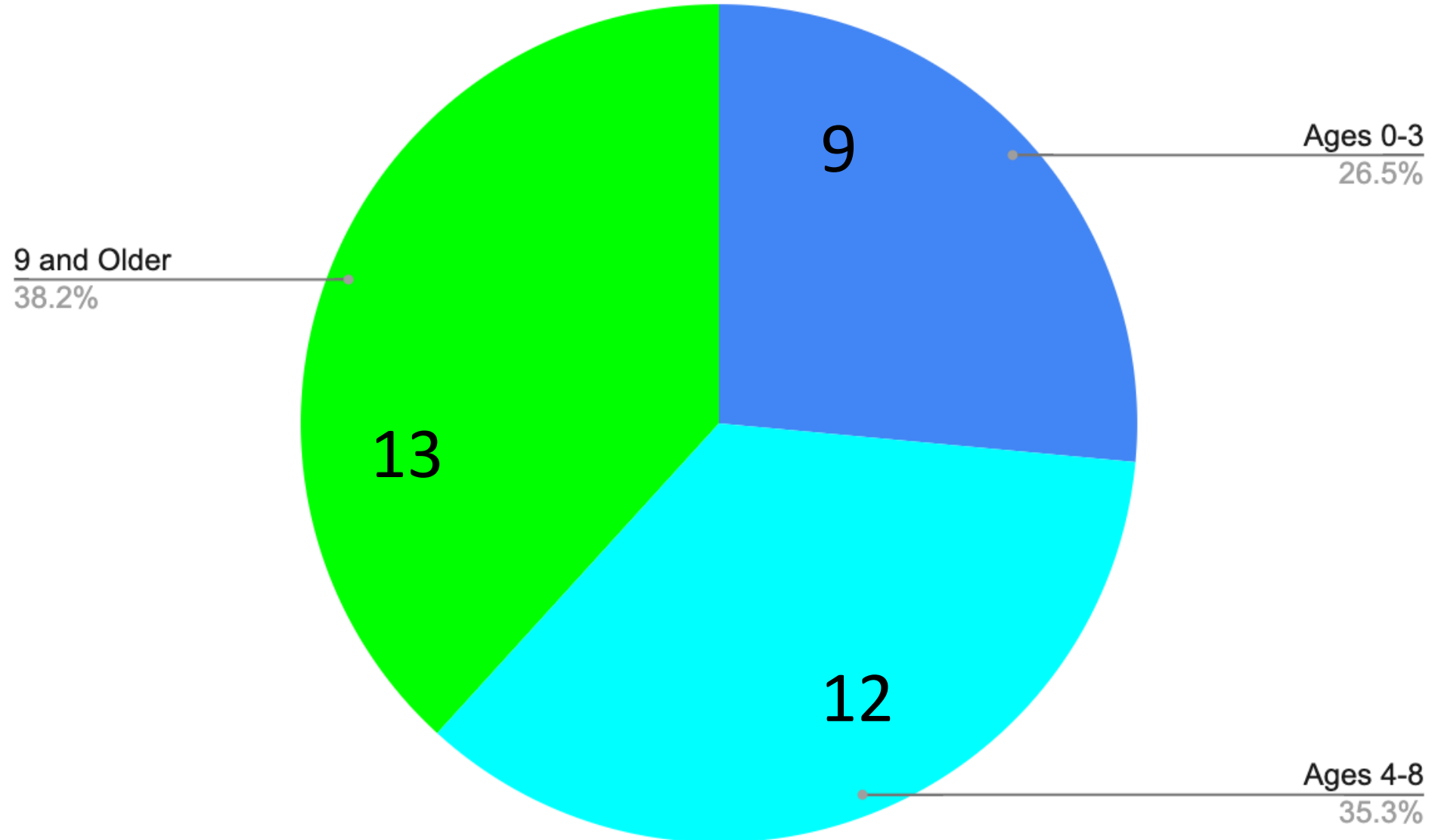
Resources Families Wish They Received
Earlier

The Difference Earlier Knowledge of ASL
and Deaf Professionals Could Have Made

Survey Participants

- Hearing parents with deaf/hh children who attend a school where ASL is the primary language of instruction
- Survey sent three times to 104 families
- 34 families participated (families with deaf parents were excluded)

Ages of survey participant's Deaf/HH children

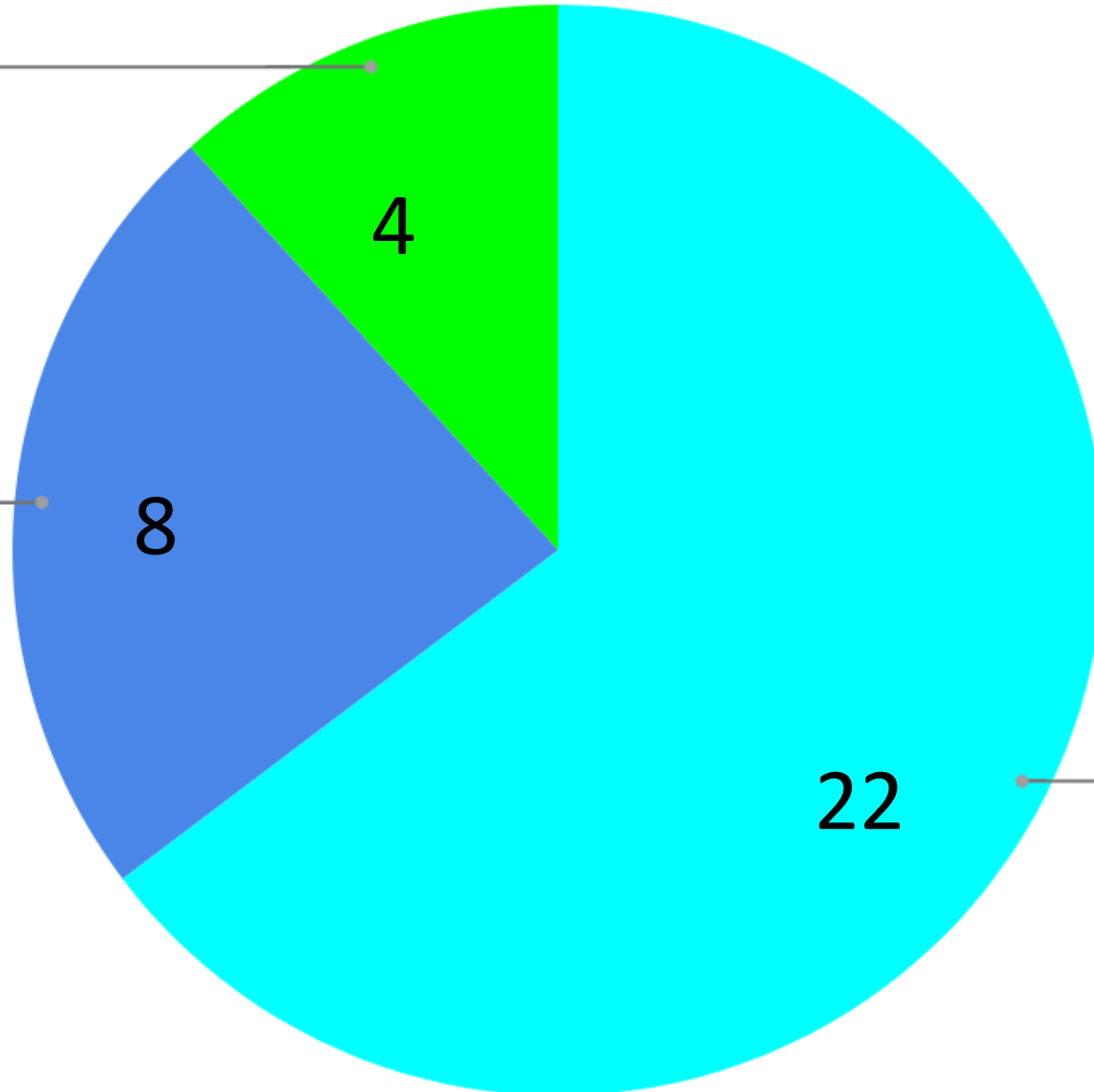


Survey participant's Deaf, HH and Deaf+ children

Deaf +
11.8%

Hard of Hearing
23.5%

Deaf
64.7%

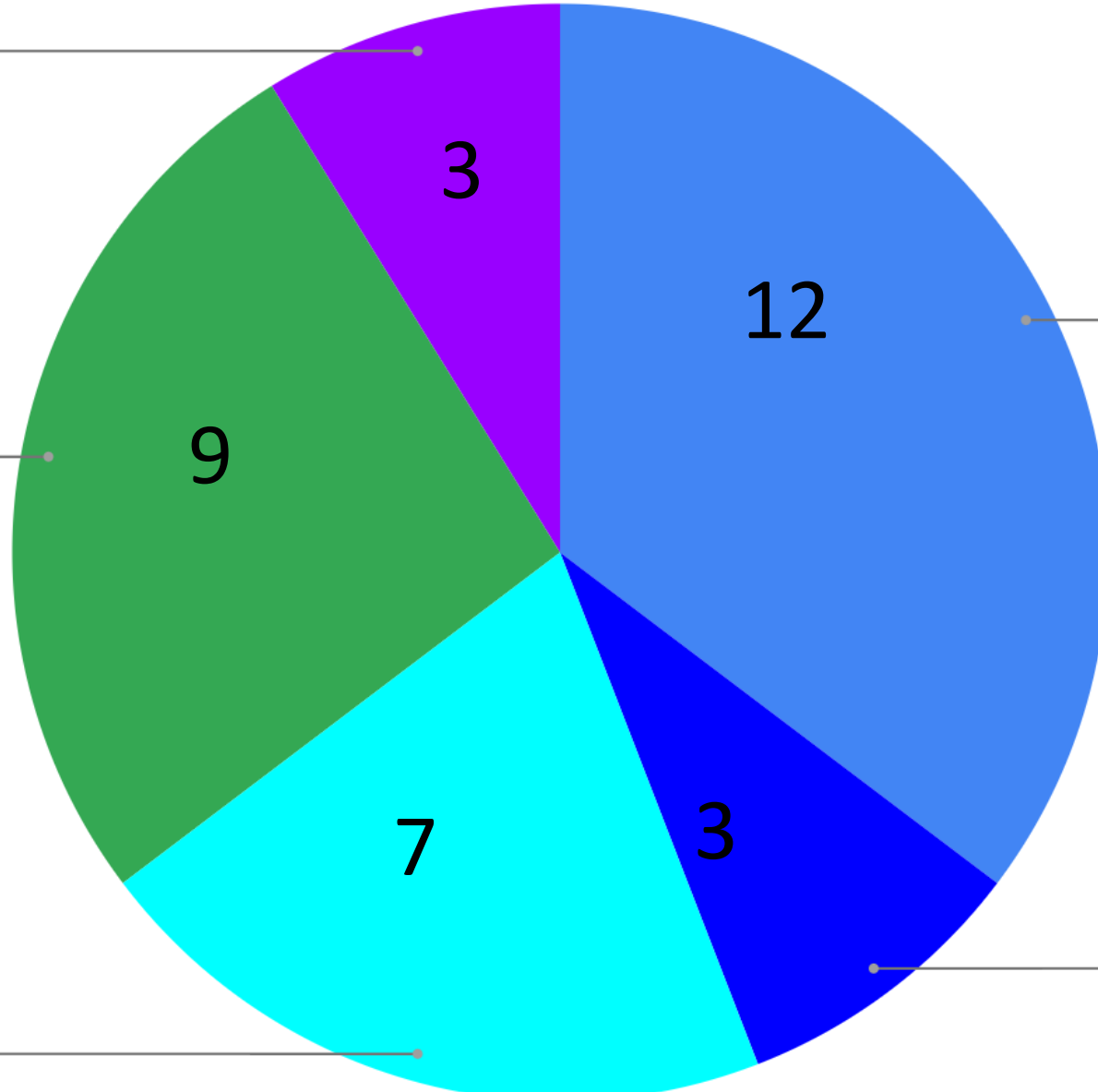


How Families Initially Communicated

Spoken English with Gestures
8.8%

Signing and Spoken Language Simulta...
26.5%

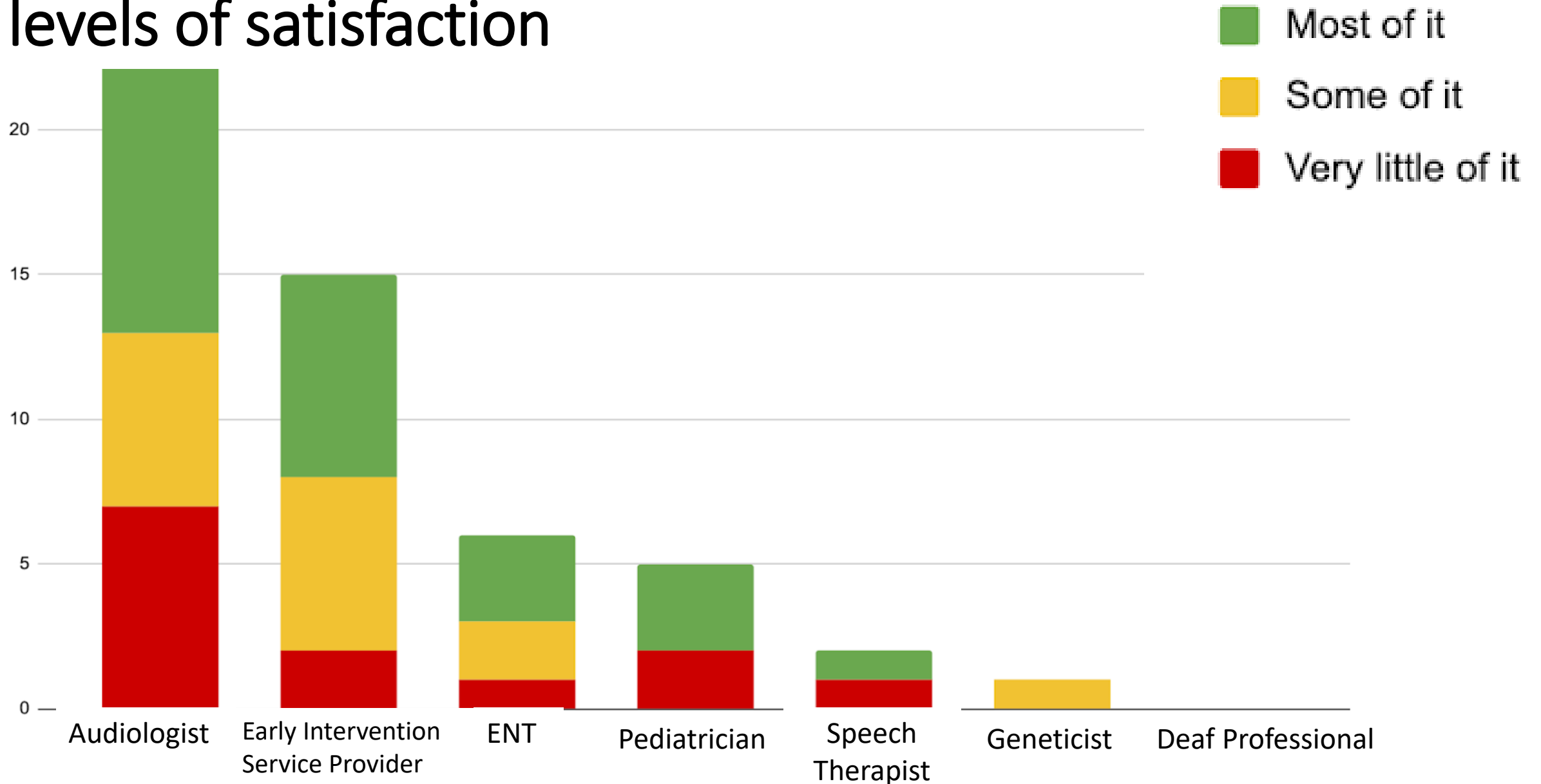
Sign Language Only
20.6%



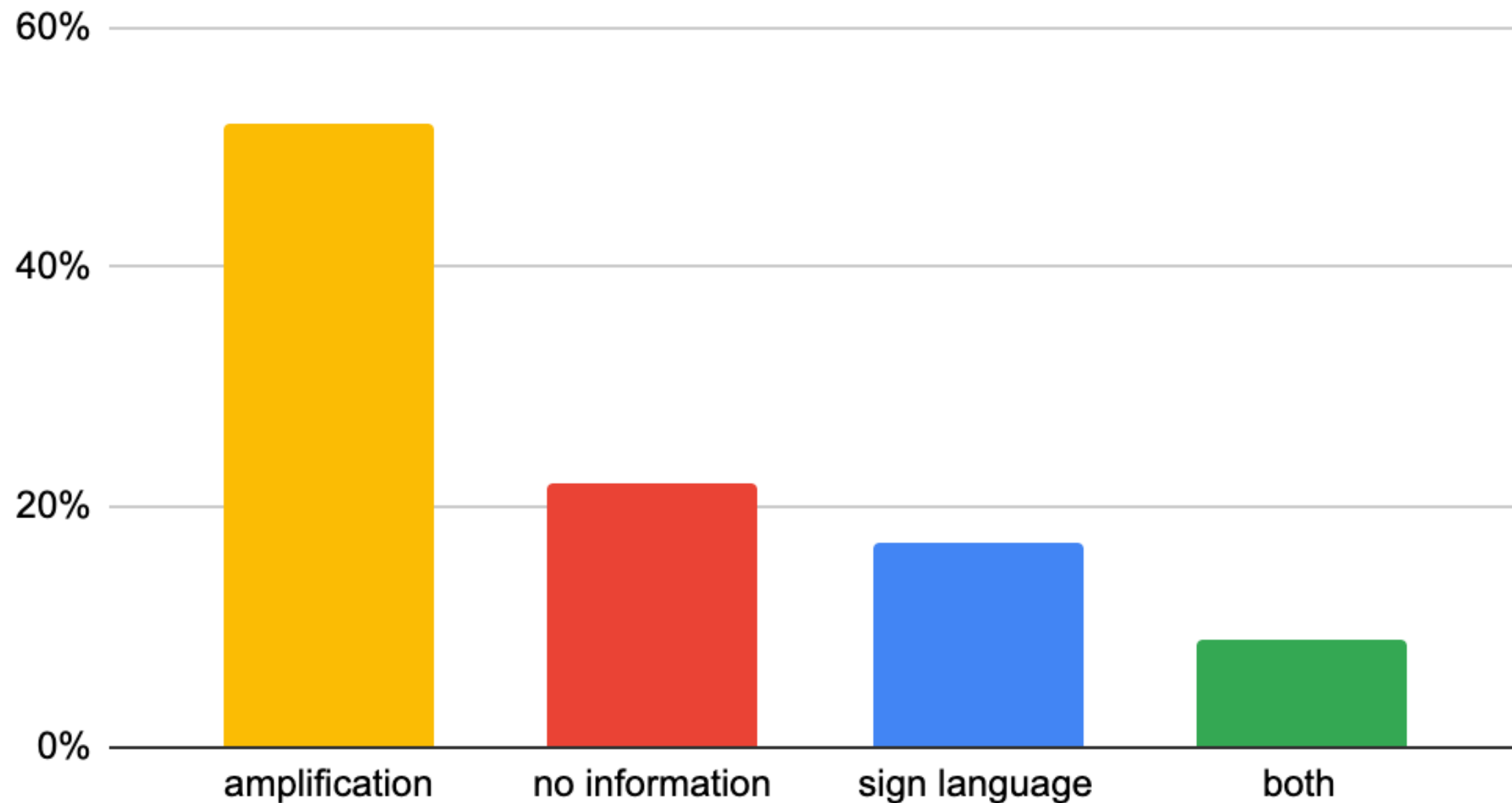
Spoken English Only
35.3%

Spoken Home Language Only
8.8%

Initial Contact with Professionals and levels of satisfaction



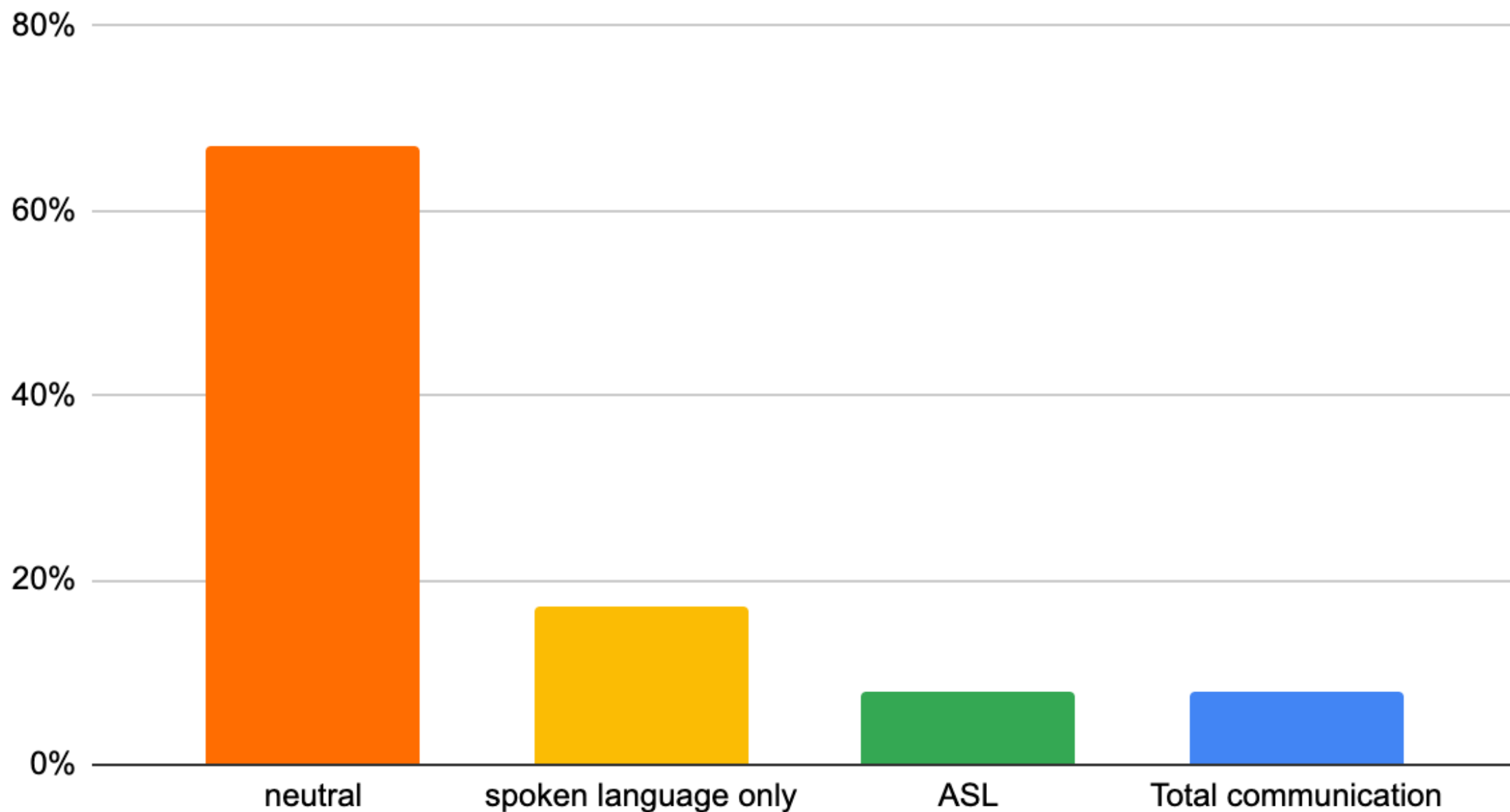
Audiologist Language Recommendations



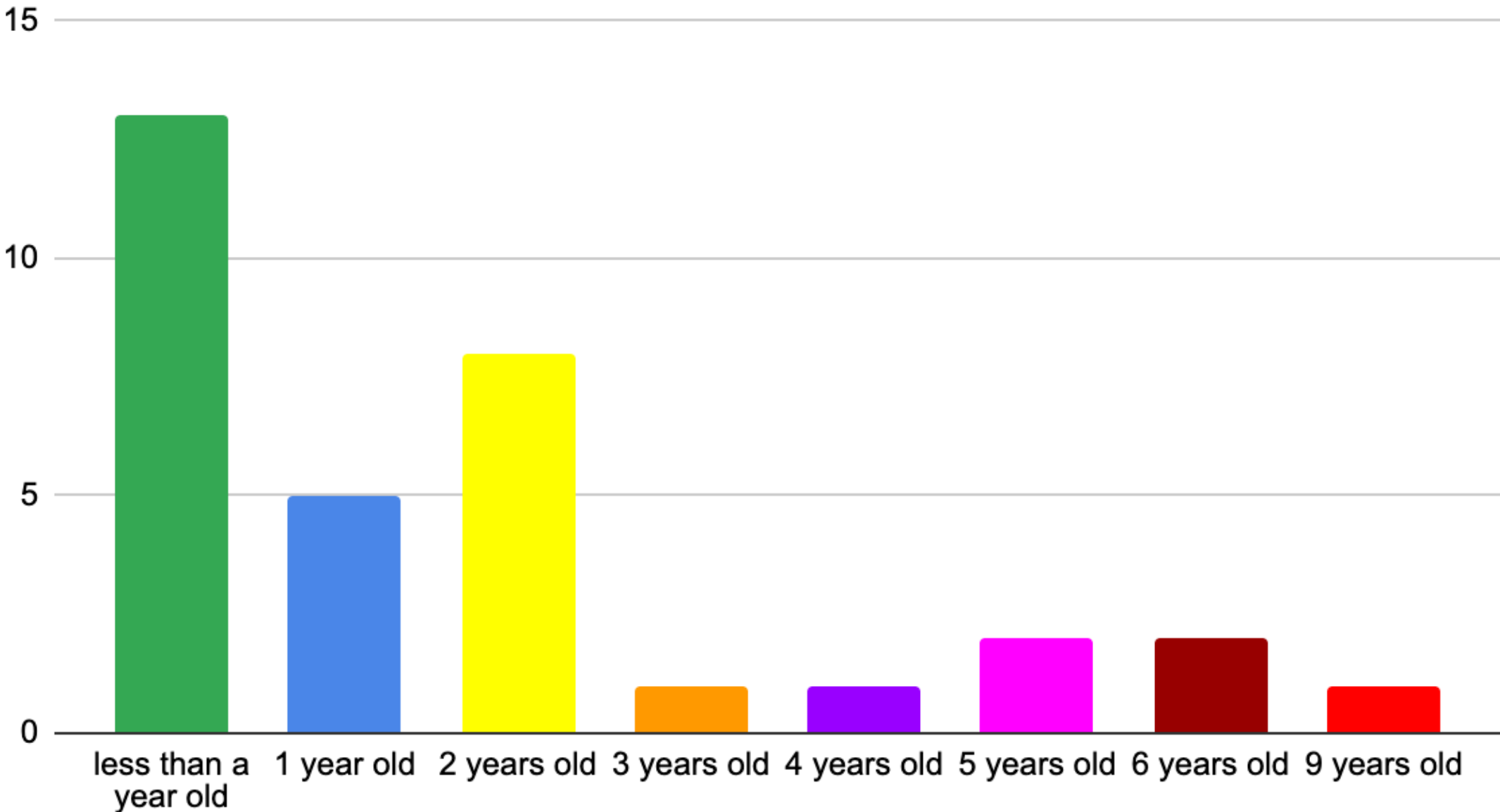
Examples of what families were told

- We were told our son was a perfect candidate for a cochlear implant when they could not have possibly known that and it has not worked out as expected.
- We never discussed what would happen if the cochlear implant failed. I wish we had begun learning ASL during the cochlear implantation process.
- We were told to wait it out with language development. My daughter's ears might grow, and they could put tubes in her ears to help clear the ear canal.

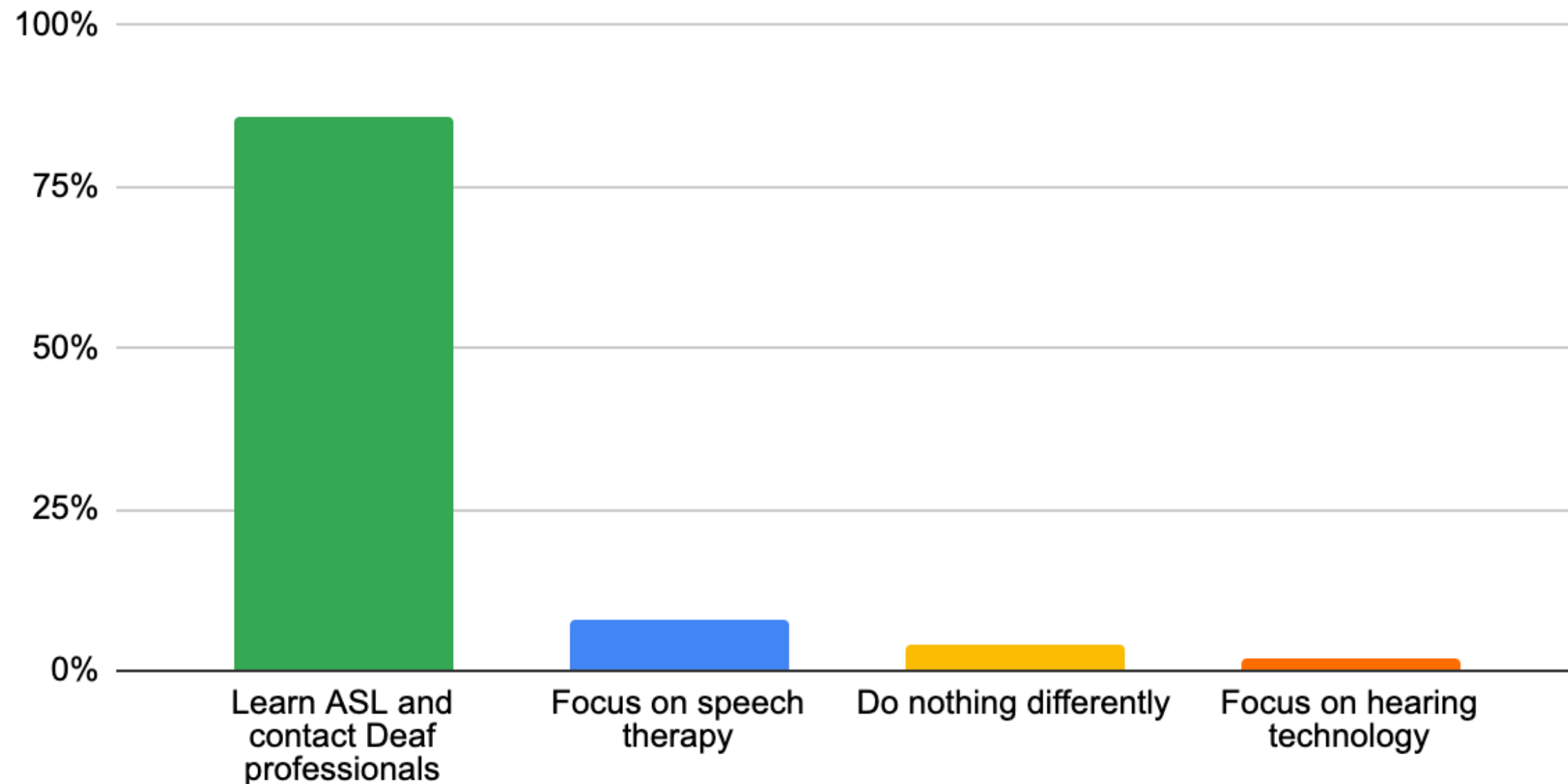
Part C Home Visitor Language Recommendations



Age my child started learning American Sign Language



What would you do differently if you could go back to when your child was born?



Most parents
wished they
learned ASL
sooner.
They said...

learning ASL would have prevented their
experience of depression

having access to ASL and classes from the
beginning would have boosted their
confidence in parenting their Deaf child,
leading to less stress and worry

many of their child's behavior issues
disappeared once they were able to
effectively communicate with them (in
ASL)

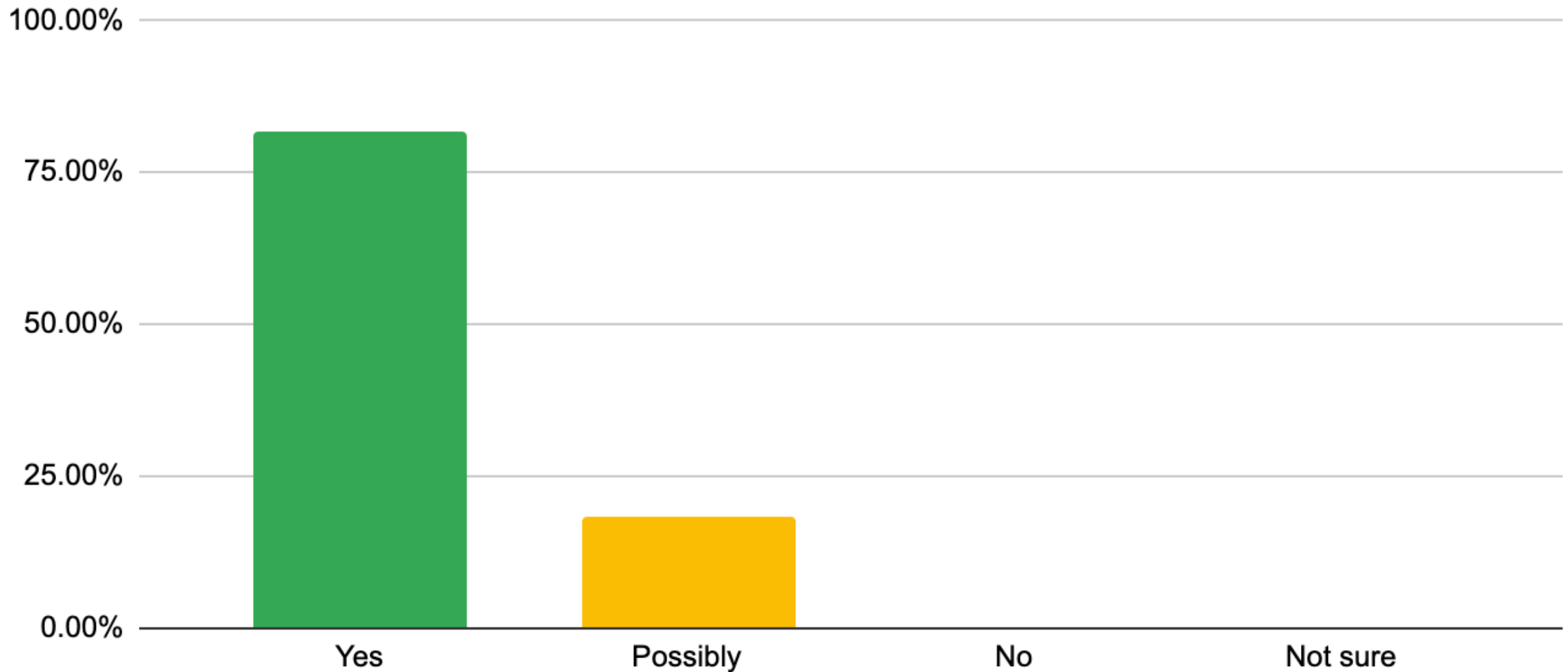
“What would be different in your child's education if you had earlier information on sign language?”

"I would have liked to have known that SEE signs, home signs, and gestures are not language."

"I feel so guilty for not having learned ASL the second I was told my child was Deaf. I cannot get those years back."

"My family would be more educated about the deaf community, and I would feel more comfortable about having discussions about my child's deaf identity."

Would it have made a positive difference in your child's development or education if you had accurate information on sign language and had met Deaf professionals?



Examples of family frustrations

ASL was never mentioned

No research-based information
about language was shared.

Primary focus on cochlear
implantation

Sign language as a last resort

Data via Interviews:

Interview questions

Is being Deaf a medical or educational issue? What did you think when your child was first identified? How has this changed?

How has a bilingual (ASL & English) early education impacted your child's language, academic readiness, and social emotional wellness?

What advice would you give to other families?

Interviews:

3 major themes

Systemic Audism

Benefits of ASL

Importance of Deaf Professionals
and the Deaf Community

Systemic Audism:

Medical system: "I experienced many doctors at the beginning saying 'Oh, your daughter does not need to go to a deaf school'."

Early intervention system: "If you want your child referred to a Deaf school, you have to convince the IFSP/IEP teams that your child needs ASL. You have to work to get past their bias."

Family members: "My family would say this about my child, 'She can hear, so she does not need services'."

Benefits of ASL:

Socialization: "My son now has both deaf and hearing friends. He is enthusiastic about socializing with others."

Literacy: "My daughter can understand concepts in ASL and connect them to English words. She has developed advanced reading skills and demonstrated confidence with 'I can attitude'."

Empowerment: "When my son struggles to express himself, we have three languages to choose from (ASL, English, and Spanish). That provides us the confidence to be able to support him."

Importance of Deaf Professionals and the Deaf Community:

Navigation: The combination of lived experience as Deaf people and the professional training that Deaf professionals have are valuable resources for helping families navigate the challenges and decisions that come with raising a deaf child.

Celebration: Deaf professionals can help families see greater opportunities that exist for their Deaf child.

Knowledge: Deaf people's lived experience is not often passed on genetically so most deaf children need to get it through their parents making connections with Deaf communities and Deaf professionals.

Discussion



"Ambivalent medicalization" (Mauldin, 2016)

- the hegemony of medicine
- how individuals surrender to the supremacy of medical thinking.

Unfair for families to navigate this journey alone.

- mental health issues
- loneliness

Families in the study probably ventured further than many

- possibly due to luck they found resources
- possibly due to wanting to learn more

Limitations

- Data only from families who were affiliated with a large school program for deaf students with an ASL and English bilingual approach.
- Need to expand in future studies to include families who do not send their deaf child to a deaf school.

Conclusions

Families should have easy access to ASL resources and services provided by Deaf professionals.

More literature on the many advantages of sign language for deaf/hh children's development

Mitigate the audist mindset of the medical and educational institutions and work towards a more inclusive approach regardless of the child's hearing levels.

Deaf professionals need to be part of the newborn hearing screening and early intervention team

Future Directions:

Creating ASL resources and expanding Deaf professionals

ASL resources should readily be available for new families within medical and educational systems.



Families should have quick access to services provided by Deaf professionals.



The Joint Committee on Infant Hearing (2013) recommended Deaf professionals to be active participants in the Early Hearing Detection and Intervention programs at national and local levels.



California has a Deaf-run, statewide EHDI program, LEAD-K Family Services, which includes providing Deaf coaching for new families with Deaf children.

Thank you!

For further information about the study, possible future studies, or references of work cited:

Julie Rems-Smario, Ed.D. JSmario@csdf-cde.ca.gov

Marlon Kuntze, Ph.D. MKuntze@csdf-cde.ca.gov

Laura T Petersen, MA Ltpetersen@csdeagles.net