WHAT WE BELIEVE:

PROFESSIONAL BELIEFS ABOUT DEAFNESS AND WHAT FAMILIES WANT US TO KNOW

Emily (Wojahn) Small, MA (she/her)
Nicole Hutchinson, MA, CED (she/her)

WHO IS IN THE ROOM?

- EARLY INTERVENTIONISTS
- EHDI STAFF
- SPEECH-LANGUAGE PATHOLOGISTS
- DHH ADULTS
- AUDIOLOGISTS
- EDUCATORS
- FAMILY MEMBERS
- MEDICAL PROVIDERS

WHO ELSE?

COMMUNITY NORMS

BE CURIOUS AND OPEN TO LEARNING

ASSUME GOOD INTENTIONS

RECOGNIZE YOUR OWN PRIVILEGE & BIASES

RESPECT OTHERS VIEWS AND OPINIONS

AGREE TO DISAGREE

BE PRESENT

AGENDA:

- Activity
- Background Info
- Literature Review
- Themes
- Self Reflection & Call to Action
- Q&A

WHO'S EVER BEEN AFRAID OF SAYING THE WRONG THING?

YES

NO

I have participated in discussions about professional bias.

YES

NO

The resources my field shares with families are free from bias.

YES

NO

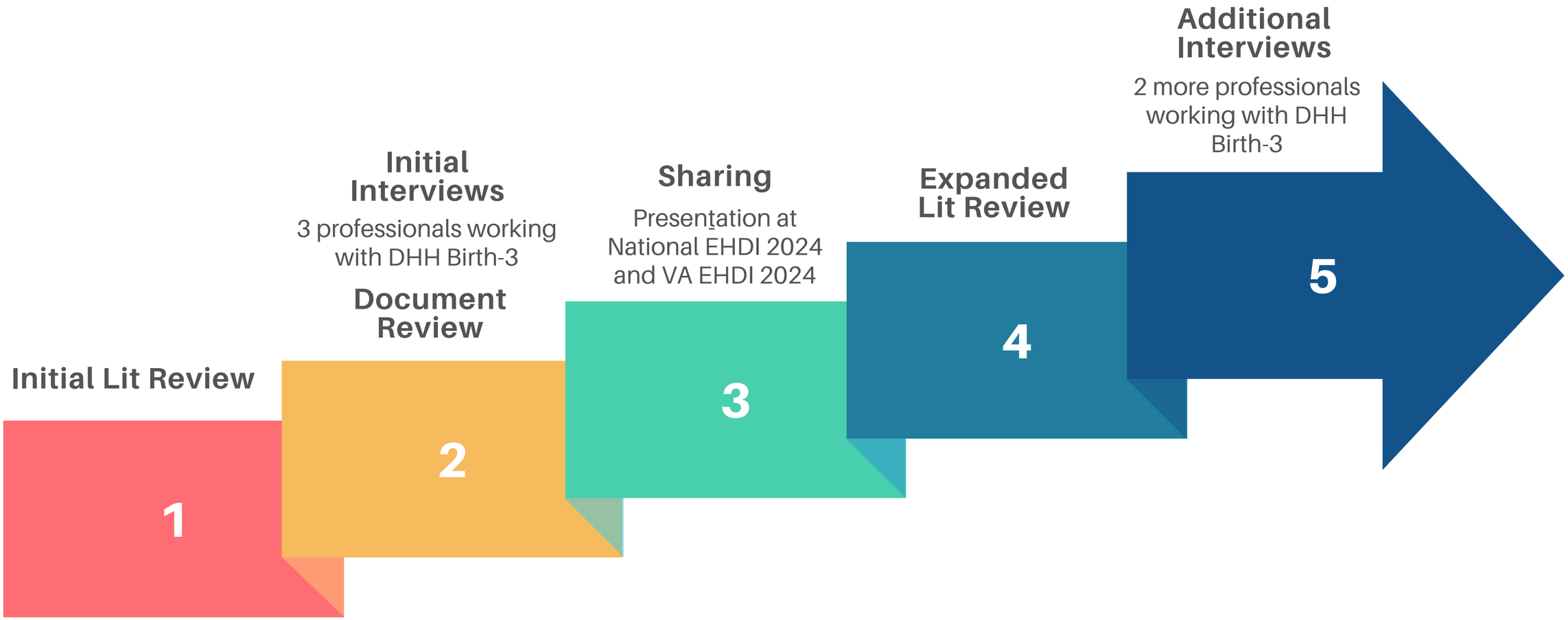
I am comfortable communicating about my professional biases with my colleagues and other professionals I work with.

YES

NO

I am comfortable communicating about my professional biases with the families I work with.

BACKGROUND:


Initial Lit Review
1
Initial Interviews
3 professionals working with DHH Birth-3
Document Review
2
Sharing
Presentation at National EHDI 2024 and VA EHDI 2024
3
Expanded Lit Review
4
Additional Interviews
2 more professionals working with DHH Birth-3
5

LITERATURE REVIEW - THEMES

FAMILY EXPERIENCES

Families want the care they receive to be focused on the skills the professional brings, clearly and empathetically communicated, without bringing the focus to the clinician.

(DesGeorge, 2016; Eleweke & Rodda, 2000; Robinson, Bowman, & Barker, 2022; Tattersall & Young, 2006).

PROFESSIONAL COMMUNCATION

Families receive information from varying sources of information with higher regard often placed on medical professionals. Professionals should use communication that is sensitive, patient, and open understanding that information delivered without counseling or emotional support leaves parents with limited understanding of next steps and difficulty finding unbiased information.

(Geise, 2020; Mushtaq, 2024; Robinson, Bowman, & Barker, 2022; Young, 2002).

LITERATURE REVIEW - THEMES

CHANGING PERSPECTIVES

- Decision making is a dynamic process (DesGeorge, 2016).
- Revision happens frequently (Young, 2002).
- Parents have limited ability to interpret and understand results at the time they make initial decisions about technology and communication (Li, Bain, & Steinberg, 2003).

What this means:

- Allow for families to change their minds!
- Give information and TIME to process and gather additional information before requiring decisions.
    - Balance of progression through a system and urgency to move things quickly.
- Parents generally want to know what you think and how you would advise them to move forward. Be cognizant of the power of that influence.

WHEN ASKED ABOUT PROFESSIONAL BIASES...

I would say a lot of the families are being told don't sign with your kid. If you sign, they're never going to talk. And then I have to provide support as to why that's false...the research as to why that's wrong, the benefits of why we need to provide them with language in general, sign, spoken, both.

RESEARCH THEMES

Perspectives on Deafness

Geographic location and service provision setting may impact perspectives on deafness (disability vs. identity).

Advocacy and Collaboration

Examine your community (geographical and virtual) for connections as a source of information.

Cultural sensitivity is critical; recognize the impact of culture.

Professional Practice and Development

Acknowledge gaps and sources of information.

Consider how you choose to share information. Does it reflect your professional experience and priorities?

Language, Communication, and Identity

Recognize how your academic, personal, and professional background impact the words you use to describe identity and language.

It is not possible to be without bias.

WHEN ASKED ABOUT TERMINOLOGY

I see why it's important to indicate the [medical diagnosis] but then to talk about calling it a hearing difference or hearing level versus hearing loss.

I think it is important, especially for the itty bitties who just started their life, we don't like the idea of them having a loss of something, right?

Their life has just started. They're going to gain everything in the world.

DOCUMENT REVIEW

COLLECTED DOCUMENTS

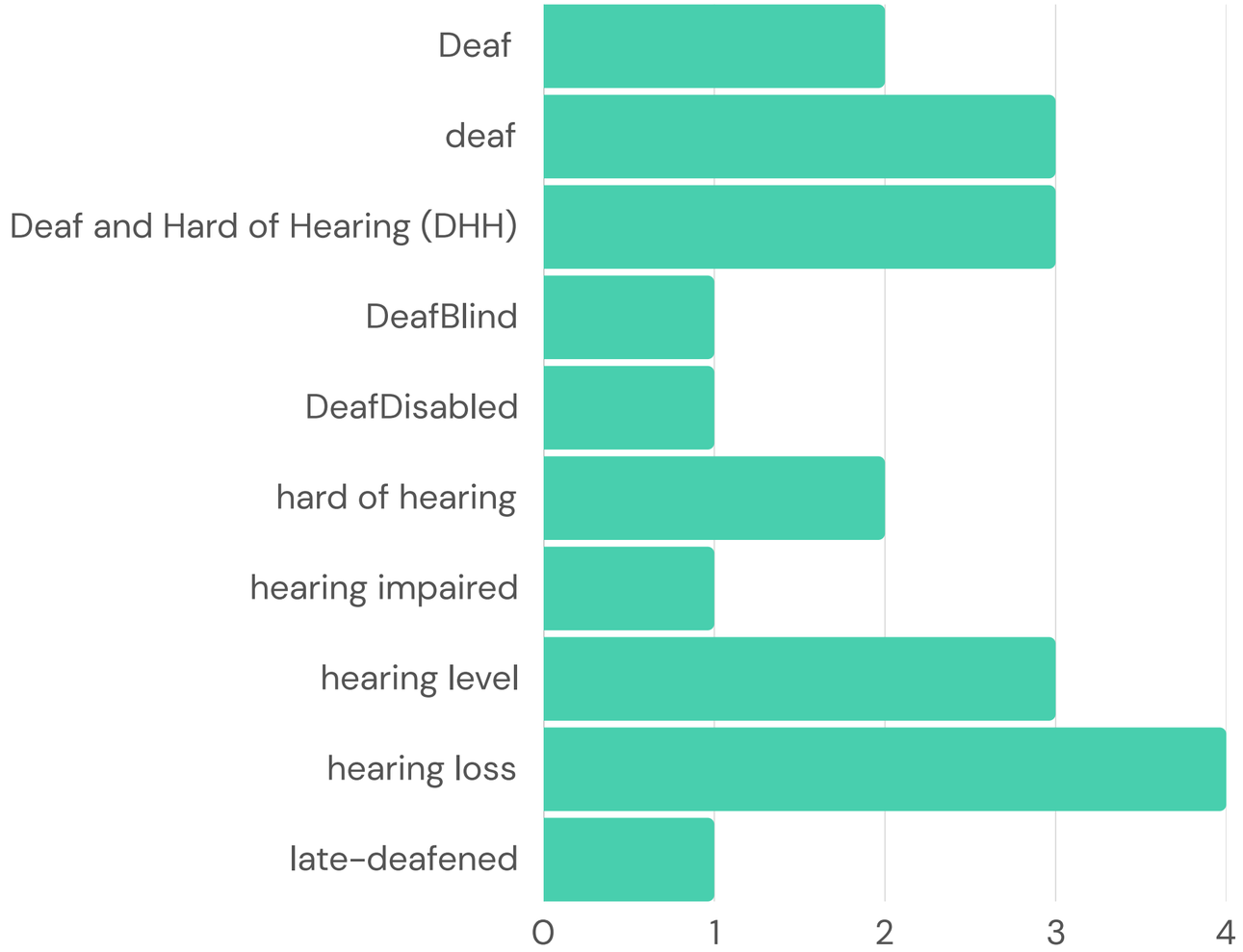
Requested documents from EI professionals that they use regularly with families in their work

IDENTIFIED UNIQUE DOCUMENTS

Compared documents and identified 5 unique documents

COUNTED TERMS

Counted which words for being deaf were used in each document



WHEN ASKED ABOUT SHARING RESOURCES

You're making me think about this now because I think a lot of this just kind of happens subconsciously, I get it [different words for being deaf] so I don't focus on it unless it sticks out like something negative or is new to me.

SELF REFLECTION

I have participated in discussions about professional bias.

The resources my field shares with families are free from bias.

I am comfortable communicating about my professional biases with my colleagues and other professionals I work with.

I am comfortable communicating about my professional biases with the families I work with.

QUESTIONS TO TAKE WITH YOU:

How can I help families identify their next steps in a balanced and supportive way?

Who in my network can I use as a resource for topics I am less familiar?

What biases exist within my field? In what ways can I work to challenge them?

What systems or processes are in place to support families who change their minds?

Q&A

CONTACT US:

emily.wojahn@gallaudet.edu
nbhutchinson@gmail.com

HANDOUTS:

REFERENCES

- DesGeorges, J. (2016). Avoiding assumptions: Communication decisions made by hearing parents of deaf children. American Medical Association Journal of Ethics, 18(4), 442-446. https://doi.org/10.1001/journalofethics.2016.18.4.sect1-1604
- Eleweke, C. J., & Rodda, M. (2000). Factors contributing to parents' selection of a communication mode to use with their deaf children. American Annals of the Deaf, 145(4), 375-383. https://doi.org/10.1353/aad.2012.0087.
- Giese, K. A., (2020). Factors that influence parent communication decisions for their deaf or hard of hearing child in Illinois (28152545) [Doctoral dissertation, Illinois State University]. ProQuest.
- Li, Y., Bain, L., & Steinberg, A. G. (2003). Parental decision making and the choice of communication modality for the child who is deaf. Archives of Pediatrics & Adolescent Medicine, 157(2), 162-168. https://doi.org/10.1001/archpedi.157.2.162
- Mushtaq, S. G. (2024). Empowering parents of deaf and hard-of-hearing children: A mixed methods study to develop a comprehensive framework for understanding and choosing communication options (31139802) [Doctoral dissertation, Alliant International University]. ProQuest.
- Robinson, T. L., Bowman, E. B., & Barker, B. A. (2022). Exploring the stories of parents' experiences with infant hearing-loss screening and diagnosis in the United States. Ear and hearing, 44(3), 518-529. https://doi.org/10.1097/AUD.0000000000001294
- Tattersall, H. & Young, A. (2006). Deaf children identified through newborn hearing screening: parents' experiences of the diagnostic process. Child: Care, Health and Development, 32(1), 33-45. https://doi.org/10.1111/j.1365-2214.2006.00596.x
- Young, A. (2002). Factors affecting communication choice in the first year of life – assessing and understanding an on-going experience. Deafness & Education International, 4(1), 2-11. https://www.doi.org/10.1179/146431502790560935