



DHH Office
Hours

April 30, 2026

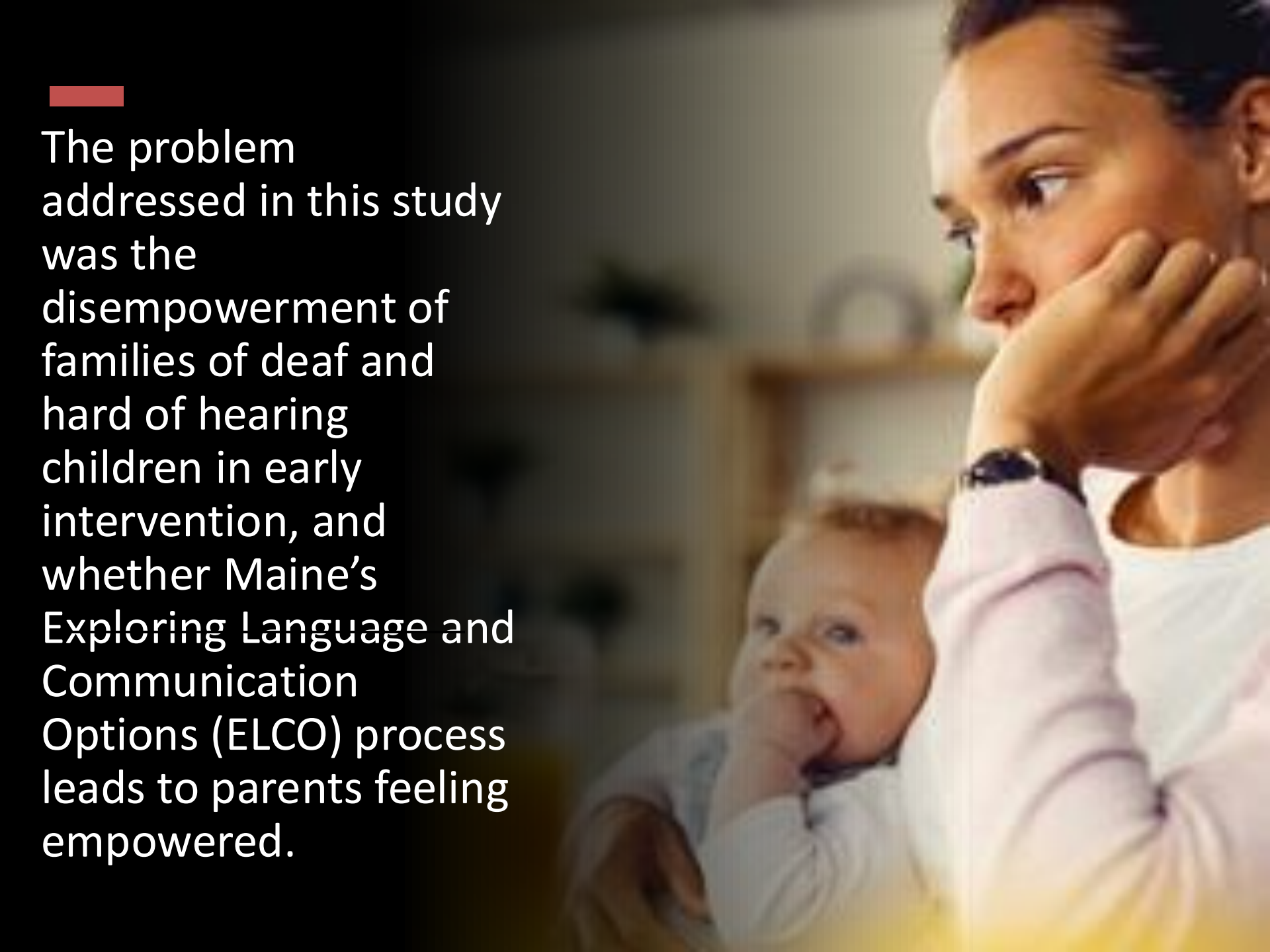
From Information to
Empowerment Through
Connections

Dr. Karen Hopkins

Session Objectives

Participants will be able to:

- Identify key research-based factors that influence family confidence and empowerment in early intervention
- Explain why connections to deaf and hard of hearing adults and other parents of deaf and hard of hearing children are critical to family engagement and decision-making.
- Identify at least one strategy or resource to support families in reflecting on and revisiting communication and language decisions over time.

A photograph of a woman in profile, looking thoughtful with her hand resting against her face. In the background, a baby is visible, looking towards the camera. The scene is set indoors with soft lighting.

The problem addressed in this study was the disempowerment of families of deaf and hard of hearing children in early intervention, and whether Maine's Exploring Language and Communication Options (ELCO) process leads to parents feeling empowered.



Exploring Language & Communication Opportunities:

*A Process Document for Professionals working
with Children who are Deaf or Hard of
Hearing and Their Families*

(Professional Guide)



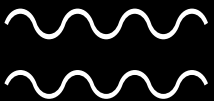
Interactive Exploring Language and Communication Opportunities Overview



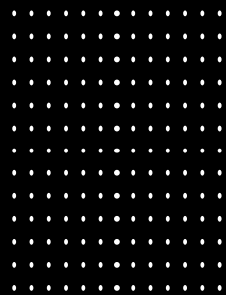


Introduction to the
Research:
Research Question

What are family's
feelings of
empowerment
after participation in
Maine's Exploration of
Language and
Communication
Opportunities
Process?



Conceptual
Framework –
Ten Principles
of FCEI
(Moeller, et.
al., 2013)



- Early, Timely, & Equitable Access to Services
- Family/Provider Partnerships
- Informed Choice and Decision Making
- Family Social & Emotional Support
- Family Infant Interaction
- Use of Assistive Technologies and Supporting Means of Communication
- Qualified Providers
- Collaborative Teamwork
- Progress Monitoring
- Program Monitoring

Results and Findings



Research Theme One:

Relationships between early interventionists and the family laid the foundation for family empowerment.

- i. The time earliest interventionists spent being present with families was supportive.
- ii. Guidance through the process is helpful to families while they guide their own journey.

Thoughts from families...



“Our relationship was just so right. If it had been too clinical in the beginning, it would have changed the relationship... We were empowered by building mutual respect and by our early interventionist being there for us.”

“Our relationship with our early interventionist felt personal... intimate... natural... like a partnership, whereas other providers and their approach felt so formal... other providers seem very uncomfortable. Our early interventionist relationship is amazing. You don't even realize how well, how well it's going, because it's so natural. There isn't a pretense of a professionals and family, there's just a partnership... figuring this out together.”

“Our early interventionist treated us and my daughter as whole people -not just ears. The doctors and audiologist tend to only talk about her ears and there is so much more to her and our lives.”



Research Theme Two

Following families' lead is important.

- i. Families are initially overwhelmed.
- ii. Too much information is provided to families early after their child's identification of deafness.
- iii. The family centered approach early interventionist utilizes with families is instrumental to families' feelings of empowerment



Family Thoughts



“I remember there being a notebook, I think I still have the notebook in my office, and just being like well...there’s a notebook. That was overwhelming at the time. I had a young baby... I didn’t know when I was going to have time to read a notebook, and I remember thinking it seemed a lot, I was supposed to read, make a choice that would be written in a plan...this felt like a forever choice” and then I had this baby.....”



Thoughts from families...



“I remember they would give me like packets of stuff, like many packets. To be honest they are still in the pile in my closet that I put them in. Who has time? But the guilt I felt for not reading all this was huge. “Another participant detailed, “Too much stuff came at us in the beginning, papers, binders, materials, and articles. Then having all the reports you're getting from the audiologist on top of all the other paperwork outside of early intervention, it's a lot.”



Research Theme Three

Giving families encouragement to explore, learn and evolve is empowering.

- i. Informed Decision Making is empowering to families.
- ii. Parents want their child to have access to all opportunities.
- i. The process of writing a language and communication plan is empowering families.
- ii. The ELCO process instills feelings of confidence in families.



Thoughts from families...



“I remember thinking, how in the world do I make this decision for somebody that I don't even know.”

“We walked through the entire process with our early interventionist. We met lots of people. The deaf adults were so helpful and gave us hope. Talking to all the specialists were incredibly helpful too. We needed to learn all the options to make the right starting decision for us. The parents we met shared their stories too...we just combined it all.”

“I felt empowered even in those first few moments of understanding that I had a choice and that we could choose how and what approach we wanted to take with our baby and family. It's so structured but flexible and feels like we're making informed decisions rather than last minute decisions.”



Research Theme Four

The opportunity to meet individuals with lived experiences empowers families.

- i. The impact of engaging with deaf and hard of hearing adults is empowering to families.
- ii. The impact of Parent-to-Parent Support is supportive and empowering to families.
- iii. Families benefit from engagement with individuals with similar experiences.



Thoughts from families...



“If I could have met deaf people earlier, meet more than one, get a broader understanding of the many ways that deaf and hard of hearing people exist in the world it makes those first few weeks easier. We need to meet someone that’s deaf or hard of hearing earlier. An adult, or even a child in their teenage years like going to high school, so they can tell us their experience of how they felt, because that is such a big thing because we were making decisions for our child and thinking what's best for her. At the same time, she can't tell us how she feels. We need someone who has been there.”

“For those parents that are struggling to find a starting point early on. I feel if you could bring someone in to meet them that is deaf before they make their initial decision that would be so helpful. It was so heartwarming to meet a deaf adult. “

“There were days I couldn't figure how I was going to be a mother to my son. My Deaf Mentor just made it so comfortable to ask whatever questions I needed and to ask what it is like to be deaf. Instead of being connected to doctors and therapists and being a patient... we are now in this community, and we are a part of something amazing. It was then I realized I could be the mother I wanted to be. “

Thoughts from Families...



“Families need to meet someone that’s Deaf or hard of hearing earlier. An adult, or even a child in their teenage years like going to high school, so they can tell us their experience of how they felt, because that is such a big thing because we were making decisions for our child and thinking what's best for her. But at the same time, she can't tell us how she feels. We need someone who has been there.”

“Meeting another an adult who is living that life and living that life successfully, and how do they navigate that, that is what you really need when you're just up against something that's really scary”

“My own instinct was, I needed to talk to Deaf community members to uncover their experience, their upbringing, their language, access, how they interacted with their families ”



Thoughts from Families...




“When our Deaf Mentor said that when the deaf community hears that, there’s a deaf baby born they are so excited I thought....wow...to have somebody say that made me so happy. What a nice way to think about this. This may sound funny, I became more excited that he gets to be part of a new community, a community that's very accepting, and we get to be part of this community too!”

“Just try. Just try to meet someone in the Deaf community and just listen to their experience, it will change your perspective”

“The first time I met an adult that was deaf in one ear like my daughter I felt grounded. To be able to get a glimpse of what her life like might be like when she grew up was so important. I just wish I had met her earlier.”

“They have been so empowering. Just seeing they are happy, and I am enjoying stories of learning where they grew up, and how they grew up, and what they've enjoyed. It's definitely it's definitely like a sigh of relief.”



Interpretations and Importance of Findings

Data gleaned from the study match the FCEI principles:

- Early, timely and equitable services
 - One system of entrance into EI
 - Seamless coordinated and trusted connection to EI provider
 - Family and provider partnerships
 - Informed Choice
 - Valued Discussions – language and communication opportunities
 - Concept of a journey was helpful
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- Delivery was “on point” in the ELCO process
 - ELCO process felt empowering with discussions, reflections and encouragement to ask questions





Important Finding to Share

- Families often felt frustrated and disempowered by their medical providers
- Families felt they were pushed in a direction they disagreed with
- Families received conflicting information



Implications




- Families were initially overwhelmed
- Relationships are important
- Family engagement and empowerment is important to the family decision-making process and successful child outcomes
- State systems should consider the impact of how families feeling overwhelmed impacts empowerment and engagement
- State systems could look at ways to streamline communication and information to families

Implications



- Participants stressed the importance of meeting deaf and hard of hearing adults and parents of deaf children.
- The ELCO process currently has embedded the engagement of individuals with lived experiences into their process:
 - It is important to look at how and when families have these opportunities and when in their journey they are being offered?



What does
this mean
for Hands &
Voices
Chapters?

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