



I couldn't stand. I couldn't walk when I heard [...] he has a hearing loss. I just sit on the floor. I didn't care the floor is dirty or not...I couldn't understand it was too much for me [...] at the beginning I was so sad because I thought I couldn't do it.

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Improving Our Understanding Of Diverse Family Experiences Within The Toronto, Canada EHDI Program

Presented by Laura Lanys (SLP), Gillian Lalonde (SLP), and Madeleine Tait (SLP)

EDHI Annual Conference

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Focus Questions

1. What does the research say about the prevalence of diverse family experiences in DHH literature?
2. What are some specific challenges experienced by diverse families within an EHDI program?
3. How can LSL clinicians increase family engagement and self-efficacy skills for diverse families?

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Acknowledgment

- We would like to acknowledge the mentorship of Professor Sheila Moodie from Western University (London, Ontario, Canada) who helped with the design of our quality improvement pilot project and provided guidance as we prepared today.

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Why Families and Why Self-Efficacy?

- ▶ Family members are the primary clients in LSL practice
- ▶ Parental Self-Efficacy:
 - Belief in their ability to perform a parenting task successfully
 - Estimations of their own competence



Photo by National Neuroscience Institute

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Why Diverse Families?



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RESEARCH

"There is limited research on family engagement among immigrant families with young children who are deaf." (Batamula, 2016)

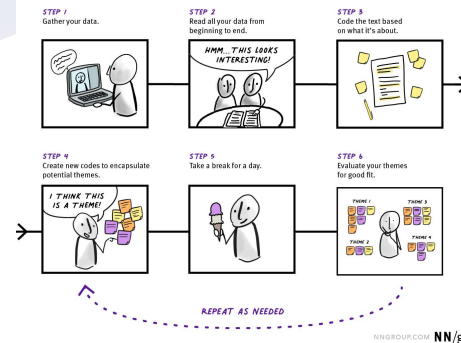
Research is both lacking and sorely needed regarding DHH learners whose families do not speak or sign the languages of the wider community at home. (Cannon & Marx, 2024)

Systemic inequities in communications sciences and disorders. Chronic underreporting and underrepresentation of sex, gender, race, and ethnicity in research. (Millager et al., 2024)

A call "for future research to elicit the voices of caregivers from a variety of cultures and backgrounds, in a range of settings, in the broader context of LSL EI services." (Noll et al., 2022)

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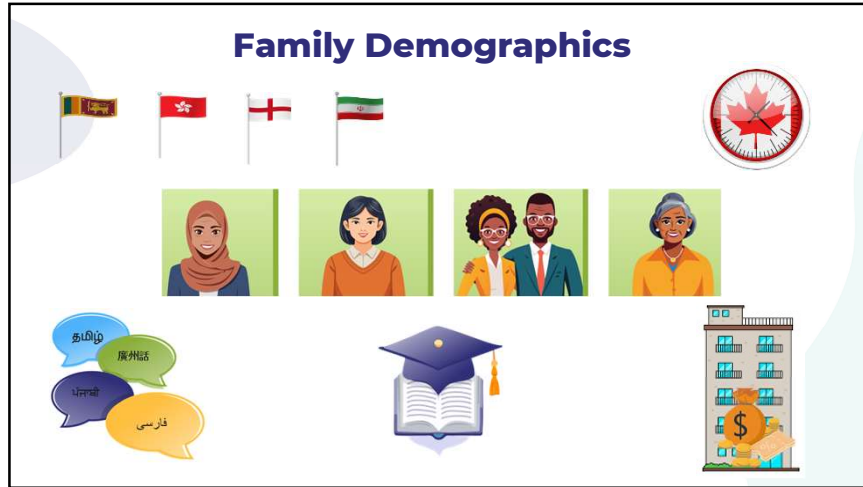
Improving our Understanding of Diverse Family Experiences within the Toronto EHD Program: METHOD



- ▶ Quality Improvement Pilot Project
- ▶ Four diverse families purposefully invited to participate
- ▶ Each family interviewed virtually by a Toronto EHD SLP
- ▶ Interviews transcribed and analyzed using thematic analysis by Toronto EHD SLP team

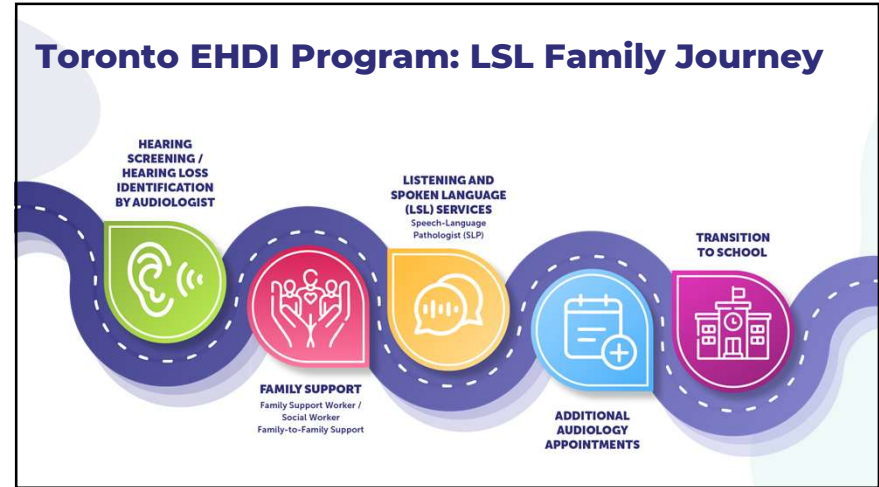
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Family Demographics



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Toronto EHDI Program: LSL Family Journey



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“
Yes, in the beginning, I couldn't accept my child to have a hearing aid. I remember it and I thought my child doesn't have a problem with hearing...it takes a year until I could accept it.



“
In my family, no one has a hearing aid. [...] Because my culture. It is not good. It's hard to explain. Is when you have a child, the child has a problem, everyone looks at you. And when you go in the street, everyone just they watch you differently, strange, and you feel so shameful. And I don't know what to do. You want to just hide yourself. [...] I didn't go back to my country. I prefer to stay here 'cause I'm not enough strong to face.



HEARING
SCREENING /
HEARING LOSS
IDENTIFICATION
BY AUDIOLOGIST



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HANDS &
VOICES™



Instagram

a.g.bell
Association for the Deaf
& Hard of Hearing

VOICE
FOR DEAF AND HARD OF HEARING CHILDREN



Photo by www.manchesterdeafcentre.com



FAMILY SUPPORT
Family Support Worker /
Social Worker
Family-to-Family Support

facebook

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“ OK, so as they were speaking the same language, it was really helpful to communicate with them. And they encouraged us because at the time [their] child was around 10 years old and the child didn't have any problems and was doing well and when we heard that it encouraged us to move forward and to think positively. So it was really helpful in that way.

“ We like the format [of a Facebook] group [...] some people they may like to share, or for [...] others they may [...] just receive some information [...] you don't have any obligations [...] Yeah, because compared to the other systems, say, like a one-to-one support, sometimes the parents may feel a little bit of pressure [...] to keep a connection.

“ I think the family to family support more focus on the mentality, on how we should deal with the kids. Yeah, instead of, you know, some very technical terms that we heard from the hearing program professionals. Say like the audiologist, they really explain the audiograms and for the Speech-Language Pathologist they focus on their speech development, but for the family-to-family support is not alike. This [...] knowledge is more on the soft side [...] some new insight on teaching how to teach our kids.

FAMILY SUPPORT
Family Support Worker / Social Worker
Family-to-Family Support



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What is Working Well (System/LSL)

“ We are blessed. We have the services. [...] back home [...] they don't even have any of this CI services [...] they don't even have the hearing screening at all. So I'm telling you, I'd like to be in this country that like in this province actually that we can get. We can find out like at very early age.

“ It's [...] very intense therapy going on with the [speech-language] pathologist, they're doing their best job and I have to do at home too, like at home is 24 hours with her.

“ Whenever the word is smaller in my language, I speak that word. And then [the SLP] learned that one too [...] "give it to me" [in] my language is 'day do'. So it's just one word [...] even if I see [the SLP] [...] [after] like two weeks or three weeks, [the SLP] still say the same words [from my language] again and again.

LISTENING AND SPOKEN LANGUAGE (LSL) SERVICES
Speech-Language Pathologist (SLP)




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System and LSL Challenges/Barriers

- ▶ Competing life demands
- ▶ Transportation
- ▶ Finding and navigating DHH services as a newcomer to Canada
- ▶ Age cut-off for LSL services
- ▶ LSL clinician and client don't speak the same language
- ▶ Consistent availability of interpretation services across all EHDI service providers
- ▶ Perceived lack of empathy or bedside manner of DHH professionals

LISTENING AND SPOKEN LANGUAGE (LSL) SERVICES
Speech-Language Pathologist (SLP)



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System and LSL Challenges/Barriers

When we went to the hospital [...] they said [my child] has this kind of hearing issue, we didn't understand because [...] at that time, they couldn't get an interpreter for us. Everything was new for us as well, so we didn't understand properly [...] They said that she needs to put the hearing aid and when they explained we didn't understand completely. And when they gave the forms to fill out, we didn't do it. We took time because we didn't understand [...] And because of our language barrier, we had to wait for awhile to do this and we couldn't get any help [...] and we didn't know to whom we have to go.



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System and LSL Challenges/Barriers



But with the audiologist, with the doctor, I think they didn't have any feeling, you know. I was miserable at that time. And I wanted to grab someone and someone to just listen to me. And they told me just go on and put something in his ear and, just they act like a robot.

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System and LSL Improvements: Incorporating Family Voices



- ▶ Increased frequency of LSL sessions
- ▶ Additional training in active, supportive listening and counselling skills for DHH professionals
- ▶ Social Worker present at time of hearing screening and identification
- ▶ Increased visibility of EHDI professionals with hearing loss
- ▶ Flexible age cut-off for LSL services
- ▶ Uber cards
- ▶ Information about EHDI services on the Canadian website

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How DHH Professionals Can Increase Family Engagement and Self-Efficacy Skills



Clear Expectations of Family as Partner

It's like new course that I'm taking [...] [LSL intervention is] for me rather than [my child] because [my child] just go[es] there and play[...] it's me who's like for one hour class. I'm learning everything and doing the same thing with her at home.

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How DHH Professionals Can Increase Family Engagement and Self-Efficacy Skills



Trust-Building, Kindness, Empathy

[My SLP], teach me a lot. And whenever I ask [...] her something. She does it. She do it right away. You know she doesn't postpone it or she doesn't [...] give me excuse...because I'm comparing her with others and she's patient.

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How DHH Professionals Can Increase Family Engagement and Self-Efficacy Skills



Clinician Model → Family as Primary Facilitator

You taught me like you teach to the little children. When you said [...] [the] tasks for the next week and then at the end of the session you will ask, OK, repeat it. What are you going to do? So it makes me clear, you know, I have to grasp that thing and [...] say it back. So it made me remember the things.

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How DHH Professionals Can Increase Family Engagement and Self-Efficacy Skills

Connect us to other families who speak the same language

Have interpreters present at all LSL sessions

Incorporate our home language into LSL sessions



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LSL Services Improvements

Additional training to enhance adult coaching skills for LSL clinicians

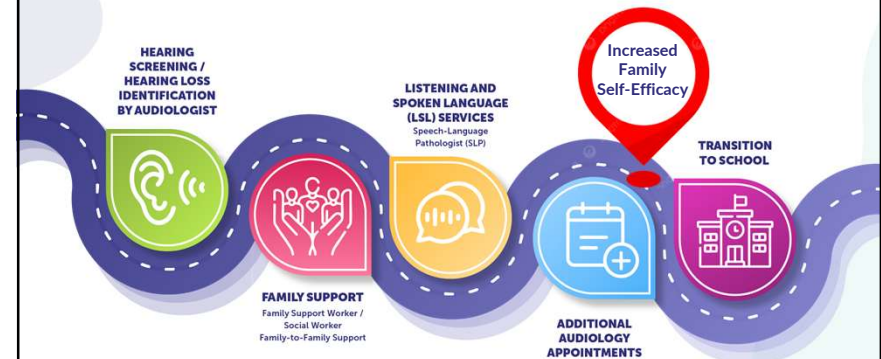
Systematic documentation of parent goals and progress

More objective tools to measure parental self-efficacy (e.g., Scale of Parental Involvement and Self-Efficacy-Revised [SPISE-R]) (Ambrose et al., 2020)




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Toronto EHDl Program: LSL Family Journey




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One of the very important factor is that hearing do affects the speech development in the future. And also the brain development because if you keep stimulating the brain with the sound and the development will get better. And also you can [...] only learn the language by listening. If you can't listen then probably in the future they can't talk or they cannot have a good pronunciation [...] All these ideas make us keep in mind that we need to put on the hearing aids.

↑ Knowledge


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When he go to daycare in the mornings and I see the teacher of daycare don't know how to talk to [him]. I explain to them. When [he] is connected to [the remote] microphone [he] can hear clearly, but if not connected, then is not clear. And I explain to them is very important for [my child].

↑ Confidence + Advocacy

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The information I get [...] from [...] the [Speech-Language] Pathologist [...] my husband and my kids like my mom and dad, they live in the same house, so I teach them as well [...] my family is just like, thank god, it's just like a team. So if I'm away, then they knows that she's supposed to have [the processors] on for all the time. Not like, the mommy will come and she will put it on.

↑ Knowledge + Application

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Advice for Other Families

The earlier you accept the [hearing loss identification], the earlier you can receive the treatment, and I think that's the best for the kids, for the brain development and the speech development and all kind of things. Yeah, it's all begin from when parents do accept the problem because you know for the infants, for the baby, they can't tell you whether they have problem or not [...] therefore the responsibility lies solely on the parents [...] don't second guess, you trust the diagnosis.

If I see another family, just I sit with them and I listen to them. I tell them just I know how do you feel, 'cause I experienced it, and it's hard to accept it.



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Limitations of Quality Improvement Pilot Project

Purposeful Sampling: Families were intentionally selected based on specific criteria, which may limit the diversity of perspectives included.

Small and specific sample (4 families)

Lack of fathers in sample (4 of 5 participants were mothers)

Use of Language Interpreter: One interview required an interpreter, which may have affected the nuances of communication and interpretation of responses.

Interviewer Bias: Families were interviewed by a member of the Toronto EHDI SLP team rather than a neutral third party.

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Limitations of Quality Improvement Pilot Project Continued

Clinician-Led Analysis: Toronto EHDI SLP team analyzed the data collected from families, which may introduce bias based on their professional perspectives

Lack of anonymity of participants to the Toronto EHDI SLP team who analyzed the data

Service Engagement: Almost all participating families were currently receiving LSL services, which may not fully represent the experiences of those who are not engaged in these programs.
All but one family was receiving listening and spoken language services with the Toronto EHDI program at the time of the interviews

Limited generalizability of findings to the broad range of families receiving Listening and Spoken Language services in the Toronto EHDI program

Inclusion of English-only studies in deaf or hard of hearing literature review

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Improvements for Future Study

Improve Representation: Ensure the sample more accurately reflects Toronto's diverse demographics.

Expand the Sample: Include a larger and more diverse group of participants to improve generalizability.

Measure Changes Over Time: Include pre- and post-assessments of self-efficacy to better understand the impact of LSL services on families.

Neutral Interviewers: Conduct interviews with a neutral third party to reduce potential bias.

Simplify Questions: Refine interview questions to make them clearer and more accessible for participants.

Independent Data Analysis: Involve a third party in data analysis to enhance objectivity.

Broaden the Study: Conduct an expanded interview-based study to capture a wider range of family experiences.

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What Did You Learn?

- | | |
|---|--|
| 1. What does the research say about the prevalence of diverse family experiences in DHH literature? | <ul style="list-style-type: none"> Underreported and unrepresented More diverse voices needed |
| 2. What are some specific challenges experienced by diverse families within an EHDI program? | <ul style="list-style-type: none"> Transportation Language barrier Finding and navigating DHH services as a newcomer Age cut-off for LSL services |
| 3. How can LSL clinicians increase family engagement and self-efficacy skills for diverse families? | <ul style="list-style-type: none"> Clear expectations that family is the primary client Build trust – respond to family identified needs Clinician model → Family as primary facilitator Incorporate home language into LSL goals and activities Purposeful family-to-family support pairing (sharing the same home language) Provide interpretation services for all appointments |

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I couldn't stand. I couldn't walk when I heard [...] he has a hearing loss. I just sit on the floor. I didn't care the floor is dirty or not...I couldn't understand it was too much for me [...] at the beginning I was so sad because I thought I couldn't do it.

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To play, to teach him.
Actually, I think [...] now I'm a speech therapist. I don't have an education, but I learn how to work with [him].

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Thank
You



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