Families with Young Children who are Deaf and Hard of Hearing in Minnesota

A Mentoring Needs Assessment Conducted for Lifetrack

Executive summary

Introduction

Wilder Research was contracted by Lifetrack to conduct a study to better understand the needs and preferences of families with young children who are deaf or hard of hearing (D/HH) related to its family mentoring programs. The results of this study will help Lifetrack to expand its outreach and offerings, particularly in terms of reaching populations that may currently be underserved, such as families in rural Minnesota, culturally diverse families, especially those who do not speak English at home, and families who choose modes of communication for their child other than American Sign Language, or ASL.

Target population

As of January 2015, 1,273 children live in Minnesota who were identified with a hearing loss before age 7. Over two-thirds (68%) of these children diagnosed have a bilateral hearing loss – of these, 19 percent have a moderately severe or severe hearing loss and 17 percent have a profound hearing loss. Seventy percent of these children have mothers who are white and 30 percent have mothers who are not white. Nearly one in five (19%) live in households that speak a language other than English.

Study methods

Wilder Research conducted a series of focus groups and interviews with 47 parents of children who are D/HH, as well as 51 adults who are D/HH, to gain an understanding of how both groups perceive D/HH mentoring programs, including benefits of and barriers to participation. Parents were also asked about their mentoring and support needs. A web survey with similar questions was conducted with 118 parents of children who are D/HH.

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We also conducted interviews with six national experts who were identified by members of our Advisory Group. (Of note, the six experts we interviewed are all ASL primary users and teachers of ASL, so that perspective is the only one represented here. We attempted to interview other experts who were also identified by our Advisory Group who are primarily oral and who share different perspectives about language acquisition. Unfortunately, none of those experts were available to be interviewed during the timeframe of this study.)

We also interviewed 13 Lifetrack staff regarding D/HH mentoring programs. Of note, for analysis and reporting purposes we grouped all Lifetrack staff together but recognize that not all of the experiences or viewpoints of staff align across the various Lifetrack programs.

We conducted a literature review of peer-reviewed research literature on the topic of D/HH mentoring programs, and we also conducted a scan of the field of other D/HH mentoring programs around the U.S.

The results from these data collection activities were triangulated and synthesized to produce the key findings and recommendations included in this report.

Key findings

This study emphasizes the needs and best interests of children who are D/HH, and recognizes that parents of children who are D/HH, adults who are D/HH (especially those who grew up with hearing parents), experts on hearing loss and the needs of children who are D/HH, and front-line Lifetrack staff who serve these children and families all have important perspectives about what families with young children who are D/HH really need in terms of mentoring and support. Therefore, the key findings reported here are themes that emerged when we synthesized and triangulated data from all of the sources noted above.

Parents of young children who are D/HH most commonly need:

- Emotional support to help them through this initial stage of grief
- To connect with other families that are currently participating in the D/HH mentoring program, and perhaps program alumni
- Having a role model the child can look up to – parents need hope for the future and children need self-esteem, positive identity, and self-advocacy skills
- Learn American Sign Language (ASL) and communication skills and tools – many parents who participated in this study also wanted to know more about other communication tools (e.g., Cued Speech)
- Information about assistive technologies – cochlear implants and hearing aids

These needs should be taken into consideration when Lifetrack is further developing its **D/HH mentoring program curriculum and content**, and Lifetrack should also consider these needs with regard to its other programs, namely Minnesota Hands & Voices.

Particular **sub-groups of families may have specific needs**, including:

- Families whose primary spoken language is not English may need better access to written materials in languages other than English, as well as trilingual D/HH mentors (mentors who are fluent in English, ASL, and the family's native spoken language) who are from the same cultural community
- Families who live in rural Minnesota may need help finding other options for program participation when travel across long distances is not feasible; this may include using technology in creative ways; families in rural areas may also need more regional events to connect to other families in their area with children who are D/HH (or they may need more outreach for the Minnesota hands & Voices events and activities that are already offered); and more mentors may also need to be recruited in some parts of the state
- Families with very young children who are D/HH may need more information about the importance of language acquisition, and the D/HH mentoring program may need to provide games and activities that are age-appropriate for very young children
- Families with children who are D/HH and have co-occurring disabilities or health conditions may need more targeted services, support, and resources
- Families who choose ASL as their primary mode of communication already have access to the Lifetrack Deaf Mentor program, which families report to be meeting most of their needs in terms of learning ASL, but parents want more information about other options for communication as well as assistive technologies they may be pairing with ASL
- Families who do not choose ASL as their primary language/mode of communication typically do not participate in the Lifetrack Deaf Mentor program because the program is currently intended to teach ASL; however, there appears to be interest and demand among parents who do not choose ASL as their primary language to have access to mentoring and support for other topics

In terms of **mentoring program structure**, families want and need:

- More customization and flexibility with regard to when, where, and how often they meet with their mentor, as well as what topics are covered and which family members are required or allowed to participate

- Increased age limits so families with older (school-age) children can participate
- More activities to help them connect with other families with children who are D/HH, especially for sub-groups such as families with very young children, families from specific cultural and non-English language groups, and families from rural Minnesota

A disconnect was observed between parents' preferences for **program intensity** and what Lifetrack staff and national experts who we interviewed feel is necessary for effective programming.

There are several **characteristics of mentors** that are commonly recognized as critical to the success of D/HH mentoring programs; these characteristics were noted by parents and adults who are D/HH as well as found in the literature and cited by the experts we interviewed. Good mentors are adults who are D/HH who are:

- Flexible, with good communication skills to work with hearing people without an interpreter
- Unbiased – accepting and supportive of families' choices about communication mode(s) and use of assistive technologies, in particular
- A good match for the family in terms of similar type of hearing loss, mode(s) of communication used, and assistive technologies used, as well as culture and language
- For mentors who are primarily supposed to be teaching ASL to the family, they should also be trained and skilled at using best practices in visual language education

It was noted that the current Lifetrack D/HH Mentors/Role Models are dedicated and passionate about their work, which contributes to the success of the program.

When asked about potential benefits to participation as a mentor, adults who are D/HH most commonly suggested the **feeling of making a difference as a top benefit of being a mentor**; some also felt mentors benefitted by making stronger connections in the Deaf community through their mentoring experience. Adults who are D/HH recommended that mentors be recruited by relying on their desire to give back to the Deaf community and by increasing the appeal of the position (i.e., making it a paid position, preferably full-time, and increasing the professionalization through a stronger training program). Lifetrack is currently working on developing more D/HH Mentor/Role Model training sessions. Some of the components of this training program include best practices in mentoring, assistive technologies for young children, understanding medical conditions of children who are D/HH, education for children who are D/HH, information on language and ASL, and Deaf culture and community.

The **travel time required, especially in rural Minnesota, and the educational requirements for Lifetrack D/HH Mentors/Role Models may be barriers to becoming mentors** for some adults who are D/HH.

The **benefits to children and families who participate in D/HH mentoring programs** are not well-documented in terms of rigorous outcomes evaluation and research. However, the parents, adults who are D/HH, Lifetrack staff, and national experts who we interviewed noted several key goals and potential benefits of D/HH mentoring programs:

- Improved language acquisition
- Making connections in the Deaf community
- Self-esteem and positive identity for the child
- Hope for the future and overall better well-being for the parents

Adults who are D/HH further supported these suggested benefits with their own experience of growing up with hearing loss. Almost half of the adults who are D/HH interviewed for this study expressed that having a mentor would have helped them (and their parents) to learn ASL and life skills at a younger age.

There are also several **barriers to families with young children who are D/HH from participating in D/HH mentoring programs, as discovered from interviews and focus groups**:

- Lack of program awareness
- Perceived mentor bias and/or parents' concern about being judged for decisions regarding communication mode(s) and use of assistive technologies
- Perception that the Lifetrack program is for families with children who are profoundly deaf who have chosen ASL as their primary mode of communication
- Parents' perceptions, or receiving misinformation from various sources, that learning ASL may have a negative impact on their child's spoken language development and literacy (whereas the literature we reviewed suggests that learning ASL supports learning of spoken language and literacy among severely and profoundly deaf children)
- Scheduling and availability – both on the part of the families and their mentors

Recommendations

Overall, mentoring programs are broadly recognized by parents, adults who are D/HH, and experts as a critical component of the Early Hearing Detection and Intervention (EHDI) services and supports offered to families with young children who are D/HH. Like most other programs around the country, Lifetrack's Deaf Mentor program is designed specifically to teach children and families ASL and learn about Deaf culture. (The pilot Role Model program that is currently serving 4 families does address some, but not all, of the other topics parents expressed interest in learning more about.)

It is important to **consider the range of strategies and approaches other D/HH mentoring programs are using to meet the needs of families with young children who are D/HH**. Most of the programs reviewed for this study use the SKI HI curriculum, teach ASL, and help the families to learn more about Deaf culture and community. Although these programs share many commonalities with Lifetrack's D/HH Mentor/Role Model programs, a few also use other practices that Lifetrack should consider, such as the 100-session model.

Very little published research exists with regard to organizational capacities to manage a successful D/HH mentoring program. Based on the results of this study and our general understanding of key aspects of program sustainability, we developed several recommendations for Lifetrack to consider:

- The population of families with young children who are D/HH in Minnesota is increasingly diverse in terms of range of hearing loss, communication modes and adaptive technologies available and used, types of co-occurring disabilities, geographic location around the state, and race, culture, and home language. The **leadership** of Lifetrack's D/HH Mentor/Role Model programs should be prepared not only to expand the program at the current time to better meet the needs of all families with children who are D/HH in Minnesota, but also to develop and implement strategies and processes for continually assessing the needs of Lifetrack's target population, so its programs and services can continue to be responsive to the ever-changing environment.
- In terms of **strategic relationships**, Lifetrack should consider its current funders (MDH and DHHSD), as well as new or innovation options for funding (e.g., health insurance reimbursements, special education funds); Lifetrack should also consider ways of building on its already strong internal partnerships (namely, Minnesota Hands & Voices and the overlapping programming needs for family-to-family support and mentoring).
- Lifetrack should consider developmental, process, and outcomes **program evaluation** and monitoring as a strategy to ensure the D/HH Mentor/Role Model program meets the needs of families, and to assess the impact of the program on children's, families', and mentors' outcomes.

Regarding **program outreach to families**, this study found that, in general, there is a lack of awareness about the Lifetrack D/HH Mentor/Role Model program among many parents of young children who are D/HH in Minnesota. Currently, the Lifetrack Deaf Mentor program reaches out to families through the DHHSD Regional Service Centers and through referrals they receive from Minnesota Hands &Voices. Additional outreach may occur at other special events, such as the statewide teachers' conference. Minnesota Hands & Voices also promotes the D/HH Role Model/Mentor program through its newsletter, Facebook page, presentations to professional groups, and they include Deaf Mentors and adult role models in Minnesota Hands & Voices events, Parent Guides directly refer families to the program, and other ways. Lifetrack should also consider branding the program and the "Family Mentor Program" and providing a menu of options along with evidence-based information for parents to review and determine which program components are the best fit for their family.

It is important for D/HH mentoring programs to reach out to families multiple times, in varying formats, in order to get their attention at a time when they are feeling overwhelmed with the amount of information they need to process, dealing with grief and possibly denial over their child's hearing loss, and sometimes also dealing with their child's serious health issues or other co-occurring disabilities. Professionals such as audiologists, pediatricians and specialists, and teachers may be able to help with outreach to families, as many families rely on these professionals for information and resources for their child.

The diversity of needs and preferences among families with young children who are D/HH in Minnesota supports a **mentoring program structure** that honors and aligns programming with the family's preferred mode(s) of communication, and offers a variety of options including instruction in American Sign Language, learning about assistive technologies, building health care and educational systems navigation and self-advocacy skills, learning about Deaf culture and connecting to the Deaf community, and connecting to other families with children who are D/HH. Lifetrack should consider ways to make participation in the intensive program easier for families, and consider further evaluation to assess the level of program intensity needed to achieve the desired outcomes for children and families.

Mentors should represent the diversity of the families being served (e.g., range of hearing loss and communication methods, culture, and language). Study participants indicated a need for the program to recruit and hire more mentors of varying ethnicity, modes of communication, range of hearing loss, language(s), and possibly in rural Minnesota.

Training for mentors is also key to ensure they are providing unbiased, accurate information to parents and children, as well as using best practices in visual language instruction (when applicable). Lifetrack should also consider other parents and teens who are D/HH (instead of only adults who are D/HH) as possible mentors, to provide support to parents and families (on topics other than ASL).

In conclusion, while the Lifetrack D/HH Mentor/Role Model may meet the needs and preferences of some families with young children who are D/HH in Minnesota, the results of this assessment indicate that **a broader array of services and supports is needed**, and that there are specific organizational capacities, program components, mentor characteristics, and approaches to family outreach that are important to consider in the development, expansion, and strategic planning and sustainability of D/HH mentoring programs.

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For more information
This summary presents highlights of the *Families with Young children who are Deaf and Hard of Hearing in Minnesota*. For more information about this report, contact Nicole MartinRogers at Wilder Research, 651-280-2682.

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