



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

*A Mentoring Needs Assessment Conducted for Lifetrack*

**J U N E 2 0 1 5**

**Authors:**

Nicole MartinRogers, M.P.P., Ph.D.; Amanda Petersen, M.P.P.; and Sera Kinoglu, M.A.

Wilder Research

451 Lexington Parkway North

Saint Paul, Minnesota 55104

651-280-2700

[www.wilderresearch.org](http://www.wilderresearch.org)

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# Contents

|  |    |
|--|----|
| Executive summary.....   | 1  |
| Introduction.....  | 9  |
| Lifetrack program overview .....   | 9  |
| History of deaf and hard of hearing mentoring programs in Minnesota.....                                       | 10 |
| The evolution of best practices in serving families with young children who are deaf and hard of hearing ..... | 11 |
| The Early Hearing Detection and Intervention (EHDI) system in Minnesota.....                                   | 13 |
| Minnesota Department of Education’s services to young children who are D/HH.....                               | 15 |
| A note on terminology .....  | 15 |
| Purpose of this needs assessment.....  | 16 |
| Methods.....   | 16 |
| Characteristics of young children in Minnesota who are deaf and hard of hearing .....                          | 19 |
| Age of hearing loss identification and diagnosis .....   | 19 |
| Demographics of all families with young children who are D/HH in Minnesota .....                               | 20 |
| Location .....   | 20 |
| Outreach by Lifetrack to these families .....  | 20 |
| Demographics of families served by Lifetrack.....  | 21 |
| Communication modes .....  | 21 |
| Location of families served by Lifetrack .....   | 22 |
| Key findings.....  | 24 |
| Mentoring program curriculum and content .....   | 24 |
| Mentoring program structure .....  | 32 |
| Mentor characteristics.....  | 36 |
| Family outreach .....  | 40 |
| Benefits to children and families who participate in mentoring programs.....                                   | 44 |
| Barriers to families participating in a mentoring program.....   | 49 |
| Key needs, and adequacy of current services, for specific sub-groups .....                                     | 53 |
| Benefits for adults who are deaf and hard of hearing to serve as mentors .....                                 | 60 |
| Barriers for adults who are deaf and hard of hearing to serve as mentors.....                                  | 60 |

# Contents (continued)

|   |     |
|---|-----|
| Recommendations.....  | 61  |
| “Best practices” from the field.....  | 61  |
| Organizational capacities needed to maintain a strong mentoring program.....      | 65  |
| Program outreach.....   | 68  |
| Program structure.....  | 69  |
| Mentors.....  | 71  |
| Other suggestions.....  | 73  |
| Bibliography.....   | 75  |
| Appendix.....   | 78  |
| Lifetrack’s principles for healthy child and family development.....              | 79  |
| Study methods.....  | 81  |
| Lifetrack key informant interview protocol – Lifetrack staff.....                 | 90  |
| Key informant interview protocol – National experts.....                          | 92  |
| Web survey questions.....   | 94  |
| Parent interview/focus group protocol, survey, consent form.....                  | 104 |
| Adults who are D/HH interview/focus group protocol, survey, and consent form..... | 111 |

# Figures

|  |    |
|--|----|
| 1. Study participants.....   | 18 |
| 2. Map of the number and location of young children in Minnesota who are D/HH, plus information about the number and location of web survey respondents, by EHDI region.....   | 23 |
| 3. The kinds of information, experiences, and interactions parents hope to gain from a D/HH adult mentor/role model – role model, self-esteem, and connection to the Deaf culture and community (web survey participants)..... | 26 |
| 4. The kinds of information, experiences, and interactions parents hope to gain from a D/HH adult mentor/role model – language acquisition and tools (web survey participants).....  | 29 |
| 5. The kinds of information, experiences, and interactions parents hope to gain from a D/HH adult mentor/role model – assistive technologies (web survey participants) ...   | 31 |
| 6. Parents’ sources of information about new programs and services for their child (web survey participants, N=118).....   | 42 |
| 7. Parents’ sources of advice about how to help and support their child (web survey participants, N=118) .....   | 43 |
| 8. How well the Lifetrack D/HH Mentor/Role Model programs meets the needs of families, (web survey respondents who participated in the Lifetrack D/HH Mentor/Role Model program).....  | 54 |
| 9. Characteristics of D/HH mentoring programs around the U.S. ....   | 63 |

## Appendix

|  |    |
|--|----|
| A1. Advisory Committee members’ characteristics .....  | 82 |
| A2. Age at which hearing loss was first identified among the children who are D/HH whose parents completed the web survey (N=99) ..... | 84 |
| A3. Hearing loss characteristics of the adults who are D/HH who participated in this study (N=51).....                                 | 86 |
| A4. Hearing loss characteristics of the children whose parents participated in a focus group or interview (N=47).....                  | 88 |
| A5. Characteristics of children who are D/HH whose parents participated in a focus group or interview (N=47).....                      | 88 |

# 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.

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.

# Introduction

Adult role models/mentors who are deaf or hard of hearing (D/HH) support the language acquisition and social development for families of infants and young children who are D/HH by sharing personal experiences or information about being D/HH, educational and communication opportunities, using hearing technology, and about the Deaf community and Deaf culture. For families who have chosen to use American Sign Language (ASL), the use of adult mentors and role models trained in ASL-based mentoring curriculums specifically supports the family's learning of ASL.

## Lifetrack program overview

The mission of Lifetrack is *to work together to develop the strengths within children, families, and adults facing the greatest life challenges*. Lifetrack achieves this work with wrap-around service delivery that addresses gaps unmet by other community programs. For this report, it is important to provide distinction between the Lifetrack D/HH Mentor/Role Model program, which is the focus of this study, and another Lifetrack program Minnesota Hands & Voices' Parent to Parent Support Program. These separate programs serve the same target population and provide services that are intertwined.

### ***D/HH Mentor/Role Model program***

Currently, Lifetrack provides the Deaf Mentor program in Minnesota, which is a 2-year program that focuses on teaching families American Sign Language (ASL) and learning about Deaf culture. Lifetrack also provides a pilot Role Model program for families who are not interested in the Deaf Mentor program. While these programs may meet the needs of many families in Minnesota who have children who are D/HH, there is a continuum of needs, preferences, and choices that these programs may not meet. In particular, there may be a need to modify or expand the program and service and resource options available to meet the needs of families who chose communication modes other than ASL as the primary mode for their child, families who live in rural areas of Minnesota, and families who do not speak English as their first language at home. The Lifetrack Deaf Mentor program focuses on the communication needs of families with children who are deaf and hard of hearing from birth to age 6. The program assists these families by providing personal experiences about being deaf or hard of hearing, instruction in American Sign Language, factual information about early visual communication methods, and Deaf culture, through a trained Deaf Mentor.

### ***Minnesota Hands & Voices***

Lifetrack is also the designated state chapter of Hands & Voices, which receives state grant support. Minnesota Hands & Voices provides direct parent-to-parent assistance to families of children who are deaf or hard of hearing. This program provides information and referrals about communication, educational, and technology opportunities to families and with emphasis on support for families with children who are newly identified with a hearing loss.

Minnesota Hands & Voices staff is made up of parents of diverse children who are deaf or hard of hearing and who act as parent guides for families with newly diagnosed children. These parent guides provide information, referrals, and educational and social networking programs for families. This program is funded by the Minnesota Department of Health's Newborn Hearing Screening Follow-up Program, among other sources.

### **History of deaf and hard of hearing mentoring programs in Minnesota**

In 1989, a group of hard of hearing adult volunteers established an ad hoc work group to provide mentors to adolescents who are hard of hearing who did not use American Sign Language. They saw the isolation that these youth experienced and wanted to do something about it. These volunteers met for four years; they provided mentorship in group events of approximately 15 students. But there was no funding, and the group disbanded.

In 1997, the national advocacy nonprofit, Self Help for Hard of Hearing (now Hearing Loss Association of America), received a national grant for a program called "Heroes with Hearing Loss Mentoring Program." The Minnesota Department of Human Services' Deaf and Hard of Hearing Services Division (DHHSD) was selected to be a site. They chose a program model for group mentoring that provided hard of hearing adolescents with opportunities to socialize while meeting with adult role models. Four mentors were trained. Parents applied for services – 10 girls and 10 boys participated. They had separate and mixed activities. The program was run by DHHSD until 2000, when funding ended. Then, the Minnesota Chapter of the Alexander Graham Bell Association ran the program for two years, but when they lost funding, the program was discontinued.

In 2002, DHHSD began the Deaf Mentor program for families with children who are deaf who wanted to learn American Sign Language. In the first year, 14 mentors were trained. Deaf Mentors completed training using the SKI-HI Deaf Mentor Training Curriculum that was developed at Utah State University and were chosen based on their fluency in American Sign Language, their ability to communicate easily with hearing families, their comfort with young children, and their ability to support family decisions. Funding and support in these early years came from a combination of sources including DHHSD, SKI-HI, and the Center for Independent Living of Northeastern Minnesota.

In 2007, the Minnesota Legislature allocated \$40,000 to DHHSD to provide mentors to families with children who have hearing loss. From 2008 through 2012, DHHSD staff administered the Deaf Mentor program, working with families to plan services and monitor progress. The legislative funding was used to pay for the mentors' services and training. In late 2012, DHHSD repurposed \$60,000 of other grant funding to increase the Deaf Mentor program funding to \$100,000 per year. A Request for Proposals was issued to transfer operation of the entire program to a community-based agency. One of the duties of the contract was to begin development of a curriculum for hard of hearing role models to support families with children who are hard of hearing. In 2013, DHHSD became the contract manager and Lifetrack became the provider of the Deaf Mentor program.

During the 2013 legislative session, the statute regarding Newborn Hearing Screening/Early Hearing Detection and Intervention (MN Statute 144.966) was amended to include a provision for individualized D/HH mentors to provide education including American Sign Language as one available option for families of children who are D/HH. It allocated approximately \$155,000 per year, collected through newborn screening fee dollars, and is targeted for children birth to six. The Minnesota Department of Health (MDH) is responsible to contract with a non-profit organization for the D/HH mentor services. MDH issued a Request for Proposals and Lifetrack was awarded the contract.

Therefore, Lifetrack is currently contracted to administer the Deaf Mentor program, funded by DHHSD and MDH, for families with children birth to age 6, who choose to learn ASL. Lifetrack also administers the Role Model program which serves families with children ages 7-14 and is funded through DHHSD.

## **The evolution of best practices in serving families with young children who are deaf and hard of hearing**

States use the Joint Committee on Infant Hearing (JCIH) position statements as the foundation for their Early Hearing Detection and Intervention (EHDI) systems. The first position statement, published in 1971 in the medical journal *Pediatrics*, listed recommendations for early identification of children with hearing loss and newborn screening protocols. Members of the Joint Committee included the American Speech Language Hearing Association (ASHA), the American Academy of Ophthalmology and Otolaryngology (AAOO), and the American Academy of Pediatrics (AAP). There was no mention of involvement of parents or adults who are deaf and hard of hearing.



Since that time, the JCIH position statement has evolved from a one-page document and three medical organizations to a 28-page comprehensive document developed by a diverse group of stakeholders including representation from the American Society of Deaf Children, the Association of College Educators of the Deaf and Hard of Hearing, the Conference of Educational Administrators Schools and Programs for the Deaf, the Convention of Instructors of the Deaf, the National Association of the Deaf, Directors of Speech and Hearing Programs in State Health and Welfare Agencies, and the American Alexander Graham Bell Association.

*The Joint Committee on Infant Hearing 2007 Position Statement: Principles and Guidelines for Early Hearing Detection and Intervention Programs* describes the critical role of D/HH mentors: “The deaf and hard of hearing community includes members with direct experience with signed language, spoken language, hearing-aid and cochlear implant use, and other communication strategies and technologies. Optimally, adults who are deaf or hard of hearing should play an integral part in the EHDI program. Both adults and children in the deaf and hard of hearing community can enrich the family’s experience by serving as mentors and role models. Such mentors have experience in negotiating their way in a hearing world...”

The supplement to the JCIH 2007 position statement further specifies best practice recommendations based on a series of goals related to serving families with children who are D/HH as part of an EHDI program. These goals cover several aspects of care, but are guided by core themes of access, training, and standards of quality, as well as the monitoring and measurement of outcomes.

Goal 3a from the JCIH supplement states: “Intervention services to teach ASL will be provided by professionals who have native or fluent skills and are trained to teach parents/families and young children.” Goal 3b states: “Intervention services to develop listening and spoken language will be provided by professionals who have specialized skills and knowledge.” Goals 3a and 3b are not intended to be mutually exclusive, but rather that these two types of services both be available to achieve the overall Goal 3: “All children who are D/HH from birth to 3 years of age and their families have Early Intervention providers who have the professional qualifications and core knowledge to optimize the child’s development and child/family well-being.” Goal 11 is also relevant: “All children who are D/HH and their families have access to support, mentorship, and guidance from individuals who are D/HH.”

Finally, the supplement to the JCIH 2007 position statement acknowledges the important role individual who are D/HH play in this system of early intervention and family support, with its Goal 10: “Individuals who are D/HH will be active participants in the development and implementation of EHDI systems at the national, state/territory, and local levels; their participation will be an expected an integral component of the EHDI systems.”

Lifetrack employs a set of principles regarding child and family healthy development to guide their approach to working with children who are D/HH. By framing this approach through a lens of healthy development, these principles aim to build resources and programs that prioritize success for children, families, and communities. These principles are further supported by specific goals that consider factors of resiliency, risk reduction (e.g., formal and informal support), cultural and family values, and relationship building. See the Appendix for Lifetrack’s full description of their principles.

Our intention throughout this needs assessment process was to be in alignment with these JCIH goals and Lifetrack principles.

### The Early Hearing Detection and Intervention (EHDI) system in Minnesota

Minnesota Statutes 2013 144.966 Early Hearing Detection and Intervention Program:

Subd. 3. **Early hearing detection and intervention programs.** All hospitals shall establish an early hearing detection and intervention (EHDI) program. Each EHDI program shall:

- (1) in advance of any hearing screening testing, provide to the newborn's or infant's parents or parent information concerning the nature of the screening procedure, applicable costs of the screening procedure, the potential risks and effects of hearing loss, and the benefits of early detection and intervention;
- (2) comply with parental election as described under section 144.125, subdivision 4;
- (3) develop policies and procedures for screening and rescreening based on Department of Health recommendations;
- (4) provide appropriate training and monitoring of individuals responsible for performing hearing screening tests as recommended by the Department of Health;
- (5) test the newborn’s hearing prior to discharge, or, if the newborn is expected to remain in the hospital for a prolonged period, testing shall be performed prior to three months of age or when medically feasible;
- (6) develop and implement procedures for documenting the results of all hearing screening tests;
- (7) inform the newborn’s or infant's parents or parent, primary care physician, and the Department of Health according to recommendations of the Department of Health of the results of the hearing screening test or rescreening if conducted, or if the newborn or infant was not successfully tested. The hospital that discharges the newborn or infant to home is responsible for the screening; and
- (8) collect performance data specified by the Department of Health.

**Subd. 3a. Support services to families.**

(a) The commissioner shall contract with a nonprofit organization to provide support and assistance to families with children who are deaf or have a hearing loss. The family support provided must include:

- (1) direct hearing loss specific parent-to-parent assistance and unbiased information on communication, educational, and medical options; and
- (2) individualized deaf or hard-of-hearing mentors who provide education, including instruction in American Sign Language as an available option.

The commissioner shall give preference to a nonprofit organization that has the ability to provide these services throughout the state.

(b) Family participation in the support and assistance services is voluntary.

**Subd. 4. Notification and information; data retention and destruction.**

(a) Notification to the parents or parent, primary care provider, and the Department of Health shall occur prior to discharge or no later than ten days following the date of testing. Notification shall include information recommended by the Department of Health and information regarding the right of the parent or legal guardian to discontinue storage of the test results and require destruction under paragraph (d).

(b) A physician, nurse, midwife, or other health professional attending a birth outside a hospital or institution shall provide information, orally and in writing, as established by the Department of Health, to parents regarding places where the parents may have their infant's hearing screened and the importance of the screening.

(c) The professional conducting the diagnostic procedure to confirm the hearing loss must report the results to the parents, primary care provider, and Department of Health according to the Department of Health recommendations.

(d) The Department of Health may store hearing screening and rescreening test results for a period of time not to exceed 18 years from the infant's date of birth.

(e) Notwithstanding paragraph (d), a parent or legal guardian may instruct the Department of Health to discontinue storing hearing screening and rescreening test results by providing a signed and dated form requesting destruction of the test results. The Department of Health shall make necessary forms available on the department's Web site. If a parent or legal guardian instructs the Department of Health to discontinue storing hearing screening

and rescreening test results, the Department of Health shall destroy the test results within one month of receipt of the instruction or within 25 months after it received the last test result, whichever is later.

## Minnesota Department of Education's services to young children who are D/HH

The Minnesota Department of Education and public school districts also serve young children who are D/HH and their families through Part C Infant and Toddler Early Intervention Services and Part B Preschool Special Education Services. Part C refers to early intervention services which are administered by participating states in accordance with Part C of the federal Individuals with Disabilities Education Act (IDEA). Early Intervention Services are provided for children through age 2 with developmental delays or who have diagnosed physical or mental conditions with high probabilities of resulting in developmental delays. This includes children who are deaf or hard of hearing. Part B of IDEA refers to special education and related services that are provided within the public school system to eligible children and youth ages 3 to 21 years of age who have disabilities.

### A note on terminology

It is important to note that throughout this report, we use the terms “deaf,” “deaf and hard of hearing,” “Deaf,” and “Deaf culture.” We understand that these terms have different meanings to different people. The authors want to acknowledge that for this report, when we refer to individuals with a hearing loss, we refer to them as being “deaf” or “deaf or hard of hearing” or “D/HH.” When we use the term “the deaf and hard of hearing community” we are referring to the community of individuals that have all types of hearing loss. When the term “Deaf culture” (with a capital letter “D”) is used, the authors are referring to the community of, by, and for individuals who identify with being Deaf as a culture and use ASL as their primary communication method.

Although we consistently use “Deaf community” (with a capital “D”), in some cases this may refer to the Deaf community made up of individuals who identify with the Deaf culture and in most cases refers more broadly to all individuals (children and adults) who are D/HH, their families, and the professionals who serve them. (There is no way through the analysis we used to determine in which cases our participants were thinking about Deaf/deaf with a capital “D” or lowercase “d”.)

Also, the use of the term American Sign Language or ASL is used very broadly throughout this report and does not necessarily reflect the strict definition of ASL as an actual language. Respondents were asked not to clarify if their references to ASL were meant in the stricter sense.

The authors consulted with the Core Group and determined that this was the preferred way to use these terms for the purposes of this report, although we recognize that study participants may have had their own understanding of the terms, and that people in the community may have different preferences for the usage of these terms and particularly when and how to capitalize D in deaf.

## Purpose of this needs assessment

This needs assessment examines the needs of families across Minnesota who have children who are D/HH, as well as the perspectives of diverse experts and adults who are D/HH about the kinds of mentoring and supports families need when they have a young child who is D/HH. The importance of having a D/HH Mentor/Role Model program in Minnesota with a component that focuses on American Sign Language has already been strongly established. The purpose of this assessment is not to question or attempt to demonstrate there is not a need for this type of programming (mentoring that includes an ASL component is required by law).

The recommendations at the end of this report are intended to inform the sustainable expansion of Lifetrack's D/HH Mentor/Role Model programs to support the diverse needs and choices made by all families in Minnesota with children who are D/HH.

## Methods

Wilder Research used a mixed methods study design to identify mentoring and support needs of families across Minnesota that have children who are D/HH. See Figure 1 for information about study participants. Several data-collection methods were used:

- **Interviews with parents and D/HH individuals.** Phone and in-person interviews were conducted with 14 parents of D/HH children and 31 individuals who are D/HH to gauge benefits, barriers, experiences, and mentoring and support needs of families.
- **Key informant interviews.** Phone interviews were conducted with 13 D/HH Mentor/Role Model and Minnesota Hands & Voices staff. In the report, all Lifetrack staff (from both the D/HH Mentor/Role Model program and Minnesota Hands & Voices) are grouped together. However, we recognize that not all of the experiences or viewpoints of staff align across the various Lifetrack programs. Six national experts were also interviewed to gain insight into mentoring program best practices and organizational strategies.
- **Focus groups.** Four parent focus groups and two focus groups with adults who are D/HH were conducted at various locations in Minnesota, which included Saint Paul, Woodbury, Brainerd, and Thief River Falls.

- **Web survey.** Wilder Research conducted an online survey of parents of children who are D/HH. Survey participants were recruited through the Minnesota Hands & Voices database, on social media, and through Advisory Committee members, who were asked to distribute the link to their social and professional networks. A total of 118 respondents completed the survey.
- **Literature review.** Wilder Research conducted a literature review and field scan to explore best practices, characteristics of other D/HH mentoring programs, barriers to participation in these types of programs, program outcomes, and organizational strategies of other programs in the United States and internationally. Literature searches were performed by Wilder Research staff librarians, covering peer-reviewed journals as well as organization-based publications and web sites.
- **Analysis of secondary data.** To explore characteristics of families with children who are D/HH, Wilder Research reviewed secondary data provided by the Minnesota Department of Health Early Hearing Detection and Intervention database and from the Minnesota Department of Education (Part B and Part C) data. At the time of the report, data were available from the Minnesota Department of Health through January 2015 and from the Minnesota Department of Education from July 1, 2013, through June 30, 2014.

Among the parents who participated in a focus group or interview, 22 had children age 5 or younger, nine had children between the ages of 6 and 9, and five had children between the ages of 13 and 18. Nearly all children of these parents (27) were diagnosed between birth and 6 months of age, with just a few being diagnosed between ages 3 and 4 (5). (Not all parents who participated in this study provided this information.)

We triangulated data from across interviews, focus groups, and the web survey to answer the primary research questions. Interview and focus group notes were systematically coded and analyzed to identify key themes. Themes presented throughout this report reflect those most frequently mentioned by the research participants. Findings from the literature review and analysis of academic achievement data provide context to the primary data collection. A detailed description of the study methods can be found in the Appendix.

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## 1. Study participants

| <b>Individual interviews</b>             | <b>Number of respondents</b> |
|--|------------------------------|
| Parents of children who are D/HH         | 14                           |
| Adults who are D/HH                      | 31                           |
| National experts                         | 6                            |
| Lifetrack staff                          | 13                           |
| <b>Focus groups</b>                      | <b>Number of respondents</b> |
| Parents of children who are D/HH (Total) | 33                           |
| St. Paul (English)                       | 8                            |
| St. Paul (Spanish)                       | 5                            |
| Thief River Falls                        | 8                            |
| Brainerd                                 | 12                           |
| Adults who are D/HH (Total)              | 20                           |
| Brainerd                                 | 10                           |
| Woodbury                                 | 10                           |

# Characteristics of young children in Minnesota who are deaf and hard of hearing

As of January 2015, the Minnesota Department of Health Early Hearing Detection and Intervention (hereafter: MDH EHDI) has a record of 1,273 children who live in Minnesota and were identified with a hearing loss before age 7. Of these children, 1,056 are currently age birth to 6 years old.

The Minnesota Department of Education also provided information about the communication modes used by the children with hearing loss who exited Part C services at age 3 between July 1, 2013, and June 30, 2014 (N=113 children), as well as those who exited Part B Early Childhood Special Education services between July 1, 2013, and June 30, 2014 (N=104 children). This was their last report before these children went to kindergarten.

## Age of hearing loss identification and diagnosis

- 70% of children reported to MDH had a congenital hearing loss/did not pass their newborn screening, 17% of children with a hearing loss passed their newborn screening and the hearing loss was identified later, and 13% have an unknown hearing loss onset (they did not receive a newborn hearing screening)
- 63% of children were 6 months old or younger when their hearing loss was identified; 18% of the children were age 3 or older.
- Over two-thirds (68%) of children diagnosed have bilateral hearing loss.
  - 62% of children that have bilateral hearing loss have a slight, mild, or moderate degree of hearing loss in their better ear, 19% have a moderately severe or severe hearing loss and 17% have a profound hearing loss.
- For children reported to MDH between 2011 and 2013, three-quarters (73%) were fit with hearing aids and one-quarter (26%) reported using no technology.
  - It is important to note that families and providers sometimes delay the use of hearing aids (particularly if the child is very young or has mild or unilateral hearing loss). Thus, these numbers represent a minimum estimate of the use of these technologies.



- Also, for families that choose hearing aids, children must do a trial with hearing aids before they receive cochlear implants. Because cochlear implantation happens later, MDH does not typically have information about the use of this technology.
- In 2013, 30% of newly identified children had a comorbid condition. The most common comorbidities include orofacial birth defects, chromosomal birth defects, central nervous system birth defects, and low birth weight.

## Demographics of all families with young children who are D/HH in Minnesota

- 70% of children who were diagnosed with a hearing loss before age 7 had a mother who identified her race as white, 14% identified as Asian, 8% as African American, 2% as American Indian, and 7% as Hispanic/Latina.
- Most children (61%) were born to mothers who were 25-34 years at the time of the child's birth, but one-quarter (24%) were born to mothers who were younger than 25 years, including 5% born to mothers age 19 or younger.
- About one-third (35%) of children are born to mothers with a high school education or less, about one-third (27%) are born to mothers with some college education, and about one-third (37%) are born to mothers with a college degree or more education.
- Nearly one in five (19%) families identified a language other than English as their preferred language.

## Location

- Nearly two-thirds (62%) of children with hearing loss identified before age 7 are located in the 7-county Twin Cities metropolitan region. See Figure 2 (map).

## Outreach by Lifetrack to these families

- Between 2011 and 2014, the vast majority of families with a child who has a hearing loss (89%) who were reported to MDH were contacted by a Minnesota Hands & Voices Parent Guide.
- Lifetrack currently serves 34 families through its Deaf Mentor program via funding provided by MDH and DHHSD.
- Of these families, four are involved in the pilot Hearing Loss Role Model Family program.

## Demographics of families served by Lifetrack

- 14 out of 34 families served by the Deaf Mentor program are age 6 and over.
  - The Deaf Mentor program coordinator notes that some parents use the oral communication method with their children until they are in school, whereupon they discover that their child has a developmental delay and need assistance in ASL; this helps to explain the large number of children who are older when they enter the Deaf Mentor program.
  - Children who participate in the D/HH Role Model program are older than those participating in the Deaf Mentor program. All four children participating in this program are ages 10-12. It is important to note that the program was designed for children in this particular age group.
- The primary language of all of the children who are served by the D/HH Role Model program is oral.
- The majority (79%) of families currently served by the Deaf Mentor program speak English in their home; 9% of families speak Spanish and 6% each speak Somali or Hmong.
- All four families that currently participate in the pilot D/HH Role Model program speak English.
- Comparatively, the majority (84%) of families of three-year-olds exiting the Part C program between July of 2013 and July of 2014 report using English at home. A few (5%) families reported speaking primarily Spanish at home while one family used ASL at home. Similarly, 86% of the families of those children exiting Part B services during this same time period reported speaking English at home while very few (6%) speak Spanish at home.

## Communication modes

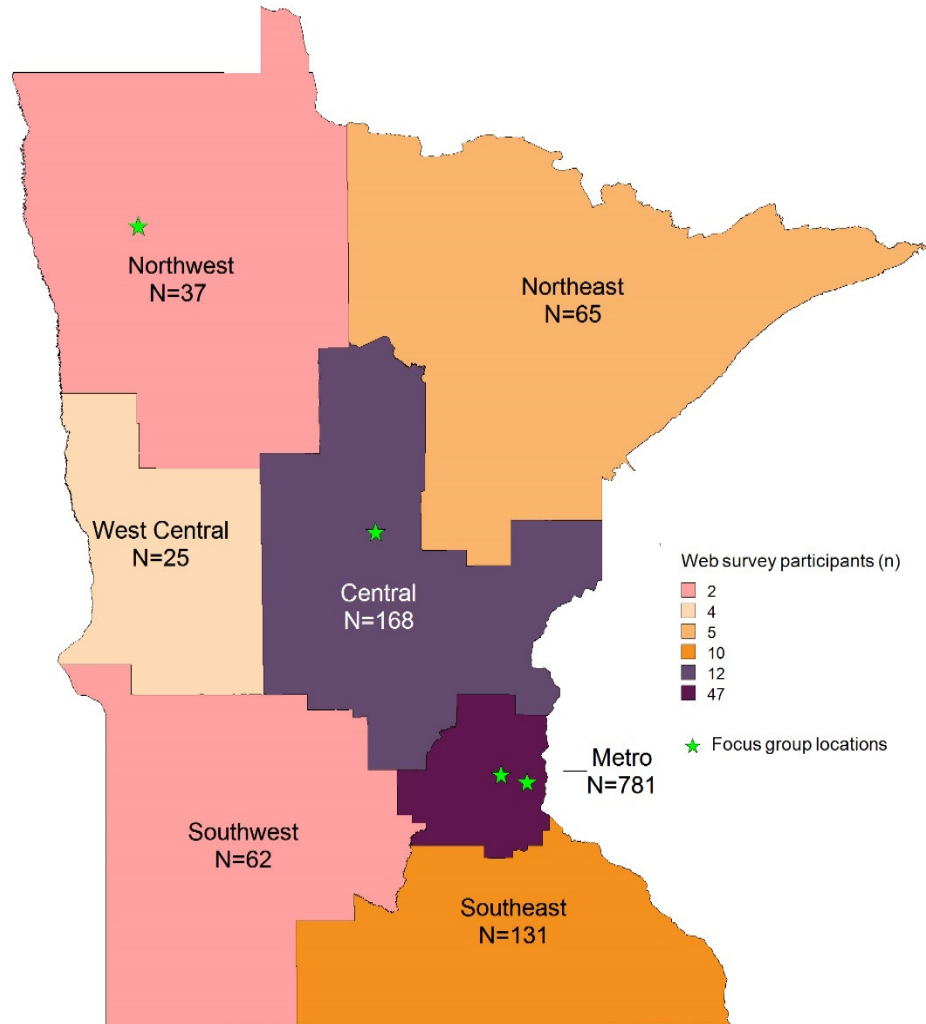
- Over half (58%) of children age 3 who recently exited MDE's Part C program who were identified as D/HH used listening and spoken language only. Two-thirds (67%) of children exiting MDE's Part B program that were identified as D/HH used listening and spoken language only.
- A few of these children (12% of children age 3 tracked by MDE's Part C program and 9% of children age 5 and under who are tracked by MDE Part B) used spoken language with gestures and a few signs.

- Very few (2% of children from both programs who were identified as D/HH) use ASL only. Nearly one in ten (9% of children age 3 from MDE's Part C program and 8% of children age 5 and under from MDE's Part B program who were identified as D/HH) use ASL in combination with other communication modes or language choices.
- One-quarter (26%) of children exiting Part C and one-fifth (21%) of children exiting Part B use a combination of communication modes.

### **Location of families served by Lifetrack**

- About half (47%) of the families served by the Lifetrack Deaf Mentor program are located in the Metro area. Twenty-one percent are located in the Central region of Minnesota. The rest of the families are located in the Northeast, Northwest, and South regions.
- Three of the families who participate in the pilot D/HH Role Model program are located in the Twin Cities, and one family is located in the South region.

2. Map of the number and location of young children in Minnesota who are D/HH, plus information about the number and location of web survey respondents, by EHD region



# Key findings

The key findings from this needs assessment are organized into nine sections: mentoring program curriculum and content, mentoring program structure, mentor characteristics, family outreach strategies, benefits to children and families who participate, barriers for families to participate, key needs and adequacy of services for specific subgroups, benefits to adults who are D/HH who serve as mentors, and barriers adults who are D/HH have to participating. Within each section, the key themes are emphasized using **bold text**, and participant quotes as well as an indication of the frequency with which this theme came up in the interviews and focus groups, web survey results, and findings from the research literature are used as supporting evidence, when available.

## Mentoring program curriculum and content

It is important for any D/HH mentoring program to meet the most pressing needs of the child and family. The most frequently identified support needs of families and children after finding out about their child's hearing loss are: emotional support for parents and connection to other families with children who are D/HH, a role model for the child and connection to the Deaf community, language acquisition and communication, information and resources, and assistive technologies.

### *Emotional support for parents and connection to other families*

The most common theme from parents regarding needs is that they need **emotional support** (theme was found in 8 out of 14 parent interviews and 2 out of 4 parent focus groups). Parent participants want to make **connections with another family who has been through the same experience**.

*"After the diagnosis, [what I needed most was] knowing there's something there we can go to and hearing from other parents there, having a safe space, talking through the emotions of what comes with a child being diagnosed with hearing loss." (Parent of a child who is D/HH)*

*"[After I found out about my child's hearing loss, what I needed most was] just to exchange ideas of how things work for them [other families], like I haven't tried something or maybe we should try that with my son - especially when it comes to school. Find out what some schools offer or what some schools don't offer. That's another big thing for me, I'm not sure what districts are required to offer them or what we have to beg for. Like the whole IEP process for him. I'm not sure..." (Parent of a child who is D/HH)*

Emotional support and mentoring for parents helps them **manage feelings of being overwhelmed as well as shock, denial, and grief** (Jackson 2011). Concern for their child's future was a frequent concern for parents after learning about their child's hearing loss (theme occurred in 7 out of 14 parent interviews and 2 out of 4 parent focus groups). This was often expressed as concern specifically for the child's school, life, and social skills: Will they fit in? Will they have the opportunity to be successful? Particularly if parents had never met an adult who is D/HH before, it was difficult for them to imagine their child's future.

Though slightly less common, some parents (1 parent interview and 3 out of 4 parent focus groups) expressed a period of **denial – not wanting to accept that their child was deaf or hard of hearing**, along with a desire for their child to be “fixed.” The national D/HH program experts (4 out of 6) and the Lifetrack staff (6 out of 13) interviewed also noted that parental support or mentoring should include **reassuring parents that their child will be okay, and should address parental grief over their child's hearing loss**.

*“You're reeling from the information, you're not thinking straight. It's a shock. They have the grief counselor for a reason and they help with the emotional part but what about the rest?” (Parent of a child who is D/HH)*

*“They want to know that their child is going to be ok and to be able to pursue higher education and communicate with the family and be part of the family culture. I think the most immediate initial needs deal with assurances that the family will be able to meet the needs of their child and that their child will be successful and happy.” (National expert)*

*“I guess everybody wants their child to be normal and not have anything wrong with them. I don't know, it was just kind of lonely, you don't know anybody else that has kids with hearing loss.” (Parent of a child who is D/HH)*

*“In the very beginning, it's so important for the family to connect with someone who's gone down that path. It's so important for them to have a parent guide. As they first process what's going on, there's oftentimes grieving and processing what the future will be like.” (Lifetrack staff)*

*“If they don't have a background or familiarity with D/HH, they often feel their child's hearing status will be a barrier to them being employed, educated, having friends, etc.” (Lifetrack staff)*

In the literature, it is noted that **connectedness to other families and the exchange of information and resources helps families to develop social identity and a sense of belonging, ultimately contributing to an increased sense of well-being**: “Parent to parent support has an appreciable quality that cannot be reproduced by clinicians; this specific support is recommended for the social and emotional well-being of families” (Henderson et al. 2014). Jackson (2011) finds that the informational resource with the highest average rating of preference among parents of a child with hearing loss is discussion with other parents. Parents may also trust other parents more than some professionals (Friedman-Narr et al. 2014). The national experts interviewed (3 out of 6) also indicated the importance of connections to other families.

***A role model for the child (self-esteem, life skills, and self-advocacy) and connecting to the Deaf community***

Parents who participated in the web survey were asked to rate the level of importance of the kinds of information, experiences, and interactions they would hope to gain from a D/HH adult mentor or role model. Over two-thirds (68%) of these parents believe it is extremely important to **include self-esteem and positive identity development for children who are D/HH as a part of a mentor program**, and one-fifth (19%) think this is very important. Nearly all respondents also believe it is very or extremely important to **include topics such as self-advocacy, survival tips, and other information** in a D/HH mentor/role model program, and for the adult mentor or role model to share their experiences and provide advice about dealing with preconceptions about hearing loss. See Figure 3.

**3. The kinds of information, experiences, and interactions parents hope to gain from a D/HH adult mentor/role model – role model, self-esteem, and connection to the Deaf culture and community (web survey participants)**

|   | <b>Extremely important</b> | <b>Very important</b> | <b>Somewhat important</b> | <b>Not too important</b> | <b>Not at all important</b> |
|---|----------------------------|-----------------------|---------------------------|--------------------------|-----------------------------|
| Self-esteem and positive identity development for your D/HH child (N=107)   | 68%                        | 19%                   | 9%                        | 4%                       | NA                          |
| Sharing experiences and overcoming pre-conceptions about hearing loss/D/HH individuals (N=104)                              | 52%                        | 30%                   | 14%                       | 3%                       | 2%                          |
| Other communication strategies and resources (self-advocacy, survival tips, etc.) that will benefit your D/HH child (N=109) | 53%                        | 35%                   | 10%                       | NA                       | 2%                          |
| Deaf culture and introduction of family to the local Deaf community (N=107)   | 21%                        | 16%                   | 31%                       | 18%                      | 15%                         |

When they were asked to identify in their own words the most important mentoring needs of the child, over half (7 out of 13) of the Lifetrack staff we interviewed noted that the most important **need for children is a role model, and that parents need to see what their child’s future may hold**. In addition, half of the national D/HH program experts interviewed noted the importance of having someone a child can look up to or identify with.

*“First of all, when you have a new person with hearing loss and no one in your family [has a hearing loss], you need someone that leads that life themselves, so they know how they felt and what’s the future for them.” (Lifetrack staff)*

*“Mentorship programs help children who are D/HH connect with the Deaf community and Deaf culture, and help them use communication with the outside world. It helps the parents get the support they need, too.” (Lifetrack staff)*

*“It’s important to let parents know that deaf adults can be leaders—lawyers, receptionists, some work for Obama, deaf scientists, deaf doctors, deaf pilots, deaf professors, deaf budget analysts. My daughter actually works at the Pentagon and is deaf. Deaf people can work in the whole spectrum of the professional sphere, the same as hearing people.” (National expert)*

Lifetrack staff also noted the importance of **connecting families with the Deaf community and Deaf culture** (4 out of 13 interviews). One-third (36%) of parents who participated in the web survey believe that it is either very or extremely important to include Deaf culture or introduce the family to the local Deaf community as part of a mentor program, and an additional 31 percent of parents believe this to be somewhat important.

*“Families need to see the Deaf community is very large and diverse, and there are successful role models from all different modes of communication.” (Lifetrack staff)*

### ***Language acquisition and communication***

The Lifetrack staff we interviewed were asked to identify in their own words what the biggest needs and concerns are of parents who have children that are D/HH. **Language and communication** was cited by five Lifetrack staff as the biggest need for young children who are D/HH and their families. Four mentors noted specifically that **learning ASL or sign language** is important. Five out of the six national experts interviewed also indicated that communication and language is the most important need of these children and families, including three respondents who specifically mentioned learning ASL.

*“That child needs to be exposed to language, lots of language exposure to learn how to watch and receive the language and how to use it to communicate.” (Lifetrack staff)*

*“Deaf children should be exposed to ASL before they turn 1, but many children come to us when they’re 2 or 3. Parents just don’t know how to communicate vital information to their child, and it’s just so important that they have that ability.” (Lifetrack staff)*

*“They need to know how they can keep living daily life in the way they’re accustomed. A role model can disperse those fears and help them understand there’s a huge range of languages and technologies that can reduce barriers. It gives hope to the parents.” (Lifetrack staff)*

*“Communication is number one. How to include the child in the hearing community is also a big need of theirs.” (Lifetrack staff)*

*“There’s a natural tendency for deaf children to do certain things to try to express themselves, but parents have no idea what they’re trying to convey. They’re trying to use body language, but parents don’t have experience with it and can’t figure it out. A deaf person can help them identify what the child is trying to communicate with the parents.” (National expert)*



*“Really, the best and ideal situation is for the children to immediately be exposed to sign language, for parents to learn sign language and sign with their child, and have a deaf mentor there who can help to communicate with the child and teach them how to read and how parents can communicate with their child.” (National expert)*

*“I think just one of the concerns families have about learning ASL is to learn it quickly enough to provide good language access to their child.” (National expert)*

Some of the adults who are D/HH who participated in this study (6 out of 31 interviews, and 1 out of 2 focus groups) recalled feeling **isolation or distance between themselves and their families as a result of being the only one in the family with hearing loss.**

*“Families don’t take the time to communicate with their child. It’s time to bring a mentor in and have the family learn how it’s important to include everyone. Even with my own family, if there’s something that I miss, it’s important that they tell me and not say things like ‘oh its ok, you can wait until later, it’s not important.’ Those things really hurt.” (Adult who is D/HH)*

*“Unfortunately I see a lot of families with deaf children where the parents don’t have communication skills to talk to their kids and the kid feels very isolated and left out... it’s really hard. We really need to improve that by having the deaf mentor, it would really improve that and prevent that from happening; it would improve the lives of deaf children.” (Adult who is D/HH)*

Some of the study participants who are adults who are D/HH (9 out of 31 interviews and 1 out of 2 focus groups) felt strongly that **ASL is a necessary tool for all children with hearing loss to have, regardless of severity of their hearing loss.** A few parents (3 out of 14 interviews, and 2 out of 4 focus groups) said that even though their child’s primary language was *not* ASL, they wanted them to learn it in case the hearing aids were lost or broken, or if their hearing loss worsened.

*“[What would have been helpful is] if I had someone to sign with regularly... My whole world was hearing people. I think the decision [my parents] made [to not focus on me signing] makes sense. I’m happy with it. That said, I think there are situations where I would have benefited from having more sign language.” (Adult who is D/HH)*

*“I want to beat the cochlear implant people, we need to ‘beat’ those people who say NO to sign - it’s important that families don’t have to pick one method! Expand deaf children’s tools to survive - don’t let deaf children’s toolbox be empty.” (Adult who is D/HH)*

*“For parents against ASL as communication that don’t want their kid to lose motivation to lip read or become oral: Deafness specifically is isolating. If the goal is to not be isolating - which can be painful as we know - when people put people in jail as punishment we isolate them, and yet we allow that for deaf children, to be isolated. So if you explain it that way, parents realize, ‘Oh, I didn’t realize that choosing not to use ASL will isolate my child.’ So it’s important to be able to explain that communication is important.” (Adult who is D/HH)*

Parents who completed the web survey were asked to rate the level of importance of the kinds of information, experiences, and interactions they would hope to gain from a D/HH adult mentor or role model. Just under half (44%) of respondents thought it was very or extremely important to **include visual language education in a D/HH mentor/role model curriculum**, whereas one-third (34%) of respondents felt that visual language education was either not too important or not at all important to include in a D/HH mentor/role model program. Thirty-eight percent of respondents said it was very or extremely important to **include visual tools and resources such as cued speech or lip reading** as a part of a D/HH mentor/role model experience. See Figure 4.

**4. The kinds of information, experiences, and interactions parents hope to gain from a D/HH adult mentor/role model – language acquisition and tools (web survey participants)**

|   | <b>Extremely important</b> | <b>Very important</b> | <b>Somewhat important</b> | <b>Not too important</b> | <b>Not at all important</b> |
|---|----------------------------|-----------------------|---------------------------|--------------------------|-----------------------------|
| Visual language education (ASL, Signed English) (N=107)             | 29%                        | 16%                   | 22%                       | 20%                      | 14%                         |
| Visual tools and resources (Cued speech, lip reading, etc.) (N=107) | 22%                        | 16%                   | 36%                       | 14%                      | 12%                         |

Some parents who we interviewed would also like **more services and support for children who are hard of hearing and who primarily use spoken language**. (They typically view the current Deaf Mentor program as tailored to children who are profoundly deaf, and whose families have opted to use ASL as their primary language.) Adult respondents who are hard of hearing also viewed this as a gap in currently available services. These respondents suggested that a mentoring program should include broader content about communication and life skills for people who are hard of hearing.

*“When you’re hard of hearing, taking out being deaf, that’s a different kind of situation - so mentoring, what does it mean to be HH. You’ll probably be in the hearing world. You don’t have that concrete language, that someone who is deaf - if they’re only using sign language, they might have a greater sense of identity or self because they’re surrounded by that culture. Whereas for HH people, might feel more like no, I’m part of the hearing world, but I have those unique experiences that nobody else really relates to.” (Adult who is D/HH)*

*“I do want to point out though - there is a more solid network of deaf than there is for HH. And we will have more kids born HH than deaf. And the opportunities for kids born deaf today is maybe greater - as far as connecting - than for HH kids, so make sure we provide opportunity for HH adults to be a part of this and that they are connected.” (Adult who is D/HH)*

Many parents who participated in this study and who use visual language with their child would like **other opportunities to practice ASL outside of mentoring sessions, and some additional ASL materials to work with**. This included wanting a copy of the program manual to keep and work with outside of mentoring sessions.

*“When we were done with the program, we were like, now what? I need to practice somehow and I forget what we learned. We tried to have a signing night with the family, but that didn’t last long, you get busy. It would be nice if there was a group that continued to meet afterwards.” (Parent of a child who is D/HH)*

*“I don’t know if they all use the teaching manual, but I would love a copy of that! Sometimes after she left, I wanted to go over it again, so having a copy of the manual would have been nice. It’s hard to practice - I want to review and really learn it.” (Parent of a child who is D/HH)*

In terms of what a D/HH mentoring program could do to support visual language acquisition, some of the web survey respondents (17%) also said that they would like the D/HH mentor/role model program to **provide resources for practicing new sign language skills**. A similar number (15%) said that they would like to see the D/HH mentor/role model recommend or **make available additional resources (such as DVDs or apps)**.

In terms of what a D/HH mentoring program could do to support the use of visual tools and resources (cued speech, lip reading, etc.), one in five (20%) parents who completed the web survey suggested that they would generally like additional resources and education. Some (16%) said they would like **more information on communication modes and options**. A few said they would like the D/HH mentoring program to include a **Cued Speech curriculum and training (9%)** or **lip reading curriculum and training (9%)**.

### ***Getting information and resources, and learning to navigate the system***

Parents receive a substantial amount of information and input from a variety of different sources at a time when they are still in shock from the diagnosis of their child’s hearing loss. This information is difficult to process, and parents don’t know what is critical and what is not; it is hard to navigate information from various sources (Earls et al 2008). Nearly all parents who participated in this study described **needing support in terms of knowing where to go or who to call to get the right services, support, or information** (theme was found in 8 out of 14 parent interviews, and all 4 parent focus groups). When asked to identify any additional needs their family might have that could be addressed by a D/HH adult mentor or role model or another similar program or service, one-fifth (21%) of parents who participated in the web survey indicated that help **navigating social services and support programs (such as educational, financial, etc.) as well as medical services** would be a valuable resource to their family.

*“She was the only one in our school district [only child with a hearing loss], so it’s been trial and error... I’ve had to fight for everything I want. And the trouble is you don’t know what you don’t know, so until you learn different, you think it’s normal.” (Parent of a child who is D/HH)*

Some parents (4 out of 14 parent interviews, and 2 out of 4 focus groups) reported **difficulty getting thorough, accurate information from doctors regarding test results and/or a clear diagnosis**. This led parents to feel that doctors or other health professionals were not being open or forthcoming with results and were trying to mollify parents by downplaying the severity of their child’s hearing loss. Luckner et al. (2014) noted that this struggle to obtain an accurate diagnosis results in delays in treatment and services for the child.

*“It was a real diagnosis we were looking for. We were not looking for the sugar-coated version. We were looking for the truth, whether they would acknowledge it or not ... There really was denial from the medical community. He is PROFOUNDLY deaf. We needed true information to parent him best.” (Parent of a child who is D/HH)*

Henderson et al.’s (2014) proposed conceptual framework posits that support services/offerings (namely parent to parent) are important in parents learning **system navigation, a skill that provides knowledge of services (being able to identify and access services to meet needs), awareness of professionals (for care, care coordination, referrals), and transitions (new school or stage in life)**. Parents in each focus group mentioned feeling that it was a challenge to advocate for their child to get them the services they needed. Despite early detection, this challenge may ultimately manifest itself in disparities in access to comprehensive, coordinated, culturally sensitive, community-based services to the child with hearing loss, as compared with a hearing child (DesGeorges 2003).

*Use of assistive technologies (cochlear implants, hearing aids)*

Parents who participated in the web survey were asked to prioritize the level of importance of the kinds of information, experiences, and interactions they would hope to gain from a D/HH mentor. **The majority (82%) of respondents said it was either very or extremely important to include information about assistive technology (cochlear implants, hearing aids, CART captioning) as a part of a D/HH mentoring program, including 57 percent who said this is extremely important.** See Figure 5.

**5. The kinds of information, experiences, and interactions parents hope to gain from a D/HH adult mentor/role model – assistive technologies (web survey participants)**

|   | <b>Extremely important</b> | <b>Very important</b> | <b>Somewhat important</b> | <b>Not too important</b> | <b>Not at all important</b> |
|---|----------------------------|-----------------------|---------------------------|--------------------------|-----------------------------|
| Assistive technology information (cochlear implants, hearing aids, CART captioning, etc.) (N=107) | 57%                        | 25%                   | 10%                       | 3%                       | 5%                          |

Web survey respondents were also asked to provide suggestions about what a new D/HH adult role model/mentor program could do to better serve families who use assistive technologies. Half (49%) of respondents said they would like to **learn about and troubleshoot how to deal with challenges specific to hearing aids or cochlear implants**. In addition, 18 percent said it would be **helpful to talk with a mentor about their experiences with these technologies**. A few (9%) said that the program should **employ mentors who use or are more open to use of hearing aids or cochlear implants**.

## Mentoring program structure

This section of the report describes key findings related to the structure of a mentoring program, which includes general aspects of program structure such as program customization and flexibility, age limits, program length, program intensity, activities and events, and including other family members.

### *Program customization and flexibility*

One parent focus group that had a balance of current Lifetrack Deaf Mentor program participants and non-participants discussed the overall rigidity of the program and felt that it was **too structured and would benefit from more flexibility**. A need for program flexibility and customization was also a theme among adults who are D/HH that participated in this study.

*“Sometimes I felt relieved when the session was cancelled. I mean I hate to say that, but when our mentor texted us and had to cancel, I felt relieved. Like, Yes! A night off! I don’t have to clean my house. It seemed so strict that it was weekly. Every other week wouldn’t be so bad. I would rather have met every other week for 3-4 years and the extra years of support would have been great, too. That way they could add more families.” (Parent of a child who is D/HH)*

*“I felt that I had to follow the curriculum, and that was limiting. And you know, families always ask a ton of questions, and it caused me to be behind with the curriculum. I didn’t want to push aside my own experiences because the family really wanted that first so that they could understand me and their child.” (Adult who is D/HH)*

In addition to increased flexibility in the curriculum or program structure, parents also have **a variety of preferences for where they would meet with a mentor or role model**. Nearly two-fifths (38%) of parents who participated in the web survey indicated that in person at the respondent’s home would be the best place to meet with a mentor, and one-fifth (19%) said that in person at another location such as child’s school, doctor’s office, or another community setting would be an ideal location. Over one-third (37%) indicated that more than one of these locations or methods listed would work for them. **Being able to have sessions at home was crucial** for parents who participated in an interview, who explained that this convenience was what made it possible to participate.

*"I think it was just good because it could be in our house when it worked with our schedule. Deaf mentor was flexible about working around what was going on and just having it at home - didn't travel anywhere with little kids. By the time we started the deaf mentor program we had our 4<sup>th</sup> one. So, it was busy, it's always good to have that little one at home." (Parent of a child who is D/HH)*

*"I think it does help to have the at-home visit though. It's more comfortable, I can think of more stuff to talk about at home, not in a sterile environment. Just being in your own environment, and they can see the kid at ease instead of flipping out. That's why the at-home visit part is important." (Parent of a child who is D/HH)*

### ***Age limits***

Both parents and adults who are D/HH want to see the **age limits for participation in the Deaf Mentor program expanded or removed**. They saw value in being able to offer the program to children in elementary school, especially as the child transitions into school. About half of the adults who are D/HH who participated in this study also expressed this perspective on expanding the age limits. Although the program guidelines say it serves children birth to age 6, the Lifetrack Deaf Mentor program currently serves families with children who are older than age 6 – all of these started the program when their child was age 6 or younger.

*"Now that he's in school, you kind of have a different outlook. Now, you're worried about him progressing, whether him not hearing everything will hold him back, or his speech. I didn't really think about some of that stuff as much when he was little. Partly because you couldn't really tell how things were going to happen and turn out. But now it's more that and also he's starting to realize he's a little different, and being a little more self-conscious about it." (Parent of a child who is D/HH)*

*"Because of first grade and the transition that happens, it can be quite difficult for any child to experience, so the support to be in place for that would be ideal." (Adult who is D/HH)*

### ***Program length***

Study participants were asked how long they would want a D/HH mentoring program to last. In general, it appears respondents from all groups feel the **length of the program should be extended beyond 2 years**. Thirty percent of parents who participated in the web survey said they would want the program to last 5 years or more. Fewer said they would want the program to last 1-2 years (27%) or 3-4 years (20%). Some of the adults who are D/HH also spoke about increasing the length of the program; over half (7 out of 13) of Lifetrack staff and five out of six national experts interviewed feel the program should be longer than 2 years.

*“To be honest, 2 years of programming with one family is just not enough ... I would rather have 6 or 7 years. Parents can’t pick up sign [ASL] that fast; they just don’t learn it fast enough. Adults don’t pick up sign fast like a child, so the parents really do need more help.” (Adult who is D/HH)*

*“It’s ideal to have education for D/HH families for 3-4 years, and deaf mentorship for at least 6 years. More than 6 years would be the ideal—I wish we could do that! From ages 0-6, they should be meeting with their mentor 2 times a week. After that, it should be weekly to biweekly. And they should use ASL as much as possible.” (Lifetrack staff)*

*“He needs to have someone. There is a definite need for someone in that 0-6 range, but what about other ages and transitions?” (Parent of a child who is D/HH)*

*“We met 2 hours per week for 2 years. It was perfect. We would have loved to keep going. It became a part of our routine.” (Parent of a child who is D/HH)*

*“Our sessions are for up to 2 hours once a week, but most families prefer an hour to an hour and a half. We give them 30 sessions a year, which gives them a lot of flexibility. The Wisconsin deaf mentor program does 6 years, which is great. It would be better to have more than two years.” (Lifetrack staff)*

*“Services should last more than a couple years—ideally 5 to 6 years, and meeting once a week. Sometimes every other week, depending on the family’s schedule.” (Lifetrack staff)*

*“I think it should last for years, ideally, as children reach different challenges and milestone.” (Parent of a child who is D/HH)*

One Chicago case study of diverse families found success in a format of a series of four, two-hour parent workshops. The goal was to achieve a balance between time for informal interactions among deaf and hearing parents and their children, and hands-on opportunities to engage in strategies that could help hearing parents shift to a more visually-oriented perspective (Hulebosch et al. 2002).

### ***Program intensity (frequency and length of meetings)***

The **preferred length of meetings between the mentor and family varied both within and across groups of respondents**. Two-thirds (68%) of parents who completed the web survey said they would like mentors to spend 30 minutes to 1 hour with their family per session, and one-quarter (24%) said they would like the mentor to spend 1 to 2 hours per visit. Lifetrack staff tended to prefer slightly longer sessions, with 5 out of 13 staff who we interviewed indicating a preference for session that last between 1 ½ hours and 2 hours. The national experts’ responses varied from 30 minutes to 2 hours per session.

Similarly, **the preferred frequency of meetings varied both within and across type of respondent**. Parents were more likely to prefer meeting once or twice per month, whereas Lifetrack staff and national experts recommended meetings should occur at least one per week.

*“There are more benefits if mentors and families meet on a weekly basis. An hour once a week should be good. It’s definitely more beneficial than just meeting once or twice a month. The child can pick up more information and see much more success.” (National expert)*

*“Families should be able to choose which mentor they have. Once a week is typically how often they meet, and I think that’s good. It’d be nice to keep it going until they’re 18. But there are challenges with that, like funding and what the family wants. It’d be nice to have about 2 hours for the session. Maybe as they get older, that can lessen it up a bit, but it depends on the family and where they’re at.” (National expert)*

### ***Activities and events***

Parents who participated in the web survey were asked in an open-ended format what suggestions they had for a new D/HH mentoring program so that the program would better serve all types of families with young children who are D/HH. One-fifth (21%) of respondents said that the program could facilitate social interaction, specifically targeting families with young children who are D/HH or families with co-occurring disabilities or families from particular cultural communities, to help them to form community connections. One-fifth (18%) also said that a mentoring program should offer more activities, events, and ways to connect in rural areas. (Minnesota Hands & Voices does offer many regional events and activities around Minnesota for families with children who are D/HH. It is unclear if the families who participated in this study are not aware of these events and activities, or if these events do not meet these families’ needs or preferences. It was also suggested by the Advisory Group that these families may specifically want to connect with other families who are participating in the Deaf Mentor program for the purposes of practicing ASL in a different, group setting.)

### ***Including siblings and other family members***

One focus group found the idea of a program add-on for siblings appealing. They wanted a way to include them in the process of mentorship and make them feel more involved/help to develop a better connection between the siblings. A similar sentiment surfaced in other groups and interviews, indicating that parents wanted ways to involve extended family members (such as grandparents), particularly if those family members were trying to learn ASL to communicate with the child. Abrams et al. (2011) proposes this as a program strategy based on the success of the New Mexico Deaf Role Model program.



## Mentor characteristics

Rogers et al.'s (2011) case study in the United Kingdom identified the following criteria for deaf role model eligibility: the person had to be D/HH; they should display an ability to share personal experiences in a professional, unbiased manner; and they must possess an understanding of the issues faced by deaf children and their families.

Abrams et al.'s (2011) New Mexico case study likewise explained the requirements of deaf mentors:

- Expected to be flexible in working with hearing people with and without an interpreter
- Must be gainfully employed, established homemakers, or college students (background checks are performed)
- Must submit required monthly documentation outlining the content and frequency of home visits
- For services to children ages 0-3, a college degree is required in order to attain New Mexico Developmental Specialist Certification

Lifetrack asks that its D/HH Mentors/Role Models have strong communication skills and an ability to interact with a variety of parents and professionals in a positive manner. Mentors and Role Models should also be unbiased, open-minded, and supportive of family decisions and be able to work effectively within a team approach. While not required, Lifetrack prefers that its Mentors and Role Models hold a bachelor's degree and one year of related work experience. (Lifetrack's D/HH Mentors and Role Models are paid staff and typically work about three hours per week on-call at \$18/hour.)

**Four Lifetrack staff also indicated that the current D/HH Mentors/Role Models are committed to the program and passionate about what they do, and this contributes to the success of the program.**

Several interview respondents who are adults who are D/HH (12 out of 31) also recommended that individuals should have some prior experience as an informal mentor before becoming a deaf mentor in the program.

## *Mentor bias*

**About half of the adults who are D/HH who participated in an interview (16 out of 31) acknowledged the potential for bias as a mentor.** This bias is particularly related to the family's choice to teach their child ASL or not, as well as if they choose to use hearing aids or cochlear implants. These respondents mostly felt that for successful mentorship, this bias needs to be removed. Olson's (no date) recommends that mentors should be open-minded in their work. They must also have an honest awareness of their personal opinions and an ability to remain unbiased as they communicate and support the families whose choices may differ from their own preference or opinion.

Lifetrack staff were asked in an open-ended format to identify the ideal features a D/HH mentoring program needs to be effective. **Just under half of the Lifetrack staff who were interviewed (6 out of 13) said that mentors need to be unbiased to make a program successful.** Some Lifetrack staff (4 out of 13) said that mentors needed other soft skills, such as communication and compassion, to help make the program successful. Two other mentors noted that mentors should be flexible.

*"[Mentors need] the ability to be unbiased when sharing with the family about the language and culture." (Lifetrack staff)*

*"It's really important for the program to be extremely supportive of all families and all choices, and it needs to pay careful attention to recruiting individuals who can really support different families in a respectful and sensitive way." (Lifetrack staff)*

The national experts we interviewed made an array of suggestions for effective programming for families that choose not to use ASL. Two of six respondents suggested that mentors should be **open-minded about family choices and meet families where they are at**. Three out of six said that mentor characteristics such as patience and an unbiased, open attitude are important to the success of a D/HH mentoring program.

*"First and most important— mentors have to have patience. They have to be comfortable with small children. They need an open mind to work with different types of families. Again, the biggest part is patience." (National expert)*

*"They need to find mentors who are flexible and sensitive to the parents' needs. They need to be sensitive to the fact that the parents are very new to hearing loss and the deaf world. They need to be sensitive to parents struggling with their child being part of a different culture than their own." (National expert)*

## ***Mentor and family matching***

The majority of parents who participated in this study stressed the importance of **matching type of hearing loss and mode of communication as closely as possible between mentor and child/family** (this theme was found in 8 out of 14 parent interviews and 4 out of 4 parent focus groups). Adults who are D/HH who were interviewed for this study also noted the importance of proper matching of a family and mentor, though at a lower frequency than parents (9 out of 31 interviews and 1 out of 2 focus groups). The national experts we interviewed made an array of suggestions for effective programming for families that choose not to use ASL; two out of six specifically indicated that mentors should match the communication style of the mentee family.

*“If we were to have a relationship with a mentor, we’d want someone who had a partial hearing loss who functions in the hearing world.” (Parent of a child who is D/HH)*

*“If we got matched with someone who has a similar loss like hers. Someone who wears hearing aids, whether that’s for unilateral or bilateral hearing loss. Someone who has something that looks like hers does. Someone who deals with life in an adult way. That would be helpful.” (Parent of a child who is D/HH)*

*“I think that it’s nice to be able to have every family meet a variety of D/HH mentors...we also have mentors who have cochlear implants, for example. We want to set it up where it matches the needs of the child and family. Not every mentor can serve every family.” (National expert)*

Parents also believe that it is important to try to **match mentors to families according to native language and culture** (this theme was found in 2 out of 14 interviews, and 3 out of 4 focus groups). Some parents suggested that Lifetrack should be more intentional in its efforts to recruit from or connect with different cultural communities. This could be through organizational outreach, person-to-person, or other methods. Adults who are D/HH who participated in this study also suggested that Lifetrack should recruit mentors from different cultural backgrounds, too.

*“Are there natural connections with other organizations that have individuals who speak other languages? Can they help them reach out? For communities that seem or feel more isolated. Not everyone has Internet or has a computer, and you have to be understanding of that, how do you reach those families? Somehow they’re being diagnosed, so right there at that level - whether at the clinic or with the audiologist - before they even get to leave, what is the information we need to help support them?” (Parent of a child who is D/HH)*

*“They always have a lot of questions about me as a deaf person and how to handle issues within the culture, the elders and what not. It’s really been a great way to help those families because I myself am Asian and that helps the process.” (Adult who is D/HH)*

*"We need diverse groups, not just white ladies...Africans, Somali, Asians. It's really important to have different mentors available - the ones that just arrived are Karen, so it's been a challenge... Some have been interested in the program and we explain that the program is pretty flexible..." (Adult who is D/HH)*

### ***Mentor recruitment***

Both parents and adults who are D/HH that participated in this study felt that **expanding the mentor pool was critical to the long-term success of the program.**

Many adults who are D/HH recommended **promoting mentorship as a way to give back to the D/HH community** (14 out of 31 interviews). This recruitment message should include an appeal to potential mentors by reminding them of their own childhood experiences and asking them to think about the ways they might have benefitted from a mentor.

*"The first question I would ask the potential mentor would be, do you remember your upbringing? Are you happy with it? If yes ... do you want to pass that onto other kids, future generations and other families? If you had a bad experience, fine. Improve it for other kids, one family at a time. How can you contribute and give your experience? ... It's important to give the opportunity to the family and our future generation to do better." (Adult who is D/HH)*

### ***Mentor training***

Adults who are D/HH suggested that **mentors should be treated as professionals in terms of training, hiring, and commitment**, even if that means having to pay mentors or making it into more of a career path for qualified adults. Olson (no date) supports this notion by suggesting that mentors need to be compensated for their time and viewed as a part of the formal family support system. Mentors need written job descriptions and training to be appropriate for their roles and influence.

*"Trying to get deaf mentors certified as a professional, one of the first people to contact families like and audiologist, a deaf mentor, and a doctor. [Mentors should] be a part of the group who first contacts the family... so it's important that we are treated as professionals." (Adult who is D/HH)*

**Perceptions about the adequacy of the current mentor training provided by Lifetrack were mixed – some felt it was adequate, while others wanted to see more in-depth review and follow-up training or continuing education.** When they were asked to identify what was working well at Lifetrack with regard to recruiting and retaining mentors, four Lifetrack staff indicated that the SKI HI Training program and curriculum is good. Two mentors specifically noted that the training is helpful. Two other mentors specifically mentioned the workshops as a strategy for recruiting and retaining mentors.

*"I am a deaf person / deaf mentor and I can't be blunt or straightforward with parents. I can't speak my mind with them. It's difficult because I do not want to offend families. I got training on how to talk to the parents, but really it's not enough... I wish I had more training on how to approach parents." (Adult who is D/HH)*

*"Lifetrack does deaf mentorship training, and has a huge curriculum book. It goes over how to work with parents and everything. It's a good training program. Every 6 months we have workshops and learn new stuff about the program. Those workshops help with retention, too. There's a new thing where we get a certificate. That helps with retention, too." (Lifetrack staff)*

*"We have great language acquisition resources that we get in training. It helps the mentors know what's needed. We're good about sharing information with other deaf mentors. It's good that the training certificate is needed. And we have lots of communication and resource sharing with other mentors." (Lifetrack staff)*

A theme that emerged from the interviews with Lifetrack staff (4 out of 13 interviews) was that **the program needs more training or funding for training**.

*"We just found out a month ago that we can't always go to the [deaf mentor] training because of funding. We don't have enough funding for that. So that's the most serious issue." (Lifetrack staff)*

## Family outreach

In this section of the report, we describe the key themes from the needs assessment as it relates to: when and how to reach out to families to provide mentoring and other forms of support, how families hear about support resources, and resources families use currently.

### *How and when to get in touch with families*

Many parents, adults who are D/HH, and the national experts we interviewed agree that it is important to get in touch right away after diagnosis (this theme was found in 8 out of 14 parent interviews, and 2 out of 4 focus groups). However, they also recognize that this is a challenging time for parents when they are typically overwhelmed with information. Therefore, they suggest following up with families several times to have a better chance of providing timely information about the program when families are most receptive.

The Lifetrack D/HH Mentor/Role Model program uses many of these approaches already. The program reaches out to families through the DHHSD Regional Service Centers connected with DHS/DHHSD. They also get referrals through MNHV, which according to Lifetrack staff account for 50 percent of their referrals. Lifetrack also uses outreach opportunities such as the statewide teacher's conference, to connect with eligible families.

*“The earlier the better! You have a million questions running around in your head. It’s better to talk to somebody at that point. Better to move forward than wait.” (Parent of a child who is D/HH)*

*“Families often see a deaf mentor as a last resort, but it should be the first stop. It’s important to inform parents right away how important mentorship programs are.” (National expert)*

*“And maybe have a follow-up. That’s the other thing - you forget. Yeah, someone tells you at 6 months there’s this great thing, but you may not be ready. But a year, year and a half later - you might be ready but have forgotten.” (Parent of a child who is D/HH)*

*“And it’s so overwhelming emotionally as well as all the stuff being thrown at you, dealing with medical things, and your life is crazy and it’s not what you expected. It can be very easy for something to pass over you. Things just don’t sink in if you’re not ready for it yet. It’s very easy for things to not be absorbed at that point, you’re on overload.” (Parent of a child who is D/HH)*

Both parents and adults who are D/HH suggest **utilizing health professionals (doctor/audiologist/speech therapist) to assist with program outreach. Providing information about the program through schools may also be an option** (suggested by both parents and D/HH respondents). A smaller number expressed interest in hearing from past participants in the program. These families could explain the benefits to parent and child, as well as the value of the program, and encourage other families to join.

*“Really, it would be helpful if we could develop relationships with hospitals and so... once the baby is identified as deaf, we are able to go to talk to families, you know, right away instead of waiting for them to refer to us - this isn’t fair, the family needs all options at the beginning.” (Adult who is D/HH)*

*“It would be nice to have the information sent out to hospitals and clinics and things right away, so that if a parent brings their child in and notices a hearing loss, and [then the hospital/clinic would be able to] refer them to the right support [which already includes things like] audiology and cochlear [resources], but [they should] put the mentor program in there as part of the support system [that parents are first told about at the hospital or clinic].” (Adult who is D/HH)*

**Parents want to be contacted using a variety of methods and at multiple points in the process**, including phone, email, U.S. mail, and in-person. D/HH respondents suggested using social media and word of mouth to help promote the program.

Four of the Lifetrack staff we interviewed noted that activities and events Lifetrack already hosts are helpful to recruit and retain families with young D/HH children. Four respondents also indicated that the partnership Lifetrack has with Minnesota Hands & Voices is helpful for obtaining referrals to the D/HH Mentor/Role Model program.

*How respondents hear about new programs or services available for their children*

Parents were asked how they hear about new programs or services available for their children who are D/HH. **Nearly two-thirds of parents said they hear about new programs through teachers who work specifically with children who are D/HH, or through audiologists.** A few parents said they heard about this program through doctors or other health care providers and other parents of children who are D/HH. See Figure 6.

**6. Parents’ sources of information about new programs and services for their child (web survey participants, N=118)**

|  | n  | %   |
|--|----|-----|
| Audiologists   | 67 | 57% |
| D/HH/hearing loss websites or social media networks                  | 20 | 17% |
| Specify:   |    |     |
| Facebook or other social media/networking                            | 8  | 40% |
| Minnesota Hands & Voices   | 11 | 55% |
| Other  | 5  | 25% |
| Doctors/healthcare providers   | 33 | 28% |
| Other parents of children who are D/HH, through a formal network     | 9  | 8%  |
| Specify:   |    |     |
| Minnesota Hands & Voices   | 8  | 89% |
| Other  | 1  | 11% |
| Other parents of children who are D/HH, informally                   | 33 | 28% |
| Adults who are D/HH who are not a part of a formal mentoring program | 7  | 6%  |
| Other organizations  | 27 | 23% |
| Specify:   |    |     |
| Other  | 6  | 22% |
| Minnesota Hands & Voices   | 13 | 48% |
| A school   | 7  | 26% |
| Northern Voices  | 3  | 11% |
| Teachers who work specifically with D/HH children                    | 73 | 62% |
| Other teachers   | 5  | 4%  |
| Other  | 4  | 3%  |

Parents who participated in the web survey were also asked about where they went to seek advice about how to help and support their children that are D/HH. **Most of these parents sought advice from teachers who work with children that are D/HH.** Many sought advice from doctors or health care providers, and a few sought advice from websites or social media networks. See Figure 7.

**7. Parents' sources of advice about how to help and support their child (web survey participants, N=118)**

|   | n  | %   |
|---|----|-----|
| Audiologists  | 18 | 15% |
| Websites or social media networks                               | 32 | 27% |
| Specify:  |    |     |
| Facebook/other social media/networking                          | 13 | 41% |
| Alexander Graham Bell   | 3  | 9%  |
| Minnesota Hands & Voices  | 11 | 34% |
| Ear Community   | 3  | 9%  |
| Google  | 4  | 13% |
| Other   | 7  | 22% |
| Doctors/HealthCare Providers                                    | 69 | 59% |
| Other parents of children who are D/HH through a formal network | 15 | 13% |
| Specify:  |    |     |
| Minnesota Hands & Voices  | 9  | 60% |
| Other   | 5  | 33% |
| Other parents of children who are D/HH, informally              | 51 | 43% |
| Adults who are D/HH but not part of a formal mentoring program  | 15 | 13% |
| Other organizations   | 34 | 29% |
| Specify:  |    |     |
| Minnesota Hands & Voices  | 11 | 32% |
| Northern Voices   | 9  | 27% |
| A school district   | 9  | 27% |
| Other   | 6  | 18% |
| Teachers who work specifically with children who are D/HH       | 90 | 76% |
| Other teachers  | 15 | 13% |
| Other   | 4  | 3%  |



### *Current resources families use*

Nearly every parent who participated in an interview or focus group mentioned the **school district and/or the school's D/HH teacher as a helpful resource** (theme was found in 9 out of 14 parent interviews, and 3 out of 4 parent focus groups). They also frequently utilized the services of the Minnesota Department of Human Services' Deaf and Hard of Hearing Services Division, Minnesota Hands & Voices, and other agencies.

Some parents preferred doing their own **self-guided research** on the Internet or through relevant books. These individuals often expressed confidence in their research skills and thus felt they did not need additional information from other sources. Earls et al. (2008) also identified a sub-set of parents who prefer self-guided research.

While the ability to speak with other parents about their experience was often stated as a desired or needed resource (6 out of 14 parent interviews, and 2 out of 4 parent focus groups), many parents also cited it as a helpful source of support that they had already used (4 out of 14 interviews, and 3 out of 4 focus groups). Similarly, parents appreciated attending events to make connections.

### **Benefits to children and families who participate in mentoring programs**

The main benefits that were identified through this study for families and children who participate in mentoring programs include: language acquisition and communication, connection with the Deaf community, self-esteem and identity, and hope for the future. (Most of these benefits were identified in conjunction with the current Lifetrack Deaf Mentor program model that focuses on learning ASL, so other benefits may be possible for the program expansion. Also, these benefits are all perceived benefits. Little published research exists that shows the actual benefits or outcomes of Deaf Mentor programs nationally, and this study was certainly not a formal evaluation to measure the impact of the Lifetrack D/HH Mentor/Role Model programs.)

#### ***Language acquisition and communication***

When web survey participants responded to an open-ended question regarding the biggest benefits of participating in Lifetrack's D/HH Mentor/Role Model program, **just under half (48%) of the parents who participated reported that learning ASL and how to communicate was among the biggest benefits.**

*"Our mentor is teaching us sign language, it brings our family together and makes us feel like we are doing something. She is someone I can ask questions to and she has direct experience in the DHH world. She provides me with videos, resources, books and more! She is a happy functional adult so it is good to see that success." (Parent, web survey participant)*

*“The biggest benefit was that we were able to learn sign language geared toward a child, and in a format made for adults who don't know any sign language and have no exposure to the deaf community. But, our deaf mentor had a cochlear implant. Since we were going through the process of deciding about a cochlear implant for our son while we were in the program, we valued having an adult in our life who we could talk to about the experience. It really helped put us at ease.” (Parent, web survey participant)*

Half (three out of six) of the national experts we interviewed for this study also noted that **communication among family members is improved by having a D/HH mentor**. About half of the adults who are D/HH who participated in this study (15 out of 31) said that developing communication skills among family members and helping them to connect were benefits of mentoring.

*“Communication barriers are less difficult for the child and the parents [as a result of their participation in a mentoring program]. Then there are fewer tantrums, less anger, parents understand needs better and know how to help. Communication is key, and we make sure they can have that communication with their child.” (National expert)*

*“I've seen how it is so beautiful to see the parents signing with their child and playing with them...it's really amazing to see.” (Adult who is D/HH)*

*“Communication and language is very important - you need to have that to keep that bond between the family. For the rest of their lives, it's important that they have the ASL skills to communicate with their child.” (Adult who is D/HH)*

*“I think that families are much more motivated to acquire a new language when they see a successful deaf adult in their lives. Their level of anxiety is reduced, their language competency is increased. And their empathy for their child's daily activities is increased as well.” (National expert)*

National experts were asked to identify any negative consequences that could occur if a child who is D/HH does not participate in a D/HH mentor/role model program. **Four of the six experts we interviewed cited delayed language skills or not learning a language or ASL as a negative consequence, and two experts cited potential developmental delays of the child who is D/HH as a negative consequence for not participating in a D/HH mentoring program. One expert described the isolation that occurs without a way to communicate.**

*“We see that as we keep assessment information on those children. Typically their language development is not as rapid. Their cognitive ability is oftentimes more delayed as well.” (National expert)*

*“Some families reach 2nd and 3rd grade when they learn spoken language won't work for the kid, but cognitive development is delayed if they haven't learned ASL until that point. The logic is already impacted. They've missed out on good language and brain development.” (National expert)*

*“If families are not using ASL, the child is missing stuff. For example, the parent will forget to look at the child in the face while they’re talking. Lots of kids are still very successful with oral methods, but miss out on things.” (National expert)*

Importantly, **published research shows that language acquisition is crucial to the cognitive and social development for children who are D/HH; delaying the onset of learning a first language for children who are D/HH often results in other developmental delays.** Experts note that language acquisition is extraordinarily similar for children developing a signed or spoken language, despite the modality differences. According to Lyness et al. (2013), there is evidence of a sensitive or critical developmental period for sign language acquisition, paralleling that for spoken language. When children who are profoundly or severely deaf are only exposed to sign language *after* attempting and failing to acquire a spoken language, this late exposure to an accessible first language (e.g., ASL) generally results in long-term language deficits (Lyness, Woll, Campbell, & Cardin 2013; Schick 2003).

### ***Connection with the Deaf community***

Developing a **connection with the Deaf community** can serve to foster a deeper sense of identity. The deaf mentor can play this role for a child. Knoors et al. (2012) notes the importance of **cultural identity**: “For deaf children, identification with deaf culture and deaf community could be an important part of social-emotional development, akin to growing up with an ethnic or religious affiliation.”

Adults who are D/HH who participated in this study expressed the importance of children and their families being exposed to Deaf culture and the Deaf community (9 out of 31 interviews), and that part of being a mentor should involve connecting a family with the Deaf community (10 out of 31 interviews and 2 out of 2 focus groups). Some parents of children who are D/HH also perceived this as a benefit of mentoring programs (3 out of 14 interviews, 2 out of 4 focus groups).

*“Contact with community events and how to get involved - and how to get information on how to be a part of the deaf community in general, the families don’t know how to do that, they need someone to lead the way so that they have a bridge into the community.” (Adult who is D/HH)*

*“The benefits are so great. The involvement in deaf events and meeting deaf people teaches them about their culture, it teaches them what it’s like to be deaf. Parents get more confident and can be more involved, and can ask any questions they have. They can then be more successful with their children.” (National expert)*

Just under half (48%) of parents who participated in the web survey said that learning about Deaf culture and building relationships with the Deaf community was a benefit of the Lifetrack D/HH Mentor/Role Model program.

*“We’re getting to learn ASL and about Deaf culture in our home. It’s a comfortable place for our kids to learn. We’re building a relationship with someone in the Deaf community. Not only are we learning ASL and about Deaf culture, but we’re learning how to better advocate for our son and that is PRICELESS!!!” (Parent, web survey respondent)*

*“It was great to learn about the [D]eaf culture and hear from a deaf person the struggles she faces with being deaf. Also, the whole family learning how to sign to be able to effectively communicate to our daughter [was helpful].” (Parent, web survey respondent)*

### ***Self-esteem and identity***

Hintermair (2000) showed that families who meet frequently with other families and who have contacts with adults who are D/HH **have a more trusting relationship with their child and a stronger sense of competence.** In addition, the parents who received parent-to-parent support or mentoring from an adult who is D/HH expressed **more contentment with life, felt more energy physically and emotionally to meet the challenge of raising a child, and made better use of coping strategies.**

Nearly all parents agreed (10 out of 14 interviews, and 4 out of 4 focus groups) that one of the top **benefits of mentorship for children would be for the child to see that they are not alone and there are other people like him/her.** Web survey participants (82%) also noted this as either extremely or very important benefit of mentorship. Participants who are D/HH also noted that **feeling less alone** was likely a key benefit for children who participate in mentoring (8 out of 31 interviews, 2 out of 2 focus groups).

*“When I was young, I was negative about my own deafness as there was that struggle, I wish that I had the opportunity to learn about being a deaf adult.” (Adult who is D/HH)*

*“We thought, well we don’t need that, but now she’s in school and seeing how much signing would be part of her life. The first time I realized how big a part of her life it would be was when we came here and seeing how excited she was to be around other people that signed. She just lit up because of being around other deaf people.” (Parent of a child who is D/HH)*

*“I think how families can benefit is just knowing they’re not alone. One of the best things about Minnesota Hands & Voices, with these big group activities, is you are with dozens of other families who have a child who is D/HH. You can be in a bigger group knowing that your child will see other children with hearing aids and that’s a powerful feeling.” (Parent of a child who is D/HH)*

*“I’ve seen the difference I’ve made by mentoring my student. She is more confident now! More outspoken for her own needs and who she is, I can really see the different and it’s really nice to see that.” (Adult who is D/HH)*

The national experts we interviewed were asked to identify any negative consequences that could occur if a child who is D/HH does not participate in a mentoring program. Four out of six identified **missing out on being a part of the Deaf community and learning about Deaf culture as a negative consequence for not participating in mentoring.**

*“At the university, kids will come when they’re 17 or 18 and they haven’t ever met a deaf person. They’re in shock when they arrive. It’s important that parents expose them to the culture so they can travel, experience the world, and meet other people. They don’t know there’s a deaf world outside. They may have low self-esteem because of it, too.” (National expert)*

### ***Hope for the future***

According to Olson (no date), D/HH mentors are uniquely qualified to provide the child, parents, and professionals with a positive and hopeful perspective from their day-to-day, real life experiences as a person who is D/HH living in a hearing world. In one deaf role model case study based in the UK, mentors helped children and families realize that deaf adults can “achieve anything” and were able to share their experiences of being deaf (Rogers et al. 2011). Parents appreciated hearing about personal experiences from a D/HH mentor, particularly that adult’s experiences growing up and navigating their own hearing loss (Pittman 2000). Even informal interaction with an adult who is D/HH was able to help parents reach the realization that people who are D/HH can be independent and successful adults (Hulebosch 2002).

Some of the parents (4 out of 14 interviews, 2 out of 4 focus groups) and Lifetrack staff (4 out of 13) who were interviewed also mentioned hope for the future as a key benefit of mentoring programs.

*“I wondered what careers would be available for the deaf, where will he go to school? Will he drive? It’s these random thoughts that flooded my mind. Knowing the deaf mentor and becoming part of the community, you see the capabilities of these great people and it gives you hope. My mentor gives me hope.” (Parent of a child who is D/HH)*

*“I always hear the same story, regardless of the family’s background. They always ask, ‘what does my child’s future hold?’ They wonder if their child will be bullied, if they’ll have to go to a different school. As they see other families, they can see that their initial fear is something they can get past. They just want a crystal ball to answer if life is going to be hard for their child.” (Lifetrack staff)*

*“Now we have a better understanding of Deaf culture and what we can do for her if that’s what she wants to do, go to deaf school, and we would support her if she wanted to go that route. It’s not as scary now.” (Parent of a child who is D/HH)*

When asked to identify the benefits to families that participate in mentoring programs, the majority (5 out of 6) of national experts we interviewed noted that families and parents gain **hope and confidence in their child who is D/HH**.

*“There are lots of benefits. Parents get hope and confidence. Some of them live in fear, and we want to give them hope and give their child high expectations and not settle for less. We want to make it a positive learning experience for them. We want to make the grief process quicker so they can get on with parenting. We want them to be happier, to see their child as whole and worthwhile, so they’re not just looking at their ears.” (National expert)*

## Barriers to families participating in a mentoring program

The biggest barriers families experience that prevent them from participating in mentoring programs are: lack of awareness of the program; real or perceived bias on the part of the mentors toward families and the choices they have made (in particular: ASL or not, cochlear implant or not); perceptions of whether the program is a fit for their family and child’s needs; their own schedule or availability, especially in the case of children who have co-occurring disabilities and other health issues; and denial.

### *Lack of program awareness*

**Lack of awareness of the program was a barrier to program participation** (6 out of 14 parent interviewees and 3 out of 4 parent focus groups). Parents explained that they were flooded with information when they first learned of their child’s hearing loss diagnosis, and if they didn’t hear about the mentoring program again, that the information was lost in this period. Similarly, the majority (71%) of parents who participated in the web survey said they did not participate because they were not aware of the program.

*“Although my child had a hearing loss since age 1 - I was not aware of Lifetrack or their programs.”—Web survey participant*

*“I wish schools, doctors, and audiologists would give more resources to students, and let them know about Lifetrack. Many parents don’t know about the program, especially in rural Minnesota. We have to keep giving info about the program.” (Lifetrack staff)*

### *Mentor bias or judgement*

A significant barrier for parents participating in the mentor program was the **perceived judgment from the Deaf community and mentors regarding cochlear implants or hearing aids** (this theme was found in 5 out of 14 parent interviews, and 2 out of 4 parent focus groups). This also relates to perceived bias against families who do not choose to use ASL as the primary language with their child, and those who do not choose to send their

child to a Deaf school. Two of the six national experts we interviewed also cited mentor bias as a barrier to family participation in mentoring programs.

*“We did a lot of online searching that turned up a lot of negative information – the Deaf community was very anti-cochlear. We’d say, we’re thinking about this...and they’d say “that’s child abuse!” (Parent of a child who is D/HH)*

*“Amplification use is contentious. They [parents] feel sometimes judged by the mentor if they choose not to use sign, or if they choose a cochlear implant.” (National expert)*

*“In Deaf culture...people who use ASL look down on people who use hearing aids and speak... People who use cochlear implants are shunned in the Deaf community. You have to choose.” (Parent of a child who is D/HH)*

*“I guess the thing, to be honest, as much as I enjoy my deaf mentor, sometimes I think it would be easier to have a deaf mentor who has same goals that I do for our daughter. I feel like our deaf mentor is always pushing for our daughter to go to [Deaf school]. I feel pressure from her. Because that’s what she did, that was her experience. But our main goal for her is to have sign, but also to be mainstream, so she doesn’t feel different from her brother and the rest of her family. So sometimes I feel like it might be helpful if our deaf mentor was someone who maybe had a cochlear implant and was also spoken. Sometimes I feel that we’re being pushed to do something we’re not wanting for her right now. I don’t want to be insulting, I’m so grateful for it, and I’ve learned so much from her. Sometimes I just feel like there’s unnecessary pressure from her. I’m not sure she understands what we want.” (Parent of a child who is D/HH)*

*“Deaf mentors sometimes have biases, which can be a problem. How to handle that is important...For example, some people grow up orally, with hearing parents. They’re biased to support the way in which they were raised.” (National expert)*

*“Making sure they [mentors] are unbiased in teaching the families about ASL and the Deaf culture. It is important that the family understands that by having a Deaf Mentor it is exposing them to an additional language and culture, and not that the ASL/Deaf Culture is replacing their normal way of communicating. Certain mentors may push the family too much.” (Lifetrack staff)*

### ***Program perceptions***

Similarly, some parents felt that the Lifetrack D/HH Mentor/Role Model program **may not be a good fit because they perceived it as serving only children who are profoundly deaf. Some parents described a feeling of not fitting in with the program.** This often overlapped with parents **not understanding how the mentor program could benefit their child and family.**

*“But there was this dichotomy of the Deaf community and the hearing community, and we didn’t feel like we really fit in, so we didn’t keep going.” (Parent of a child who is D/HH)*

*“Right now, I feel like it’s not a good fit. Just because my son is hard of hearing, but he can function in the hearing world. He doesn’t require ASL. He’s not a part of a Deaf community. I don’t know if he needs that.” (Parent of a child who is D/HH)*

*"I [was] wondering if it would be beneficial because we get so much other information from his D/HH teacher and speech [therapist]. And I know they're not D/HH, but would it be the same information we're getting from the school district? Not that we wouldn't want it, but time is limited." (Parent of a child who is D/HH)*

**The name of the program deterred some parents from pursuing participation.** Some parents felt that because it was called a "Deaf Mentor" program that it was not a good fit for their family if their child is not profoundly deaf or if their child primarily uses oral language. There may also be a lack of available mentors who are not ASL-primary communicators.

*"I guess I wasn't fully aware of what it meant. You hear 'Deaf Mentor program,' and it's like well my kids aren't deaf... and their hearing loss is mild, and that's not us. I'm not interested in doing signing with them with the plethora of other stuff we're going through. I thought, it's not for me. And I don't feel like there was enough information out there to really comprehend it as something that may or may not have been a good fit." (Parent of a child who is D/HH)*

*"I want to find these mentors who are using different modes of communication, but they're harder to find. Minnesota Hands & Voices have identified a good number from within the metro, though. I would love to see that continued, so parents can get that continuum. Parents don't always know that's all out there. They don't necessarily feel the mentor program will meet their needs if they don't use ASL." (Lifetrack staff)*

Three Lifetrack staff noted that there is a **lack of information about language acquisition and ASL that prevents families from participating**. Three of the national experts we interviewed also noted the **inaccurate or insufficient information about ASL provided from other parents or the medical community**, as barriers to families joining D/HH mentor/role model programs.

*"The biggest barrier is the parents' attitudes and desires and beliefs. If doctors or audiologists say you don't need to sign, if they give that inaccurate info, parents believe that and that's a huge barrier. Then they won't want services from the mentor." (National expert)*

*"Lots of families think they can only choose one language modality, which can make it tough when they don't want ASL to be the only thing they use." (Lifetrack staff)*

Experts and adults who are D/HH feel parents are oftentimes exposed to one perspective or get misinformation that leads them to believe that learning ASL could negatively impact their child's ability to speak or read. In fact, many studies refute the position that learning ASL hinders spoken or written English development and instead show that the **learning of signed language may have a positive effect on the spoken language skills of young children who are profoundly or severely deaf** (Snodden 2008; Preisler, Tvingstedt, & Ahlström 2002; Schlesinger & Meadow 1972; Yoshinaga-Itano & Sedey 2000). Preisler et al. (2002) observed that children with cochlear implants who developed the most spoken language also had well-developed signed language. Although a proficiency in signed language by itself did not guarantee the development of spoken language, those children



who had insufficient (or discontinued) signed language development also had more limited spoken language abilities. Snodden (2008) also found that the children in their study who had little signed language improved their signing abilities, their spoken language also improved.

**Proficiency in ASL has been shown to support English literacy in students who are deaf** (Snodden 2008; Hoffmeister 2000; Padden & Ramsey 1998, 2000). In a position paper on early childhood development and education for children who are D/HH, the National Association for the Deaf (2014) also links fluency in ASL and reading achievement.

### *Scheduling and availability, especially when dealing with other issues*

**Scheduling was another concern for families, which includes both time spent on the mentoring sessions and simply finding available times to meet between the family's and mentor's schedules.** Some parents (5 out of 14 interviews, and 3 out of 4 focus groups) felt that adding mentoring sessions to their schedule was daunting. Some of the adults who are D/HH (9 out of 31) and Lifetrack staff (6 out of 13) who we interviewed also cited scheduling and availability when asked about potential barriers to participation from parents.

*"Part of it would honestly be finding the time. That's a lot of a time commitment when they're in school full time and we work full time. It would have to be on the weekend. Finding that time to dedicate is so hard, unless it was a necessity, it's difficult to take it on because we get so little family time together." (Parent of a child who is D/HH)*

*"I think of all those doctors, the last thing we would have done is go somewhere else to learn about it. You're already taking so much time off work and already drained from that, to spend more time going somewhere else..." (Parent of a child who is D/HH)*

*"We are supposed to meet once a week, but with our schedule - between ours and hers, it doesn't line up very good. Sometimes it's a month before we can even connect. That's been hard. Or planning on it, and then last minute I'll get an email that she's not coming. Or waiting around and she's a no-show. That's been frustrating, but what can you do?" (Parent of a child who is D/HH)*

**Additional medical diagnoses or issues complicated matters further for many families** (this theme was found in 3 out of 14 parent interviews, and 3 out of 4 parent focus groups). In some cases, the child's medical issues were so severe that dealing with their hearing loss became a secondary concern. (Some parents reported not knowing if their child would even survive.) One-fifth (20%) of parents who completed the web survey also noted that they were dealing with other health issues.

*"Our Deaf child also has many other health issues so we needed to balance our time between managing his medical, communication and community needs." (Parent, web survey respondent)*

*“Our biggest needs and concerns were his overall health and wellbeing.” (Parent of a child who is D/HH)*

Parents in one focus group discussed how **challenging it was that the mentoring sessions required all family members to be present**, particularly in cases where parents had different schedules.

*“We were so busy, I was exhausted, and I had this vision of him - you read those stories of kids who don't sign with their parents - we were not going to be that. I was desperate to learn. But he [my spouse] was like 'More class, are you kidding me?' And he did it, god bless him. But I would have loved more flexibility. It honestly was a source of marital stress; forcing both parents to be available.” (Parent of a child who is D/HH)*

Similarly, when asked what would be a barrier for them to participate in a mentoring program, 50 percent of survey respondents noted that it was a challenge to make time in their schedules for the program. In addition, some respondents (11%) noted that the program required two parents to be present and that caused a difficulty for them.

*“I work overnights and my husband works days so we were limited on times/days we could meet.” (Parent, web survey respondent)*

*“My husband works long and late hours. He travels often for work. He isn't able to always make it or is so exhausted that he doesn't want to meet with the Deaf Mentor. Our Deaf Mentor didn't move forward with our lessons for a while because he wanted my husband to attend. It just wasn't possible. Secondly, my kids are a big distraction during the ASL time with the mentor. My son who is hard of hearing is benefitting from the mentor but he doesn't have the attention span to sit and learn after being in school all day.” (Parent, web survey respondent)*

## ***Denial***

About one-quarter of adults who are D/HH who participated in this study suggested that **parents' denial of their child's hearing loss could be a barrier to their participation** in a mentoring program.

## **Key needs, and adequacy of current services, for specific sub-groups**

This section of the report examines the needs, and extent to which the Lifetrack D/HH Mentor/Role Model programs meet the needs of specific sub-groups, including families who are non-English speaking, from rural areas, with young children (age birth to 6), or whose children have co-occurring disabilities, as well as families who use visual language, visual tools and resources, or assistive technology.

Parents who participated in the web survey and who had participated in Lifetrack’s program were asked to indicate how well the program meets the needs of families with a variety of characteristics. See Figure 8 for a summary of these results. The following subsections of the report further discuss these results and the related findings from the interviews and focus groups.

**8. How well the Lifetrack D/HH Mentor/Role Model programs meets the needs of families, (web survey respondents who participated in the Lifetrack D/HH Mentor/Role Model program)**

|   | <b>The program fully meets these needs</b> | <b>The program partially meets these needs</b> | <b>The program does not address these needs</b> | <b>Not sure</b> |
|---|--|--|---|-----------------|
| Families who use visual language education (ASL, Signed English) (N=20)                               | 85%  | 5%   | NA  | 10%             |
| Families who use visual tools and resources (Cued speech, lip reading, etc.) (N=20)                   | 35%  | 5%   | 10%   | 50%             |
| Families who use assistive technology (cochlear implants, hearing aids, CART captioning, etc.) (N=20) | 55%  | 15%  | 5%  | 25%             |
| Families who use other communication strategies and resources (N=17)                                  | 18%  | NA   | 6%  | 77%             |
| Families with young children, ages birth to 6 (N=20)  | 60%  | 35%  | NA  | 5%              |
| Families with children that have co-occurring disabilities (N=20)                                     | 30%  | 10%  | 5%  | 55%             |
| Families who live in rural Minnesota (N=20)   | 35%  | 20%  | 10%   | 35%             |
| Families who speak languages other than English at home (N=20)  | 20%  | NA   | NA  | 80%             |

***Families who speak a language other than English***

Language barriers exist for parents who do not speak English to participate in mentoring programs. **All of the application forms, materials, and curriculum for the Lifetrack program are in English**, and some of the non-English speaking Deaf Mentors in particular noted a need for these materials to be translated and for more resources to be available in non-English languages (Spanish, Somali, Hmong, and Karen were mentioned).

*“They could provide more information to the Latino community. If you don’t speak English and the information is in English, It could be right in front of you but you don’t know what it means. The point is there is a lack of information in Spanish and to the Latino community.” (Parent of a child who is D/HH)*

*“Usually I send them an application. Some of them say ‘can you explain how this works?’ They need someone to translate what the application is asking for; I need to explain it to them. It’s not easy. Sometimes I call the family and I help, but that’s not my job. But sometimes I help even though I have lot of other work to do...If they could have different applications for different groups, that process would be easier.” (Lifetrack staff)*

*“We need more curricula for different cultures. For the Spanish speaking families, I only have 4 books in Spanish that I can use. More technology would also be helpful.” (Lifetrack staff)*

*“The curriculum is entirely in English. I’m working with other Spanish speaking deaf mentors to help translate the curriculum into Spanish. Then, families can learn both languages from that. It’s really tough for my Spanish-speaking families to have to work with this curriculum.” (Lifetrack staff)*

In addition, many of the parents, adults who are D/HH, and Lifetrack staff who participated in this study noted the **importance of having mentors who are trilingual (English, ASL, and the family’s native spoken language) and from the same cultural communities as the families they are mentoring**. It appears that Lifetrack has recently increased the number of trilingual staff, and several staff who we interviewed expressed a positive attitude about their progress on this issue, although they also indicated that more progress is needed.

*“As a Latina, you sometimes want to speak to another Latina and say my child has this, or my child is deaf, or all of these problems, but you don’t have anyone to talk about these things with. I know a lot of American women and I can speak English, but it is not the same as speaking with someone in your native language.” (Parent of a child who is D/HH)*

*“It’s emerging. They’ve hired a couple role models who are culturally based—Spanish and Hmong, particularly.” (Lifetrack staff)*

*“They are still thinking about that [recruiting/retaining diverse families] and trying to do education and training – they ask me for my input, how can we make this better? They’re trying to go to schools and ask families and get ideas. They’re trying to get better. But they’re still figuring it out. It’s just brand new – before it was waitlist, but now referrals are coming often, for us it’s every month. Those families are Somali families. We’re still trying to figure it out.” (Lifetrack staff)*

*“We need more mentors from different backgrounds. I’m the only Spanish speaking mentor, and we only have one Hmong mentor. I worry about wait lists for these families to get a mentor.” (Lifetrack staff)*

*“We have insufficient staffing. We need to hire more people. We have families that wait years because there isn’t anyone to help them. We need Somali Mentors, but the problem is also within the recruiting standards for the mentors.” (Lifetrack staff)*

Further, **cultural differences could also act as barriers to program participation.** Specifically, stigma associated with hearing loss may be more prominent for some cultural groups. In one case study of parent to parent support, the authors found that Spanish speaking families were more frequently identified as “denying” their child’s hearing loss and that cultural differences may play a part in how a family identifies their child’s hearing loss (Friedman-Narr et al 2014).

*“My husband doesn’t like anyone to know that our son has a hearing loss. And I think that is a big problem in the Latin community that they don’t want other people to be aware of that. That is something they don’t talk about.” (Parent of a child who is D/HH)*

*“There are sometimes lots of cultural differences and language barriers. Families from different cultures may not see it [hearing loss] as an issue.” (Lifetrack staff)*

Adults who are D/HH noted the **importance of cultural sensitivity among mentors.** It is critical that mentors understand that mentoring families of varying ethnicities means **being open to learning about new cultures.** Respondents also recommended more targeted efforts to reach families of different ethnicity, culture, language.

*“I think the same thing applies to those people of different cultures, you need to learn about them before you work with them. Cultural appropriateness training is important... A program that can test your people to see their cultural awareness and cultural competency, then figure out what weakness that they have. And have more cultural exposure so that mentors understand better and what to expect when they meet families of other cultures and ethnicity.” (Adult who is D/HH)*

Two Lifetrack staff feel that that the ASL instruction that is a part of the current mentoring program **helps families to learn English.**

*“I’ve mentored Spanish speaking and Somali families, which has been a big success. When we teach these families to sign, it can also help them learn English.” (Lifetrack staff)*

### ***Families in rural areas***

The primary challenge in serving children and families in rural Minnesota is the greater **geographic distances among families, mentors, and potential meeting locations for mentoring sessions and/or group activities or events.** Children who are D/HH who live in rural areas may experience even more isolation than their urban peers, as they may be the only child in their town or school who has hearing loss. This makes mentoring and contact with other families who have children who are D/HH through mentoring and other informal programs even more critical for families in rural areas.

*“We are in a rural area. All the play dates and picnics seem to be in the greater Twin Cities area. Would be nice to have a few more activities or mom to mom connections within the counties we are in.”—Web survey participant*

*“We’re too far north for that. At least that’s how I see it. I work with Minnesota Hands & Voices, and I’ve tried to get help through the Deaf Mentor program but there are not enough people up here.” (Parent of a child who is D/HH)*

Some study participants noted that **technology, such as video chat options, can be used to bridge the geographic divide in rural areas**; however, other respondents noted the **challenges associated with slow and spotty Internet connections** (which can be particularly troublesome for a video chat using ASL).

Some respondents also noted that **rural areas have fewer resources in general** to work with and this can contribute to a lower level of services for families in rural areas.

On the other hand, it appears from the comments of several of the Lifetrack staff that there is an adequate supply of mentors to meet the demand in at least some areas of rural Minnesota. Two Lifetrack staff questioned the degree to which mentors who are working in rural Minnesota have had the opportunity to be trained. Currently, Lifetrack conducts training for the D/HH Mentors/Role Models that includes best practices in mentoring, understanding medical conditions, teaching ASL, Deaf culture and community, and other important topics. These topics are taught during a weekend retreat-style workshop. This training is open to all D/HH Mentors and Role Models. Recently, Lifetrack’s Educational Services created a video for adult role models who will be volunteering at Minnesota Hands & Voices family events, including D/HH Mentors/Role Models.

Lifetrack is also making efforts to infuse its D/HH Mentors/Role Models into all Minnesota Hands & Voices family events in order to increase families’ exposure to successful adults with various types of hearing loss and who use a variety of communication modes. It also offers an opportunity to raise awareness of the various programs available for families with children who are D/HH. Pittman (2000) also suggests that mentors accompany families to community events and introduce them to other people who are D/HH.

*“We do have people located in different areas of the state. That in itself is a successful part of the program. In some situations, we have technologies that we can use, so we need to be considering other options that might be more useful for rural families.” (Lifetrack staff)*

*“They have mentors in different places and usually they use the computer and they can use technology and sign language.” (Lifetrack staff)*

Families in rural Minnesota would like to see **more regional events that would allow them to connect with other families that participate in the deaf mentor program**. Adults who are D/HH who participated in this study also suggested this as a way to connect families with support and/or services. They see a great benefit for their children to meet other children with hearing loss, especially because they are often the only one in their school who is D/HH. (Of note, Minnesota Hands & Voices does have regions and staff in each of 7 regions of Minnesota who have a caseload and hold events in that region. It is unclear if the parents who participated in this study are not aware of this program, if it does not meet their needs, or some other reason for making this suggestion for more events.)

*“More, more, more events and social opportunities [in rural areas] where parents can connect and kids can meet other kids.”—Web survey participant*

*“Maybe have some kind of support system in each county? Like a centralized spot? There might only be a few people with hearing loss in the county, but making it part of the public health system. I know there’s more centralized in the cities with the higher population, but it would be nice if there was something out here in the sticks too!” (Parent of a child who is D/HH)*

### ***Families with young children (age birth to 6) who are D/HH***

Although Lifetrack staff noted the importance of starting to work with young children as soon as their hearing loss is diagnosed to avoid delays in language acquisition, some of these staff feel they **reach families later than is ideal for language acquisition for the child**.

*“The problem with this age group is that the families usually don’t find out about us until too late! We would ideally want to start children out as babies in the program, but there are not enough resources or funding to find these families.” (Lifetrack staff)*

Eleven percent of parents who participated in the web survey said it would be helpful if a new mentoring program offered **ASL-focused games and ways to include younger kids and keep them engaged and learning**. Two of the Lifetrack mentors we interviewed noted that the activities and games for young children that they currently use are good.

*“Bring fun family friendly games for the whole family to play & incorporate signing into the game. Our mentor is excellent at this!”—Web survey participant*

Two of the Lifetrack mentors also noted that some families do not choose ASL and it is **difficult to navigate family preferences for language and assistive technology for very young children**. Additionally, two mentors noted that time and scheduling is particularly difficult for families with very young children.

### *Families whose children have co-occurring disabilities*

Ten percent of parents who participated in the web survey said **offering more targeted services, support, and resources or referrals to families with children that have co-occurring disabilities** would be a way to ensure the mentoring program meets those families' needs.

### *Families who use visual communication, visual tools and resources, and assistive technologies*

**Meeting the needs of families who use visual communication appears to be a relative strength of the Lifetrack mentoring program. Additional support may be needed for families who use visual tools and resources and those who use assistive technologies.**

The majority (85%) of parents who completed the web survey and who have participated in the Lifetrack program said that the program fully meets the needs of families that use ASL or other visual communication. Over half (55%) said that the current program fully meets the needs of families who use assistive technology (such as cochlear implants, hearing aids, CART captioning, etc.). One-third (35%) thought that the program fully meets the needs of families that use visual tools and resources (Cued Speech, lip reading, etc.)

### *Families who do not use ASL*

Five Lifetrack staff indicated that a challenge that they have serving families who do not use ASL is that the **current curriculum used by Lifetrack is intended primarily for teaching ASL**. (As previously described, Lifetrack manages a pilot Role Model program for children who are hard of hearing, it is shorter in duration – 6 weeks – and focuses on self-advocacy and identity, instead of ASL and Deaf culture.)

*“Our program is focused on ASL, and isn’t advertising or providing services for other options yet. We need to know more for curriculum development and training.” (Lifetrack staff)*

*“We give ASL books to families, and really only have involvement with ASL. Lifetrack resources are only ASL. The curriculum is shaped for ASL. We have to refer them to other programs if they don’t want ASL.” (Lifetrack staff)*

With regard to serving families that do not choose ASL as a primary mode of communication, the Lifetrack staff we interviewed offered a variety of answers. Eight of the staff noted that families are exposed to ASL as a part of the program and that families who choose to participate want to learn sign language. Three staff said that families should learn ASL. Two mentors said that families get exposure to all types of communication methods in the mentor program. Two mentors indicated that the curriculum is good and helpful for families that use all types of communication modes. And finally, two mentors stated that the program tries to meet the needs of every family, regardless of the communication type that they choose.



## Benefits for adults who are deaf and hard of hearing to serve as mentors

By far the most common response from adults who are D/HH, (18 out of 31 interviews) when asked about what benefits mentors might experience, was the **feeling of making a difference**. Responses overlapping with this perceived benefit suggested that mentor recruitment messaging should focus on the role of mentors in helping a young child who is D/HH, as well as strengthening the Deaf community and displaying support for one another.

*“Some past trauma can be healed by making a difference for the next child.” (Adult who is D/HH)*

*“You become a better person as a mentor because this person is looking up to you for ideas, for sharing moments, for compassion, for similarities as well as differences and for support. The child or teen is also looking at you and thinking if you can make it, I can. As a mentor you look at the child and you give commitment, hope, and assurance: you will make it!” (Adult who is D/HH)*

A smaller number of adults who are D/HH (7 out of 31 interviews) also indicated **learning more about and connecting more with their own Deaf culture** as a potential benefit of participating in the program as a mentor.

## Barriers for adults who are deaf and hard of hearing to serve as mentors

Having to **travel too far** to visit a family’s home was considered a potential challenge by 4 of the 31 of the adults who are D/HH who participated in this study.

Another barrier mentioned by one Lifetrack staff was that the **educational requirement of mentors is prohibitive**. Though it is not required, it is preferred that mentors have a college degree.

*“Again the standard requirements of being a Deaf Mentor causes a barrier. The system doesn’t allow us to train people. If they don’t have a college degree we cannot train them. There are bureaucratic problems in the system.” (Lifetrack staff)*

As noted above, **program funding and resulting staff capacity** may be the biggest challenge for Lifetrack in terms of recruiting, training, and retaining an adequate supply of mentors, and diverse mentors who reflect the variations in communication modalities, assistive technologies used, and native language (English or non-English).

# Recommendations

Overall, mentoring programs are broadly recognized by parents, adults who are D/HH, and experts as a critical component of the Early Intervention services and supports offered to families with young children who are D/HH. Like most other programs around the U.S., Lifetrack’s Deaf Mentor program is designed specifically to teach children and families American Sign Language (ASL) and learn about Deaf culture.

## “Best practices” from the field

Wilder Research reviewed the websites of several D/HH mentoring programs around the U.S. and spoke with several national experts who are affiliated with one or more mentoring programs to understand what, if any, program characteristics and organizational strategies could be useful as Lifetrack expands the D/HH Mentor/Role Model program. Although none of these programs would be considered a “best practice” in the strict sense of having strong research evidence to demonstrate the outcomes achieved by the program, it is important to consider the range of strategies and approaches other reputable mentoring programs are using to meet the needs of families with young children who are D/HH.

A study of the New Mexico Deaf Role Model Program by Abrams et al. (2011) identified the following effective strategies:

- Share experiences about growing up as a D/HH person.
- Encourage family to attend special activities that broaden their community of D/HH contacts, enhance their communication/language model, and provide opportunities for interaction using sign language.
- Share career goals, work experiences, and enthusiasm about the future potential of the child who is D/HH.
- Model natural communication and teach sign language.
- Focus on language and communication, making the child’s world accessible, Deaf culture, literacy, and building community.

Many of the programs reviewed here use the SKI HI curriculum, teach ASL, and help the families to learn more about Deaf culture and the Deaf community. The supplement to the 2007 Joint Committee on Infant Hearing position statement offered the SKI-HI Deaf Mentor program as an example of a program model that produces positive outcomes for children,

namely, that they learn ASL and also develop English skills more rapidly than children who are D/HH that did not receive mentoring services. The supplement also suggested that mentor-family interactions have a positive effect on parents' perspectives of adults who are D/HH as well as their child's future. See Figure 9.

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. More specific recommendations are provided in the following sections with regard to organizational capacity, program outreach, program structure, and mentor training and characteristics.

Through this study, no literature was identified that demonstrates strong evidence-based practices in terms of mentor training or program curriculum. Lifetrack should consider its role, both locally and nationally, in terms of contributing to the body of knowledge about what works in terms of mentoring programs for families with young children who are D/HH.

## 9. Characteristics of D/HH mentoring programs around the U.S.

| Program   | Services provided  | Curriculum and training   | Communication modality/ languages taught   |
|---|--|---|--|
| Lifetrack's Deaf Mentor Family Program  | The Deaf Mentor Family program assists families by providing mentorship, introduction to deaf culture, instruction in ASL, early visual communication methods, and Deaf Culture through a trained Deaf Mentor.   | SKI-HI Deaf Mentor Training Curriculum and an in-house training model   | ASL  |
| Deaf Counseling, Advocacy, and Referral Agency (DCARA) Family Connections Program--California | Role model program includes mentorship, deaf culture introduction, classes, workshops, consultation, parent education, Family ASL immersion, Family ASL classes, Literacy Day Camp, family events  | N/A   | ASL  |
| Georgia PINES (Parent Infant Network for Educational Services) Deaf Mentor Program            | Provides Deaf Mentoring, teaching family ASL, introduction to d/Deaf culture, sharing personal experiences growing up, and activities for families   | SKI HI/Utah State University Deaf Mentor Model<br>Deaf mentors (who have a college degree) receive 3 days of training in the curriculum focused on service delivery to families in language development, exposing families to culture and history of deaf individuals, collaboration with the parent advisor and other professionals working with the family, and cognitive development | ASL, Conceptually Accurate Signed English (CASE), sign supported speech, using sign as transition or bridge to Cochlear Implant (CI) |
| Deaf Mentor Services (Illinois)   | Provide families in Early Intervention with mentorship, a language model, activities around this language model, information on assistive technologies, link to local resources for individuals who are D/HH   | N/A   | N/A  |
| Indiana Deaf Mentor Program   | Meets with the family regularly (in home or an informal setting) to teach parents/family members ASL, share their life experiences as a deaf person, introduce parents/families to the Deaf community and Deaf identity. Program includes mentorship, Deaf culture introduction, and family activities.  | SKI HI Deaf Mentor Curriculum   | ASL  |
| New Mexico School for the Deaf  | Provide families with mentoring services that focus on language/ communication, making the child's world accessible, Deaf culture, literacy, and building community  | Deaf Mentor Curriculum and Shared Reading Project<br>Deaf mentors receive quarterly trainings and are certified by the state of New Mexico.   | ASL  |
| Utah School for the Deaf: Parent Infant Program (PIP)   | Provide high-quality hearing and vision services to children under age three who have vision or hearing impairments and their families. Family activities are also provided.   | Unknown if a curriculum is used.<br>Services are delivered by credentialed Early Intervention Vision and Hearing Specialists  | N/A  |
| Wisconsin Educational Services Program for the Deaf and Hard of Hearing (WESP-DHH)            | Provide mentorship, introduction to Deaf culture, comprehensive education, and support services to all Wisconsin children who are deaf, hard of hearing, and deafblind, their families, and service providers. Utilize evidence-based practices and supports, services, and resources to enable all children to reach their maximum academic, social and emotional potential | BravoASL! Program<br>Mentors have 2 trainings per year to keep up with their skill set.   | ASL  |

| <b>Program</b>  | <b>Program length and/or duration</b>   | <b>Funding sources</b>  | <b>Other helpful supports/program characteristics</b>   |
|---|---|---|---|
| Lifetrack's Deaf Mentor Family Program  | Focuses on children who are D/HH from birth to age 6. Families meet with the mentors for one weekly session for two hours.  | Minnesota Department of Human Services Deaf and Hard of Hearing Services Division, Minnesota Department of Health, school districts, special education, Medical Assistance waiver programs, or parents themselves | Services are available for Hmong and Spanish-speaking families; Program collaborates with other D/HH services for referrals in the metro and across the state to make sure all families in Minnesota are served.  |
| Deaf Counseling, Advocacy, and Referral Agency (DCARA) Family Connections Program--California | Serves children from birth to 21 years of age (not sure if this is duration or just age limits)   | State of California Department of Social Services, United way, city grants, private donations   | Offers a multicultural program that has community education and socialization opportunities for these families, offers advocacy for families regarding the IEP/IFSP, serves grandparents or other adult relatives raising children, provides peer counseling communication assistance, and information and referral   |
| Georgia PINES (Parent Infant Network for Educational Services) Deaf Mentor Program            | Early intervention program for birth-age 5,   | State of Georgia Department of Education  | All services are free to GA PINES families; provide emotional support to parents by answering questions and addressing concerns, helping parents to learn about child's diagnosis/available options; connecting families to experienced parents, professionals, and school systems; providing assessments to help parents make informed decisions   |
| Deaf Mentor Services (Illinois)   | N/A   | Illinois Department of Human Services   | Deaf mentors are a part of a child's Early Intervention team in Illinois and are considered to be a service provided by the state; Mentors provide 6-month and annual reports and attend Individual Family Service Plan (IFSP) meetings; mentors work closely with the teams Developmental Therapist Hearing (DTH)  |
| Indiana Deaf Mentor Program   | N/A   | Indiana Department of Health  | Parents and families will gain exposure to and learning ASL as well as learning about development of communication skills (both auditory and visual),   |
| New Mexico School for the Deaf  | Serves children from birth to 6 years of age, usually they get services for 2-3 years, home visits 90 minutes long up to 2 times per week                                       | New Mexico Medicaid   | Deaf Mentor program is free for New Mexico residents; services are individually tailored through state and federally regulated practices to meet each child and family's needs; services are offered in Spanish and English   |
| Utah School for the Deaf: Parent Infant Program (PIP)   | Serves children and families from birth to age 3  | Utah Department of Health   | Services are implemented through Individual Family Service Plans (IFSPs); specialists are scheduled with a frequency based on child's individual needs; information, training, modeling, and consultation to parents and the family to increase understanding of child's needs; networking opportunities to meet families who have children with hearing impairments; resources for instruction designed to prepare children with sensory impairments to reach their highest potential in preparing for further education |
| Wisconsin Educational Services Program for the Deaf and Hard of Hearing (WESP-DHH)            | 16 web sessions of ASL instruction (30-45 minutes) via the web first, after that 100 in-home sessions for 2 years (weekly 1-1 1/2 hour sessions). Serves children ages birth-6. | Wisconsin Department of Public Instruction  | Families must go through the DMP First Step, which is 16 sessions of ASL curriculum via Skype. After successful completion they can receive DMP services. Mentor program services are provided up to 100 sessions (approximately 2 years of weekly session); matches families with a Deaf Mentor via Skype (or other web-based technology), \$20 co-pay   |

## Organizational capacities needed to maintain a strong mentoring program

Although very little published research exists with regard to organizational capacities to manage a successful D/HH mentoring program, we can glean some information from the interviews we conducted with national experts and Lifetrack staff. In this section, we also provide more general recommendations for strategies to ensure the Lifetrack D/HH Mentor/Role Model programs are able to respond to families' needs and to be proactive about addressing changes in the external environment – opportunities as well as threats or challenges.

### *Leadership*

As illustrated throughout this report, the population of families with young children who are D/HH in Minnesota is very diverse in terms of range of hearing loss, communication modes and adaptive technologies used, types of co-occurring disabilities, geographic location around the state, and race, culture, and home language. Furthermore, the environment has changed significantly over the past several years with regard to new assistive technologies, increasing number of non-English speaking families in need of services, new technologies that can be used for programming such as video chat, families' changing expectations for program flexibility and their general availability, etc.

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 your target population, so your programs and services can continue to be responsive to the ever-changing environment.**

### *Strategic relationships*

We were asked to consider how Lifetrack can best partner with internal and external stakeholders to support the program. An obvious partnership is with MDH and DHHS in terms of the funding that is provided for these programs, via statute.

Strategies that were mentioned by the national experts we interviewed in terms of funding include **obtaining funding through health insurance** co-pays (though this expert noted that it is a challenge to get funding from insurance), and **strategic budgeting.**

*“Once, 8 or 9 years ago, we ran out of funding and weren’t able to provide services for 3 months. That was a learning experience. We got more funding the following year. We also made things more efficient, and cut training to once a year. We’re always looking for ways to save. We make sure to budget and spend money appropriately. Also, we have changed a lot in the last few years to make the funding more efficient, specifically, we adopted the 100 sessions model. I think that works better than the length of time. It focuses on providing the right services at the right time—the families can make the sessions work with their schedules.” (National expert)*

*“We can bill Medicaid for developmental instructional lessons here in New Mexico. Our mentors have certification from the state that allows for that.” (National expert)*

Another option Lifetrack could consider is partnering with school districts and accessing special education funding, especially funds designated for children from birth to age 3.

Three out of six national experts we interviewed said that **program capacity, such as a lack of money and a lack of mentors in certain areas, are barriers for D/HH mentoring programs.**

*“The hardest thing is if the particular area has a mentor. I think there’s a capacity issue. There’s a capacity issue here, and we’re well funded. We’ve have our program in place for 20 years, and yet still it’s finding people in very rural areas that is hard. Finding people with expertise in rural areas can be very difficult. The biggest barrier is that capacity piece.” (National expert)*

*“Money is a challenge for the program. It’s always a challenge.” (National expert)*

**Another strategic relationship that should be further explored is the overlap between Minnesota Hands & Voices and the Lifetrack D/HH Mentor/Role Model programs; overlap also exists with D/HH teachers.** As noted below, there are many indications that parents benefit from mentoring they receive from other parents as well as the mentoring they receive from adults who are D/HH.

In general, more options for parent-to-parent support, family events, youth activities, connecting to the Deaf community should be considered. Parents who participated in the web survey were also asked to identify in their own words one thing that would help the most to meet their family’s mentoring and support needs. Nearly one in five (19%) said they would like more opportunities to meet/connect with other families who have children who are D/HH.

*“I would like connections with other families that have children with similar hearing loss. Having a group that I can reach out to when I need advice.” (Parent, web survey participant)*

*“I would love to find more families in our area with D/HH kids. I feel like we don’t have that support.” (Parent, web survey participant)*

## ***Program evaluation***

Two of the experts we interviewed mentioned **evaluation of their programs** as a strategy to ensure that the programs are meeting the needs of the community and collecting parent and family testimonials. One expert mentioned that evaluation works well for them because it allows them to get feedback from families and allows them to modify their program.

*“What works well is getting feedback from families, parents, and mentors. We find out how long we should gather info, how often the families should get a mentor’s visit.” (National expert)*

The JCIH 2007 position statement supplement recommends implementing a system of monitoring and follow-up intervention to improve outcomes for the child. Although monitoring is different than evaluation, a good initial program evaluation could help Lifetrack establish systems for ongoing monitoring at the individual child and family level (i.e., case management tools).

One condition of Lifetrack’s grant is to participate in evaluation, in which they report indicators related to state and national EHDI goals. Currently, most of the monitoring of the Lifetrack Deaf Mentor program occurs through satisfaction surveys received by families who participated in the program. We specifically recommend that Lifetrack consider three types of more rigorous evaluation in the near future to help with program sustainability and strategic expansion:

- **Developmental evaluation** for any new program model or component, which would provide real-time feedback loops to Lifetrack and program participants to help refine the programming and to insert evaluative thinking into every programmatic decision that is made.
- **Process evaluation** to understand the experiences with and satisfaction of mentors, families (both parents and children), and other program partners and stakeholders, and how these experiences may be contributing to or hindering positive outcomes for participants.
- **Outcomes evaluation** to determine the impact on children, families, and mentors. This could involve less rigorous (i.e., self-reported) outcomes or it could include actual assessments of things like language acquisition, family functioning and communication, child academic outcomes, etc.

Wilder Research would be happy to discuss any or all of these evaluation strategies with Lifetrack, MDH, DHHS, and other project stakeholders.



## Program outreach

It appears that there is a **general lack of awareness of the Lifetrack D/HH Mentor/Role Model programs among families**. When asked what Lifetrack could do to make the D/HH Mentor/Role Model program meet the needs of families like theirs, 69 percent of web survey respondents who had already participated in the program noted that Lifetrack should increase and improve communication and outreach, specifically informing families about the program in general as well as program benefits.

As previously noted, Minnesota Hands & Voices has promoted the Lifetrack D/HH Mentor/Role Model program through the organizational newsletter, Facebook page, presentations to professional groups, and has included Deaf Mentors in Minnesota Hands & Voices events. Parent Guides also directly refer families to the D/HH Mentor/Role Model program and do other methods of outreach on behalf of the D/HH Mentor/Role Model program.

As noted above, **multiple points and methods of contacting families may be needed**. Parents may not fully track on the information they are receiving because of the flood of information from all sources, the shock and grief many parents experience when they first find out about their child's hearing loss, and because many families are also dealing with other health issues from co-occurring conditions (not to mention the fact that they are dealing with a new baby, which is stressful even when the child is completely healthy). It appears that Lifetrack does currently use several points of outreach but more options and greater intensity of outreach may be needed.

One specific suggestion that was made by a study participant was to have Lifetrack check in with the family on the child's first birthday, even if they initially declined to participate. An expert we spoke with suggested that all parents should have to have an opportunity to meet with a D/HH mentor or other D/HH (who is specially trained in working with parents at this early stage in the process) before they decide to move forward with any assistive technologies, and before they decide which communication mode(s) they want to use. This same expert also suggested that D/HH mentors should be included as a part of the child's care planning team. (These families almost always have multiple points of contact with an audiologist or medical doctor who may present some of the options and one perspective to them, and these professionals are almost always involved in helping families make decisions about communication mode(s) and assistive technologies, so the idea would be to ensure that parents are exposed to mentors -- who may have a different perspective to offer on the choice of communication mode(s) and assistive technologies -- before making fairly permanent and significant decisions that will impact their child's language acquisition, access to communication, and self-identity for a lifetime.)

One additional recommendation that came out of discussions with Advisory Board members was the **need for clear branding of the Lifetrack D/HH Mentor/Role Model program** for effective promotion to all types of families. It was suggested that perhaps the program can work under an umbrella label such as “Family Mentor Program” and then provide promotional materials that clearly explain the different programming options available to families. Suggestions include providing a menu of options to families to aid them in deciding how best to support their children. This menu could potentially include evidence-based information about what outcomes should be expected so that families can clearly identify whether or not their children are on track for healthy development, and which programming options are best suited for their family.

Lifetrack should also consider D/HH teachers, audiologists, speech therapists, and other health care professionals as other possible avenues for connecting to families with children who are D/HH. Finally, Lifetrack should consider a “professional mentoring” track whereby adults who are D/HH (and who are professionals in their respective fields) would mentor hearing professionals who are serving children who are D/HH and their families. More discussion is needed about the purpose and content of this type of mentoring.

## Program structure

Writing about communication modes and assistive technologies, Knoors and Marschark (2012) note that while a correlation exists between sign language skills and reading proficiency, there is no convincing evidence for or against bilingualism for children who are D/HH. Rather, they suggest the need to revisit language policies for children who are D/HH now that cochlear implants are becoming commonplace for many babies born with hearing loss: “We should start with acceptance of the fact that many younger deaf children have greater opportunities to acquire a spoken language than ever before and that spoken language will be the first language for many of them. Communication between parents and child, in particular, will mostly occur in spoken language. At the same time, we believe it is still worthwhile to encourage parents to learn and use sign language regularly, especially as a support to spoken language” (p. 299). **This research and the findings from this study, which indicate the diversity of needs and preferences among families with young children who are D/HH in Minnesota supports an overall mentoring program approach with the child’s best interests in mind, that honors and aligns programming the family’s chosen/preferred mode(s) of communication, with a variety of options to use American Sign Language provided among those options.**

Therefore, Lifetrack should consider reformatting the program so that multiple communication modes are represented. In other words, Lifetrack could offer various sessions/sequences related to each modality such as ASL, signed English, spoken English, Cued Speech, etc.

These tracks would not need to be mutually exclusive, and would help to support a broader spectrum of families whose children have varying levels of hearing loss and communication needs. Many of the parents interviewed and surveyed for this study had children with cochlear implants or hearing aids, and most of these families (as well as the majority of families with young children who are D/HH in Minnesota) communicate mainly using spoken English or their family's native non-English spoken language.

At the same time, there is a **need to address the conflicting information that parents may receive from other parents, doctors and audiologists, and the Internet about the social, emotional, and academic benefits of learning ASL.** In other words, it is important for the Lifetrack D/HH Mentor/Role Model program (and others) to use a research-based approach that is communicated in a way that is meaningful to parents, with an awareness of and sensitivity to the messaging parents are receiving from other angles.

On the other hand, **it is important to ensure that parents do not feel judged and that mentors are providing helpful information to parents going forward based on the choices they have made.** So, for example, if a parent has decided to get a cochlear implant for their child, it may be best to consider pairing that family with a mentor who also has a cochlear implant, or who has experience with and a positive attitude toward cochlear implants.

Many parents expressed a **need for information about assistive technology**, which appears to be a gap in the current program model. (Some of this may already be provided by other resources such as audiologists, etc. but parents repeatedly cited this as a need when they were asked about their preferences for a *mentoring* program.) Lifetrack should consider providing mentoring sessions, bringing in expert speakers, or providing other resources to help families learn about and care for their child's assistive devices.

Similarly, **systems navigation (meeting the child's educational and health care needs) is an area that parents expressed a need for more information and support.** Lifetrack should consider developing mentoring sessions or resources for systems navigation. (Some of this may already be provided by other resources such as PACER, etc. but parents repeatedly cited this as a need when they were asked about their preferences for a *mentoring* program, so Lifetrack should at least consider making information or resources available on this topic via its mentors.) Lifetrack should also consider the possible role of systems navigators on staff that could serve the Lifetrack D/HH Mentor/Role Model program as well as Lifetrack's other programs.

Based on widespread agreement from the parents, Lifetrack staff, and experts who participated in this study, we recommend that Lifetrack consider **offering an array of programming for families with children of all ages. This includes ensuring that the curriculum and specific programs/sessions/activities are appropriate for different age**

**groups.** It appears that the current Lifetrack D/HH Mentor/Role Model programs do provide services to some younger and older children, but it is possible that the officially stated age limits for the program may result in some interested families not participating.

An important **disconnect was observed between the program intensity that experts and Lifetrack staff believe is needed to achieve the desired outcomes and the intensity that most parents prefer or able to accommodate within their busy lives.** Lifetrack should consider ways to make participation in the intensive program easier for families, for example the 100-sessions model. Lifetrack should also consider further evaluation to assess the level of program intensity needed to achieve the desired effect. (This would also be an important consideration for sustainability. For example, if only 12 2-hour sessions are needed to produce the desired impact and the model currently includes 25 sessions, that would be an opportunity to increase efficiency.) Once research findings are available to “prove” why fidelity to the program model is important, this message could be more effectively communicated to parents, which could ultimately increase their buy-in and willingness to participate in the full program.

Acknowledging the growing number of culturally diverse families with children who are D/HH, the JCIH 2007 supplement notes that these families are at a higher risk of being unable to access or benefit from “traditional education services,” and that there are both cultural and linguistic barriers to overcome in order to ensure access. Therefore, in addition to the recommendation below to increase the diversity of mentors, Lifetrack should consider other programmatic elements that could make the program more accessible to families that do not speak English. For example, **ensure that program materials, including outreach materials, are translated into commonly spoken non-English languages, and consider other options (such as translation services) for families who speak another language for which written translations are not provided.** Also, consider the ways in which program curriculum and activities reflect the diverse cultures (languages, religions, foods, child rearing practices, etc.) of the families being served.

## Mentors

In terms of recruiting mentors, particularly in rural areas, one of the national experts we interviewed suggested **creating full-time paid positions for mentors.** In rural Minnesota in particular, creating full-time paid positions may result in a larger pool of adults who are D/HH who are able to get involved. Further research would be needed to determine the extent of interest among adults who are D/HH in rural areas of Minnesota to participate as mentors.

*“One thing that’s helped us is being able to hire people full-time. That means that this is what they do, this is what they think about. The training is more helpful then. It’s not like we train contractors and then they leave after a bit. They’re here with us.” (National expert)*

Two experts mentioned **training for their mentors** as a strategy for program sustainability. One expert noted that keeping trainings up-to-date is important and the other expert said that they have formalized trainings. Lifetrack training workshops include the components such as best practices in mentoring, learning and language, Deaf culture and community, and education for children who are D/HH.

*"I think that we're also trying to develop more formalized trainings with our own state resources and national resources. There's a need for continued training and specific training with providing these services." (National expert)*

It is also important to note that the Joint Committee on Infant Hearing 2007 position statement supplement emphasizes **the importance of additional, specialized training that is required for someone who is fluent in ASL to become a visual language educator**. Specifically, goals 3a (Visual Language Instructors) and Goal 11 (D/HH role models). It is important that these two functions are separated in the JCIH recommendations.

The JCIH 2007 position statement supplement also emphasized the **importance of providers and mentors being unbiased in their delivery of information and services**. It appears that the best way to do this is to match mentors with a child based on mode(s) of communication. However, all Lifetrack D/HH Mentors/Role Models should receive initial training, monitoring, and re-training and on-the-job support and training to ensure their interactions with families, especially their early interactions, are supportive and affirming of the parents' choices while also providing accurate, thorough, unbiased information about all options. One expert we spoke with specifically suggested training mentors in motivational interviewing or other techniques to help draw out and understand the parents' rationale and basis for their choices about mode(s) of communication and assistive technologies, which would then help the mentors address parents' needs in a sensitive manner.

Finally, the JCIH 2007 position statement supplement recommended that **mentors should represent the diversity of the families being served** (e.g., range of hearing loss and communication methods, culture, and language). The research literature also supports these recommendations (Olson, no date). Study participants from this Lifetrack needs assessment also indicated a need for the program to recruit and hire more mentors of varying ethnicity, mode of communication, range of hearing loss, and language(s) spoken.

Along with the recommendation above to consider various program tracks or components, Lifetrack should consider **recruiting different types of mentors to serve in different capacities and in different phases/tracks to match their interests**. For example, some adults who are D/HH may need a more regular, paid position in order to be able to participate whereas others may be interested in very limited topics and/or lighter engagement with the

program, such as only being involved in sessions about cochlear implants, hearing aids, systems navigation or self-advocacy, etc.

When we asked parents about their mentoring needs, they often talked about family-to-family and parent-to-parent support (instead of, or addition to, mentoring from adults who are D/HH). Lifetrack does provide parent-to-parent support through the Minnesota Hands & Voices Parent Guide program. It is not clear if the parents who participated in this study were not aware of that program or if they are aware but the program does not meet their needs. On the other hand, they may be involved with Minnesota Hands & Voices events and activities and want more or similar opportunities from Lifetracks' other programs. The JCIH 2007 position statement supplement recommend that both parents and individuals who are D/HH be part of the development and implementation of programming, thereby providing more holistic support and information for families. In particular, the committee proposes a model that includes family-to-family support.

Lifetrack should also **consider teens who are D/HH as possible mentors** for younger children. A parent in one focus group suggested that their child may be able to relate to a mentor who is an older child rather than an adult. Teens may also be a less intimidating mentor from the parents' perspective, especially when it comes to learning ASL.

*"Having somebody older he could look up to, see this kid, and hang out with and do things together, and see that kid is a big kid and has hearing aids just like him. At that age you always look up to the big kids." (Parent of a child who is D/HH)*

## Other suggestions

**Parents expressed the need for some sort of directory of audiologists, speech therapists, doctors, and other relevant professionals.** Of note, Minnesota Hands & Voices created a services directory in 2003 and has updated it annually since then. This online directory lists state and national organizations and their websites to assist families with children who are D/HH. Minnesota Hands & Voices staff noted that this directory is not comprehensive. Minnesota Hands & Voices and Lifetrack should consider updating and expanding the directory to include a listing of professionals, books, and other resources for families who want to access information and do research on their own. (It would be important that resources are provided that reflect the diversity of perspectives regarding cochlear implants, ASL, language acquisition, etc.) Additionally, Minnesota Hands & Voices and Lifetrack should conduct more promotion around the resource directory and encourage parents to use this as they begin the Lifetrack D/HH Mentor/Role Model program.

In conclusion, while the Lifetrack program 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. It also appears that, in general, there is demand for mentoring among more families of children who are D/HH than the program currently serves.

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# Appendix

Lifetrack's principles for healthy child and family development

Study methods

Key informant interview protocol – Lifetrack staff

Key informant interview protocol – National experts

Web survey questions

Parent interview/focus group protocol, survey, consent form

Adults who are D/HH interview/focus group protocol, survey, and consent form

## Lifetrack's principles for healthy child and family development

### Principles for supporting children's safety, health, social-emotional, cognitive (developmental), and educational progress and family success: July, 2014

Lifetrack believes child and family success maximizes the potential for individuals, communities and generations. These principles frame Lifetrack's approach to Child and Family Healthy Development:

- I. Success for each child includes physical, social-emotional, cognitive, and educational development. Children with early, equal and consistent access to nurturing care, developmental opportunities, basic needs, safety and self-advocacy are prepared to overcome adversity, excel in learning and lifelong success. Fostering success for each child requires a continuum of prevention, early intervention to deep intervention based on validated strength based approaches grounded in the protective factors for healthy development and resiliency in children
- II. Success for each family includes basic needs, parenting resources, real supports, and informed access and choices. Children are the beneficiaries of all work with adults and families. Every family has the ability to vision and achieve their unique goals and aspirations. Strengthening families requires cross-generational approaches, culturally affirming practices and mentorship through side-by-side partnership building knowledge, skills and confidence for self-advocacy, action and greater functionality grounded in the protective and risk reduction factors for families.
- III. Success for each community includes investment and opportunities for each family and child. Communities are the beneficiaries of all our work with children and families. Successful communities embrace and empower the unique potential of all families and children in all facets of community life - economic, cultural, civic, education and employment. Supporting resiliency and highly functioning families and children is the best strategy for economic success and for avoiding the public and individual burdens of remediation such as educational failure, crime, unemployment, medical and mental health crisis, and violence. Healthy communities embrace true investment in families and children and appreciate the generational impact of actions and decisions.

Child and Family Healthy Development approaches and resources are built on these above principles and include the following in their design and goals:

1. Protective factors for healthy development and resiliency in children:
  - A relationship with a caring, responsive adult outside the family
  - Ability to communicate needs appropriately
  - A sense of self-worth and empowerment
  - A full range of affect and healthy expression

- Empathy for self and others
  - Opportunities for play and exploration
  - Ability to accept and provide nurturing
  - Positive peer relationships
  - Stability during family crisis with access to support
  - Self and Family advocacy and empowerment to act
  - An understanding that any maltreatment she/he experienced is wrong
  - Understanding of the reason for any family difficulty
2. Protective and risk reduction factors for families:
    - Parental resilience: The ability to cope and bounce back from all types of challenges – economic, health, emotional, etc.
    - Social connections: Friends, family members, neighbors, and other members of the community who provide emotional support and concrete assistance to parents from education, to prevention to early and crisis intervention needs.
    - Knowledge of parenting and child development: Accurate information about raising children and appropriate expectations for their behavior.
    - Concrete support in times of need: Financial security to cover day-to-day expenses and unexpected costs that come up from time to time, access to formal supports like TANF, health insurance, Medicaid, and informal support from social networks
    - Nurturing and attachment: A child’s early experience of being nurtured and developing a bond with a caring adult affects all aspects of behavior and development
  3. Individualized and flexible services to meet the needs of each child and family verses a prescribed case management approach based on child/adult (staff) relationship
  4. Relationship-based attachment as the core approach in serving at-risk children and families with customization based on deep knowledge of evidence based methods and best practices.
  5. Research, measurement of results and adjustment in practices based on the proven benefits to children and families
  6. Culturally affirming, respecting families’ values, culture and experiences.
  7. Building from and growing the strengths of the child and family
  8. Support for parents as a child’s first teacher and care giver
  9. Adequate intensively engaging both child and parent/caregiver together
  10. Use of integrated/cross discipline team
  11. Enriching and improving the quality of individual and family life by providing information, skills, experiences and resources intended to strengthen, improve, or enrich their family experience.
  12. Focusing on healthy family functioning within a family systems perspective and providing prevention to intervention approach to health and well-being.

## Study methods

This Appendix describes in detail how we gathered information to answer the following research questions:

- What types of services provided by trained D/HH Adult Mentors/Role Models do families of children who are D/HH want that may or may not be currently available to them?
- Who are the current recipients of D/HH Adult Mentor/Role Model services? Who will be the recommended recipients of the expanded services?
- How do families want to receive information about these programs and services?
- How do families prefer that these services are delivered? Do families prefer one-on-one methods, group methods, in person, via technology, or a combination of these?
- What are things that work and do not work for families of children who are D/HH in this and similar D/HH Adult Mentor/Role Model programs and services in terms of recruiting, securing full participation, and participant satisfaction? In other words, what are best practices for these types of programs and services, and what organizational capacities are necessary to be able to implement them? What kinds of outcomes can be expected from programs that use best practices?
- How do the needs and preferences of families vary by geographic region of Minnesota? In particular, what is the role of technologies to serve families who are located in more remote parts of greater Minnesota?
- What are the unmet mentoring and language/culture support needs among families with children who are D/HH? What are the challenges to accessing appropriate services provided by D/HH Adult Mentors/Role Models?
- What are the critical cultural issues that should be considered when developing programs and services for the target population?
- What are the recommendations for program sustainability and expansion of the D/HH Adult Mentor/Role Model program?

We worked with an Advisory Committee that provided advice about all aspects of the project. We gathered input from national experts on D/HH mentoring, Lifetrack staff, adults who are D/HH, and parents of children who are D/HH.

## *Advisory Committee*

The needs assessment was guided by an Advisory Committee comprised of individuals from the D/HH community, including parents of children who are D/HH and professionals (teachers and other professionals who work with children who are D/HH). See Figure A1. Of the 21 Advisory Committee members, 10 are adults who are D/HH. (See the list of Advisory Committee members in the Acknowledgements.)

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### **A1. Advisory Committee members' characteristics**

|                                  |           |
|----------------------------------|-----------|
| State Agencies                   | 6         |
| Lifetrack/MNHV                   | 5*        |
| Parents of children who are D/HH | 5         |
| Schools                          | 5         |
| <b>Total</b>                     | <b>21</b> |

*\* 3 of which are involved in the Deaf Mentor Program*

The Advisory Committee met once during the design phase, once as data collection was getting underway, and once at the end to review a draft of the final report and provide feedback. A subgroup of the Advisory Committee also met once with Wilder during data analysis to review our analysis framework and to advise us on key themes and interpretation of the data. A key purpose of the Advisory Committee was to ensure that the study was inclusive, respectful, and appropriate for the community's needs. The Advisory Committee included 48 percent of members who are D/HH themselves, and who represent a range of experiences and communications preferences found in the D/HH population.

Because the Advisory Committee only met a few times, there was also a Core Group of study advisors from Lifetrack and the two state agencies (MDH and DHHSD) who funded this study and the D/HH Mentor/Role Model programs that Lifetrack currently operates. This Core Group advised Wilder on day-to-day project decisions and provided their approval for all stages of the project.

### ***Literature review and field scan***

Wilder Research conducted a literature review and field scan to explore best practices, characteristics of other D/HH mentoring programs, barriers to participation in these types of programs, program outcomes, and organizational strategies of other programs in the United States and internationally. Literature searches were performed by Wilder Research staff librarians, covering peer-reviewed journals as well as organization-based publications and web sites. Wilder Research staff reviewed the literature to synthesize common characteristics and best practices of D/HH mentoring programs. In particular, there is a dearth of research regarding mentorship and any other types of communication and assistive technologies/modalities other than ASL or sign language across the board; this includes barriers, best practices, outcomes, and how to include these modalities in D/HH mentoring programs. (In other words, most of the literature focuses on mentoring programs that are designed for the primary purpose of ASL instruction. Published research was not available about D/HH mentoring programs for individuals who are hard of hearing or other types of hearing loss, and about programs that are focused on topics other than ASL.) Results of the literature review are summarized throughout the report. See the Bibliography for a full list of sources reviewed.

### ***Review of secondary data***

Wilder Research obtained summary data from the Minnesota Department of Health Early Hearing Detection and Intervention (EHDI) database about the population of young children in Minnesota who are D/HH, including their county of residence, type and severity of hearing loss, age hearing loss was first identified, and demographic characteristics of the mother. We also received data from the Minnesota Department of Education Part C and Part B Early Interventions programs about children they serve who are D/HH.

### ***Key informant interviews***

National experts were identified by requesting suggestions from our Advisory Committee as well as through a scan of the field for relevant experts and organizations. They were then contacted via email and phone to request an interview; all interviews were conducted by Wilder Research staff. Wilder Research invited national experts with a variety of programmatic experience who worked different types of D/HH issues. The national experts that were available for interviews come primarily from programs that are strongly ASL-focused. Wilder Research attempted to contact experts from the HH community and others, however, these individuals were unable to participate. Eight Lifetrack staff who were involved with the D/HH Mentor/Role Model programs and five Minnesota Hands & Voices Parent Guides were also interviewed. Of note, we grouped all Lifetrack staff together in the report and identified them as such.



However, the authors recognize that not all of the experiences or viewpoints of staff align across the various Lifetrack programs. A total of six national experts and 13 Lifetrack key informants were interviewed. Their responses were coded for themes and are incorporated into the Key Findings. See the Appendix for the key informant interview protocols.

### ***Web survey with parents of children who are deaf and hard of hearing***

By coordinating with Lifetrack’s Minnesota Hands & Voices database, 1,097 families with children who are D/HH were invited to participate in a web survey through a letter sent by Lifetrack with an invitation and link to the web survey. The link and invitation were also posted on social media, and Advisory Committee members were asked to distribute the link to their social and professional networks. The web survey questions asked dealt with parent perspectives of mentoring, as well as parents’ experiences with formal and informal mentoring.

Respondents were mainly the biological parents of a child who is D/HH (95%) and the remainder (5%) were adoptive parents or caregivers. Nearly all respondents (96%) were female, which supports the anecdotal observations of some interview and focus group participants that women are more involved than men in dealing with their child’s hearing loss. Non-white parents represented less than 30% of the sample, and 93% of respondents said that English was the primary language spoken in their home.

Most respondents had one child with hearing loss (92%); none of the respondents had more than two children with hearing loss. (We targeted hearing parents of children who are D/HH to participate in this study.) Most of these children (78%) were diagnosed with hearing loss by the time they were 6 months old. See Figure A2.

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#### **A2. Age at which hearing loss was first identified among the children who are D/HH whose parents completed the web survey (N=99)**

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|                 |     |
|-----------------|-----|
| At birth        | 63% |
| 0-6 months old  | 15% |
| 7-12 months old | 4%  |
| 1-2 years old   | 8%  |
| 3-5 years old   | 10% |

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The web survey also included some open-ended questions, mainly regarding the most significant benefits and barriers to participation in a mentor program. These responses were coded for themes and analyzed along with the other web survey data. See the Appendix for the web survey questions; data tables of raw results are available upon request.

### ***Interviews and focus groups with adults who are deaf and hard of hearing***

As a part of this needs assessment, Wilder Research conducted interviews and focus groups with 51 adults who are deaf and hard of hearing (D/HH). The interview and focus group instruments included questions about respondent experiences with their own hearing loss, mentor program set-up, and perspectives of benefits and barriers to mentor programs. See the Appendix for the interview/focus group protocol and consent form.

All but one of the 31 individual interviews were conducted by Aaron Gutzke, an independent contractor who was hired for this project. The interviews were conducted in ASL using video chat.

Two focus groups were conducted with adults who are D/HH; one in greater Minnesota and one in the metro area. Participants were recruited through the social and professional networks of our Advisory Committee members, as well as by reaching out to relevant organizations. Half of these respondents were ASL users and half communicated with spoken English as their primary language. The groups were facilitated by Wilder Research staff. Both focus groups included ASL interpretation by two contractors. Focus groups were audio recorded for accuracy after receiving verbal consent from participants.

Interviewees were asked a brief series of questions about their hearing loss at the start of the interview; focus group participants were likewise asked to fill out a paper version of the same survey before the start of the focus group. Aside from these initial survey questions, the interviews consisted of open-ended questions and which were coded for common themes, discussed in the Key Findings section. See Figure A3.

**A3. Hearing loss characteristics of the adults who are D/HH who participated in this study (N=51)**

| <b>Type of hearing loss</b>                         | <b>Number of respondents*</b> |
|---|-------------------------------|
| Bilateral hearing loss                              | 50                            |
| Unilateral hearing loss                             | 1                             |
| Mild to moderate hearing loss                       | 3                             |
| Severe/profound hearing loss                        | 48                            |
| <b>Age hearing loss was first identified</b>        | <b>Number of respondents*</b> |
| Birth to age 3                                      | 27                            |
| Ages 3 and 4  | 18                            |
| After age 4   | 20                            |
| <b>Mode of communication/assistive technologies</b> | <b>Number of respondents*</b> |
| Spoken/oral language (English or other language)    | 12                            |
| American Sign Language (ASL)                        | 39                            |
| Signed English                                      | 10                            |
| Pidgin Signed English                               | 32                            |
| CART captioning                                     | 24                            |
| Lip reading   | 45                            |
| Cochlear implants                                   | 17                            |
| Hearing aids  | 32                            |

**\*Note.** The responses do not add up to 51 total because response options were not mutually exclusive (i.e., respondents could mark more than one response) and not all respondents answered every question.

## ***Interviews and focus groups with parents of children who are deaf and hard of hearing***

As a part of this needs assessment, Wilder Research conducted interview and focus groups with 47 parents of children who are deaf and hard of hearing (D/HH). Most parents interviewed had young children under the age of six (See Figure A5). All but five reported that they learned of their child's hearing loss either at the newborn hearing screening or shortly thereafter (within the first six months of the child's life). The interview and focus group instruments included questions about respondent experiences with their child's hearing loss, formal and informal experiences with mentoring, perspectives of benefits and barriers to mentor programs, and preferences for mentor program content and structure. See the Appendix for the interview/focus group protocol and consent form. Aside from the initial survey questions, the interviews consisted of open-ended questions and were then coded for common themes, which are discussed in the Key Findings.

All 14 individual interviews were conducted over the phone by Wilder Research.

Four focus groups were conducted by Wilder Research with 33 parents of children who are D/HH; two in Greater Minnesota and two in the Twin Cities metro area. Participants were recruited through two means: web survey referrals and networking via our Advisory Committee and other formal and informal parent-to-parent networks and organizations that serve these families. Web survey respondents were asked if they would like to participate in an interview or focus group, and participants were recruited in this way. Focus groups were audio recorded for accuracy after receiving verbal consent from participants.

Of the families who responded to the question asking about their primary or preferred language used to communicate with their child, a majority (36 out of 47 respondents) cited spoken language only; in some cases, this was Spanish or Somali; five parents reported ASL as their primary language only, with four parents indicating that they use both spoken language and ASL with their child. See Figure A4.

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**A4. Hearing loss characteristics of the children whose parents participated in a focus group or interview (N=47)**

| <b>Type of hearing loss</b>                         | <b>Number of respondents*</b> |
|---|-------------------------------|
| Bilateral hearing loss                              | 39                            |
| Unilateral hearing loss                             | 6                             |
| Mild to moderate hearing loss                       | 17                            |
| Severe/profound hearing loss                        | 27                            |
| <b>Mode of communication/assistive technologies</b> | <b>Number of respondents*</b> |
| Spoken/oral language (English or another language)  | 36                            |
| American Sign Language (ASL)                        | 23                            |
| Signed English                                      | 5                             |
| Pidgin Signed English                               | 4                             |
| Cued speech   | 1                             |
| Lip reading   | 8                             |
| Cochlear implants                                   | 11                            |
| Hearing aids  | 36                            |

*\*Note.* The responses do not add up to 47 total because response options were not mutually exclusive (i.e., respondents could mark more than one response) and not all respondents answered every question.

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**A5. Characteristics of children who are D/HH whose parents participated in a focus group or interview (N=47)**

| <b>Age of child now</b>          | <b>Number of respondents*</b> |
|----------------------------------|-------------------------------|
| Ages 0-5                         | 22                            |
| Ages 6-9                         | 9                             |
| Ages 13-18                       | 5                             |
| <b>Age of child at diagnosis</b> | <b>Number of respondents*</b> |
| From birth to 6 months           | 27                            |
| At age 3 or 4                    | 5                             |

*\*Note.* The responses do not add up to 47 total because not all respondents answered every question.

### ***Data analysis, synthesis, and making recommendations***

Wilder Research completed the analysis and triangulation of information from all of these sources to produce this needs assessment report. We used open coding to analyze the interview and focus group transcripts. Open coding involves identifying the key themes within the respondents' own words, instead of starting the analysis process with a pre-defined set of analysis themes or codes. This approach allowed us to identify the key themes and most important results from the participants' perspectives. We use descriptive statistics such as frequencies (the number and percent of respondents who gave each response) to indicate the relative prevalence of each finding.

In this report, we synthesize the key themes that were identified through this process, and we also use quotes from participants to illustrate these themes.

Through an iterative process, we communicated the key themes to various project stakeholders including the independent consultant Aaron Gutzke who conducted many of the interviews with adults who are D/HH, the Core Group, the Advisory Committee, and analysis subcommittee of the Advisory Committee. We worked with these project stakeholders to solidify the recommendations included in this report.

## Lifetrack key informant interview protocol – Lifetrack staff

### ***Introduction***

Greetings! My name is \_\_\_\_\_ (name of interviewer) and I am from Wilder Research. Our company was hired by Lifetrack to conduct a needs assessment for families with young children (age 0-6) who are Deaf or Hard of Hearing (D/HH) in Minnesota. As part of our work, we are conducting key informant interviews with people who have key expertise and experience relevant to D/HH mentor and role model programs and services. Because of your work with Lifetrack, you were identified as one of these people. Your responses to this interview will be confidential. They will be combined with the responses from other key informants and analyzed for themes. Quotations, if used, will be edited so that the speaker is not identifiable. Is now still a good time for the interview? [CONTINUE OR RESCHEDULE]

### ***Introductory questions***

1. To begin, what is your role with Lifetrack?
2. How long have you [worked/volunteered] there?

### ***Service and Mentorship Needs***

Now, I'd like to ask you a few questions about the needs of families with young, D/HH children and hearing parents/caregivers.

3. When a young child (age 0-6) is identified as D/HH and has parents/caretakers who do not have a hearing loss, what are the most important mentoring and role model needs for the child?
4. Typically, what are the parents'/caretakers' biggest needs and concerns?

### ***Mentor Program: Specific components***

The next questions are about the Lifetrack Deaf Mentor Program, specifically.

5. What is working well for the Lifetrack Deaf Mentor Program regarding recruiting, training, and retaining mentors?
  - a. What do you think has been challenging about these activities?
6. What is working well for the Lifetrack Deaf Mentor Family Program regarding recruiting and retaining families with young, D/HH children?

[PROBE about:

  - Families who use various modes of communication – ASL, cued speech, lip reading, hearing aids, cochlear implant, etc.
  - Families with young children age 0 – 6
  - Families around Minnesota, including rural areas
  - Diverse families, including those who are not white and those who speak a language other than English as their primary home language]
  - a. What do you think makes recruiting and retaining families challenging?

[PROBE about:

- Families who use various modes of communication – ASL, cued speech, lip reading, hearing aids, cochlear implant, etc.
  - Families with young children age 0 – 6
  - Families around Minnesota, including rural areas
  - Diverse families including those who are not white and those who speak a language other than English as their primary home language]
- b. As far as you know, what, if anything, has Lifetrack done, to address the challenges of recruiting or retaining mentors and families?
- c. Are there certain types of families Lifetrack is particularly successful at recruiting and retaining?
7. As you likely know, the Lifetrack Deaf Mentor Family Program serves D/HH children and their families with varied experiences and backgrounds. Please tell me what you see as the success and challenges Lifetrack is having serving each of the following groups I name. [PROBE ABOUT successes and about challenges for each group)
- a. Families who use various modes of communication – ASL, cued speech, lip reading, hearing aids, cochlear implant, etc.
  - b. Families with young children age 0 – 6
  - c. Families around Minnesota, including rural areas
  - d. Diverse families including those who are not white and those who speak a language other than English as their primary home language
8. What, if anything, has Lifetrack done to address the challenges related to working with the groups we just discussed?
9. Are there certain types or groups of families that the Lifetrack Deaf Mentor Family Program serves especially well?

### ***Mentor Program Overall***

Lastly, I have a few questions about mentorship programs overall.

10. What features or practices does a D/HH mentor program need to have in order to be effective with young D/HH children and their families? [PROBE regarding type, intensity and duration of services]
- a. Thinking specifically about families who are not using ASL as their primary mode of communication with their child, are there any different features or practices that are important for services to be effective?
11. What barriers make it difficult for families with young D/HH children to participate in a D/HH mentor program?
- b. Again, thinking specifically about families who are not using ASL as their primary mode of communication with their child, how are the barriers different, if at all?

That was the last of my questions. Do you have anything else you want to say about mentorship programs for D/HH young children and their families? Thank you so much for your time!



## Key informant interview protocol – National experts

### ***Introduction***

Greetings! My name is \_\_\_\_\_ (name of interviewer) and I am from Wilder Research. Our company was hired by Lifetrack to conduct a needs assessment for families with young children (age 0-6) who are Deaf or Hard of Hearing (D/HH). As part of our work, we are conducting key informant interviews with people who have key expertise and experience relevant to our research questions. Because of your work with [Name of organization/Program], you were identified as one of these people. Your responses to this interview will be confidential. They will be combined with the responses from other key informants and analyzed for themes. Quotations, if used, will be edited so that the speaker is not identifiable.

Is now still a good time for the interview? [CONTINUE OR RESCHEDULE]

### ***Introductory questions***

#### ***[FOR EVERYONE]***

1. What is your role in [Name of organization/Program]?
2. How long have you work worked with [Name of organization/Program]?

#### ***[FOR KII WHO DON'T NECESSARILY WORK WITH D/HH CHILDREN AND THEIR FAMILIES]***

3. How often, if at all, does your organization serve children who are D/HH or their families?

### ***Service and Mentorship Needs***

#### ***[FOR EVERYONE]***

Now, I'd like to ask you a few questions about the needs of families with young, D/HH children and hearing parents/caregivers.

4. What services and/or program does [Name of Organization/Program] offer to families of young children who are D/HH? [PROBE, if needed to ensure they still operate a D/HH mentorship program]
5. When a young child (age 0-6) is identified as D/HH and has parents/caretakers who do not have a hearing loss, what are the most important mentoring and role model needs for the child?
6. Typically, what are the parents'/caretakers' biggest needs and concerns?

### ***Mentor Programs***

#### ***[ONLY FOR KEY INFORMANTS WITH A DEAF MENTOR PROGRAM]***

The last set of questions is about D/HH mentorship programs.

7. What features or practices does a D/HH mentor program need to have in order to be effective with young D/HH children and their families? [PROBE regarding type, intensity and duration of services]

- a. Thinking specifically about families who are not using ASL as their primary mode of communication with their child, are there any different features or practices that are important for services to be effective?
8. What barriers make it difficult for families with young D/HH children to participate in a D/HH mentor program?
  - a. Again, thinking specifically about families who are not using ASL as their primary mode of communication with their child, how are the barriers different, if at all?
9. How have you addressed these barriers with families who do use ASL as their primary means of communication with their child and with families who do not?
10. What are the benefits to D/HH children and their families of participating in a D/HH mentor program, if any?
11. What negative consequences or experiences might D/HH children and their families have from the D/HH mentor program?
12. For D/HH children and families who do not participate in a D/HH mentor program, what might be the negative consequences?
13. What strategies is your organization using to help ensure the continuation of its D/HH mentor program?  
[PROBE RE: funding, policies, infrastructure, external supports, other types of resources]
  - a. What, if anything, has worked well in regard to those strategies?
  - b. What, if anything, continues to be challenging as you work to ensure the future of the program?

That was the last of my questions. Do you have anything else you want to say about mentorship programs for D/HH young children and their families?

Thank you so much for your time!

## Web survey questions

You are invited to participate in the following web survey. It is part of a needs assessment (research study). The study is being conducted by Wilder Research on behalf of Lifetrack, the Minnesota Department of Health (MDH), and the Minnesota Department of Human Services (DHS). The survey will take about 10 to 15 minutes to complete.

As the parent of a child who is Deaf or Hard of Hearing (D/HH), you will be asked several questions. The questions will focus on your experiences and needs related to mentor and/or role model programs for families with younger children who are D/HH.

Adult mentor/role model programs focus on the communication needs of families with children from birth to age 6 who are D/HH. Assistance to families is provided by adults who are D/HH. These adults are trained to serve as mentors and role models to the families. They provide instruction in communication strategies and other related resources.

### What is the purpose of this study?

The purpose of this needs assessment is to better understand the needs and preferences of families. It will focus on families across Minnesota who have young children (age 0-6) who are Deaf/Hard of Hearing (D/HH). We will use this information to help improve the quality of the current D/HH Adult Mentor/Role Model Program. The goal is to expand the program to better serve all families with young children who are D/HH.

Your participation is **voluntary**. Your decision whether or not to participate, and your responses if you do participate, will not affect your relationship with Lifetrack, MDH, DHS, or any other project partner. **Refusal to participate in the study or leaving the study early will involve no penalty or loss of benefits to which you are entitled.**

Your participation is **confidential**. We will never use your name or any other identifying information in any reports. Only Wilder Research staff/consultants will see your identifying information. Lifetrack, MDH, and DHS staff will not see any identifying information. Your responses and the responses of other participants will be analyzed together to understand key themes and findings. These will be used to make recommendations for program improvement and expansion. (We may use your comments in study reports as long as they do not identify you.)

### What are the risks of participating in this study?

There are minimal risks related to study participation. Some of the survey questions might make you feel uncomfortable. You do not have to answer any questions with which you are uncomfortable.

One risk to you is that we could accidentally reveal your personal information. Wilder Research treats all data with a high level of security. We will always take measures to ensure confidentiality. Only staff directly involved with the project will have access to electronic/paper records. Your identifying information, such as your name and address, will be stored in a separate file from your responses during the focus group/interview. It is very unlikely that your information will be released accidentally. However, if it is, Wilder Research will notify you immediately.

## Benefits to you

The only benefit to you from participating in this study is that you may contribute information that will result in improved services. By improving services, Lifetrack can better meet the needs of all families with young children who are D/HH in Minnesota.

## Compensation

At the end of the survey, you will be given an opportunity to enter a drawing. You will have a chance to win one of five \$100 Visa gift cards. (Only one completed survey per household please.)

## Who to contact for more information

If you have questions about your participation in this research study, please contact Sera Kinoglu from Wilder Research. She can be reached at 1-888-328-2972 or [sera.kinoglu@wilder.org](mailto:sera.kinoglu@wilder.org). For questions about your rights as a participant in this research, contact Peter Rode, Administrator of the Minnesota Department of Health Institutional Review Board. He can be reached at 651-201-5942.

## *Participation in D/HH role model/mentor programming*

1. Did your family participate in the Lifetrack Deaf/Hard of Hearing (D/HH) Adult Role Model/Mentor program?
  - Yes
  - No [**SKIP TO 2A**]

### **IF YES TO Q1...**

1a) Please indicate how well the Lifetrack D/HH Adult Role Model/Mentor program met your family's needs, on a scale from "0 = the program did not meet any of our mentoring needs" to "10 = the program met all of our mentoring needs."

0   1   2   3   4   5   6   7   8   9   10

- 1b) What were the biggest benefits of participating in the Lifetrack D/HH Adult Role Model/Mentor program?  
**[open end]**
- 1c) Was there anything about the program itself that made it really difficult to participate in the Lifetrack D/HH Adult Role Model/Mentor program?  
**[open end]**
- 1d) Was there anything about your family and what is going on in your lives that made it really difficult to participate in the Lifetrack D/HH Adult Role Model/Mentor program?  
**[open end]**
- 1e) What are three things Lifetrack could do to make the D/HH Adult Role Model/Mentor program better meet the needs of families like yours?

**[open end]**

1f) In your opinion, how well does the Lifetrack D/HH Adult Role Model/Mentor program meet the needs of families...

|   | The program fully meets these needs | The program partially meets these needs | The program does not address these needs | Not sure |
|---|-------------------------------------|---|--|----------|
| Who use visual language – ASL, Signed English, Pidgin Signed English (mixed with ASL)             |                                     |   |  |          |
| Who use visual tools and resources (Cued Speech, lip reading, etc.)                               |                                     |   |  |          |
| Who use assistive technology information (cochlear implants, hearing aids, CART captioning, etc.) |                                     |   |  |          |
| Who use other communication strategies and resources, specify: _____                              |                                     |   |  |          |
| With young children, ages 0-6   |                                     |   |  |          |
| With children that have co-occurring disabilities   |                                     |   |  |          |
| Who live in rural parts of Minnesota  |                                     |   |  |          |
| Who speak languages other than English at home  |                                     |   |  |          |

**[CONTINUE TO Q3]**

**IF NO TO Q1...**

2a) What were some of the reasons you did not participate in Lifetrack’s D/HH Adult Role Model/Mentor program? Check all that apply.

- I was not aware of this program
- This program was not available in the area where I live
- This program was not available at a time/date that was convenient for my family
- This program did not offer support for the communication modes/tools/assistive technologies that we use for our child
- I was told that this program would not be a good fit for my family
- I had a negative initial experience with the program
- We had other family or work responsibilities that prevented us from participating in the program
- The program does not meet our needs due to co-occurring disabilities in our child(ren)
- Other, please specify: \_\_\_\_\_

2b) What could Lifetrack do to encourage and assist families like yours to participate in the D/HH Adult Role Model/Mentor program?

**[open end]**

3. Did you seek out D/HH adult mentors or role models on your own (separate from Lifetrack’s program)?

- Yes
- No

4. Where have you gone to seek advice about how to help and support your child(ren) who are D/HH? Please check all that apply.
- Audiologists
  - Deaf/hard of hearing/hearing loss websites or social media networks, specify: \_\_\_\_\_
  - Doctors/health care providers
  - Other parents of D/HH children, through a formal network, specify: \_\_\_\_\_
  - Other parents of D/HH children, informally
  - D/HH adults who are not a part of a formal mentoring program
  - Other organizations, specify: \_\_\_\_\_
  - Teachers who work specifically with children who are D/HH
  - Other teachers
  - Other, specify: \_\_\_\_\_

***Program characteristics***

The next set of questions asks about the characteristics of a D/HH Adult Role Model/Mentor program to meet your family’s needs and preferences. **When you are answering these questions, think back to the time when your child’s hearing loss was first identified, and imagine that you had an adult who was D/HH to provide mentoring and support to you and your child...**

5. What kinds of information, experiences, and interactions would you hope to gain from a D/HH adult mentor/role model? For each item, please indicate if this is extremely important, very important, somewhat important, not too important, or not at all important to your family.

|   | <b>Extremely important</b> | <b>Very important</b> | <b>Somewhat important</b> | <b>Not too important</b> | <b>Not at all important</b> |
|---|----------------------------|-----------------------|---------------------------|--------------------------|-----------------------------|
| Visual language education – ASL, Signed English, Pidgin Signed English (mixed with ASL)                             |                            |                       |                           |                          |                             |
| Visual tools and resources (Cued Speech, lip reading, etc.)   |                            |                       |                           |                          |                             |
| Assistive technology information (cochlear implants, hearing aids, CART captioning, etc.)                           |                            |                       |                           |                          |                             |
| Other communication strategies and resources (self-advocacy, survival tips, etc.) that will benefit your D/HH child |                            |                       |                           |                          |                             |
| Deaf culture and introduction of the family to the local Deaf community   |                            |                       |                           |                          |                             |
| Self-esteem and positive identity development for your D/HH child   |                            |                       |                           |                          |                             |
| Sharing experiences and overcoming pre-conceptions about hearing loss and D/HH individuals                          |                            |                       |                           |                          |                             |

6. In addition to the items noted in the previous question, does your family have any additional needs that could be addressed by a D/HH adult mentor/role model or another similar program or service?  
**[open end]**
7. What is the best place or method for your family to have meetings and interactions with a D/HH adult role model or mentor? Please rank your top 3 choices.
- In person, at our home
  - In person, at another location, such as your child's school, doctor's office, or another setting in the community (coffee shop, library, etc.)
  - Skype or other visual web-meeting technology or videophone
  - Other, please specify: \_\_\_\_\_
8. How often did you want a D/HH adult role model/mentor to meet with your family initially?
- Daily or nearly every day
  - Once or twice per week
  - Once or twice per month
  - Several times per year
  - Once or twice per year
9. How much time did you want the D/HH adult role model/mentor spend with your family at each visit?
- Less than 30 minutes
  - 30 minutes-1 hour
  - 1-2 hours
  - More than 2 hours
10. How long did you want the D/HH adult role model/mentor program to last?
- Less than 3 months
  - 3-6 months
  - 7 months-1 year
  - 1-2 years
  - 3-4 years
  - 5 years or more

11. How do you hear about new programs or services available for your D/HH child(ren)?
- Audiologists
  - Deaf/hard of hearing/hearing loss websites or social media networks, specify: \_\_\_\_\_
  - Doctors/health care providers
  - Other parents of D/HH children, through a formal network, specify: \_\_\_\_\_
  - Other parents of D/HH children, informally
  - D/HH adults who are not a part of a formal mentoring program
  - Other organizations, specify: \_\_\_\_\_
  - Teachers who work specifically with children who are D/HH
  - Other teachers
  - Other, specify: \_\_\_\_\_

***Serving all families in the D/HH community***

These next questions ask about how a new program could best serve all families in the D/HH community.

12. What is one thing that a new D/HH adult role model/mentor program could do to better serve families...
- a. Who use visual language education – ASL, Signed English, Pidgin Signed English (mixed with ASL)?  
**[open end]**
  - b. Who use visual tools and resources (Cued Speech, lip reading, etc.)?  
**[open end]**
  - c. Who use assistive technology information (cochlear implants, hearing aids, CART captioning, etc.)?  
**[open end]**
  - d. With young children, ages 0-6? **[open end]**  
**[open end]**
  - e. With children that have co-occurring disabilities?  
**[open-end]**
  - f. Who live in rural Minnesota communities?  
**[open end]**
  - g. Who speak languages other than English at home?  
**[open end]**
13. What is the one thing that would help the most to meet your family’s mentoring or support needs?  
**[open end]**



## General information

Now, for some questions about you and your family. Remember, your answers are confidential...

14. How many children do you have living in your household?

- 1
- 2
- 3
- 4
- 5
- 6 or more

15. How many of these children have hearing loss?

- 1
- 2
- 3
- 4
- 5
- 6 or more

16. What label do you use for your child?

- Deaf / deaf
- Hard of hearing
- Unilateral hearing loss
- Other, specify: \_\_\_\_\_

17. At what age was this child (were these children) diagnosed with a hearing loss? (Provide a drop down box for each child that is D/HH)

- At birth
- 0-3 months old
- 4-6 months old
- 7-9 months old
- 10-12 months old
- 13-15 months old
- 16-18 months old
- 19-21 months old
- 22-24 months old
- 3 years old
- 4 years old
- 5 years old
- 6 years old or older

18. What types of communication mode(s), tools, and assistive technologies does your family use? Check all that apply.

- American Sign Language (ASL)
- Signed English
- Pidgin Signed English (mixed with ASL)
- Cued speech
- Lip reading
- Cochlear implants
- Hearing aids
- CART captioning
- None of the above
- Other, specify: \_\_\_\_\_

19. Are you...

- Male
- Female
- Other

20. What is your age?

- Under 18
- 18-24
- 25-34
- 35-44
- 45-54
- 55 and older

21. What is your race/ethnicity? Check all that apply.

- African American/Black
- African-born
- American Indian/Alaska Native
- Asian
- Hispanic/Latino
- Native Hawaiian or Pacific Islander
- White/Caucasian
- Other, specify: \_\_\_\_\_

22. What is your marital status?

- Married or living with a partner
- Single, divorced, separated, or widowed
- Other, please specify: \_\_\_\_\_

23. What is the primary language spoken in your home?
- English
  - Spanish
  - Hmong
  - Somali
  - Other, specify: \_\_\_\_\_
24. Do you have access to reliable transportation?
- Yes
  - No
25. Which of the following best describes your current work situation?
- Working full-time
  - Working part-time
  - Stay-at-home parent
  - Currently unemployed, but actively seeking work
  - Other, please specify: \_\_\_\_\_
26. How many times did your family move during the past 12 months?
- 0
  - 1
  - 2
  - 3 or more times
27. What is your zip code? \_\_\_\_\_
28. What was your total household income before taxes in the past year?
- Less than \$19,999
  - \$20,000-\$34,999
  - \$35,000-\$49,999
  - \$50,000-\$74,999
  - \$75,000-\$99,999
  - \$100,000 or more

**Thank you very much for taking the time to fill out this survey! The answers to these questions will help to improve and expand the Lifetrack Deaf/Hard of Hearing Adult Role Model/Mentor Program. We have some additional opportunities for you to participate in this study below.**

***Enter a drawing***

**Parents who complete this survey are eligible to be entered into a drawing for one of five \$100 Visa gift cards.**

Would you like to be entered into this drawing? Only one completed survey/entry per household please.

Yes → Please provide your name and contact information at the bottom of this page.

No

***Participate in a focus group or individual interview***

Wilder Research will be conducting several focus groups and individual interviews with parents of children who are D/HH around the state of Minnesota over the next several months. This will be done to better understand the results of this survey and will help to expand the Lifetrack Deaf/Hard of Hearing Adult Role Model/Mentor program. **As a participant in one of these focus groups/interviews, you would receive a \$25 gift card to thank you for your time.** Are you interested in participating?

Yes → Please provide your name and contact information at the bottom of this page. Note that indicating your interest in participating does not guarantee that we will contact you to participate (we need to wait and see how many people sign up).

No → We will not contact you about being in a focus group.

|                  |        |
|------------------|--------|
| Your name:       |        |
| Mailing address: |        |
| Phone number:    | Email: |

*NOTE: Your personal contact information will not be connected with your survey responses.*

## Parent interview/focus group protocol, survey, consent form

### Parent Focus Group Protocol

#### **Introduction**

Greetings! My name is \_\_\_\_\_ (name of facilitator) and this is \_\_\_\_\_ (introduce note takers, interpreters, etc.) We are from Wilder Research. Our company was hired by Lifetrack to do a needs assessment for families with young children (age 0-6) who are Deaf or Hard of Hearing (D/HH).

**Before we begin, I'd like for everyone to fill out this brief form about your child's hearing loss.**

First, let's review the consent form that describes the study and your participation, and then I'll give you a chance to ask questions.

#### *Instructions for facilitator:*

- Go over the main points (bolded text) and give them a chance to read the consent form (5 min.)
- Take and answer questions (or defer the questions to those listed on the consent form if you are not able to answer them).
- Get everyone's signed consent form before proceeding.

Now, let's quickly go over the ground rules for this conversation: *(list on flip chart)*

- Please participate actively and allow others to do so as well.
- Be respectful of others' opinions and decisions.
- We'll keep your information confidential. Please do the same for each other.
- Eating during the discussion is fine.
- We will not be taking any official breaks, but we will end on time, at \_\_\_\_\_.
- The restrooms are located \_\_\_\_\_.
- Others?

Describe purpose of note taker and recorder *(to use as back-up in case we miss anything in the notes – we want to record your thoughts accurately)* and ask everyone's permission to turn it on.

Agenda for the focus group *(list on flip chart)*

- Your child's and family's characteristics and mentoring needs
- Your family's experience with mentors & role models
- Challenges to participating in mentoring programs
  - Program characteristics & accessibility
  - Family and child characteristics and needs
- Design a mentoring program to meet your family's needs
  - Develop a "sales pitch" to recruit other families like yours to participate

### ***Your child's and family's characteristics and mentoring needs***

By way of introduction, let's go around the room. Please say your first name, the name and age of your child who has a hearing loss, the type of hearing loss your child has, and at what age your child's hearing loss was identified.

Think back to the time when your child's hearing loss was first identified. At that time...

What were your child's primary needs?

[PROBE FOR] What kinds of things did you have to do first to meet your child's most pressing needs?

What were your biggest issues or concerns as a parent?

At the time that your child's hearing loss was first identified, where in that range of needs did mentoring from an adult who is D/HH fit?

### **FOR PARTICIPANTS WHO WERE/ARE INVOLVED IN THE LIFETRACK PROGRAM, OR OTHER FORMAL MENTOR PROGRAM:**

#### ***Your experiences with the Lifetrack D/HH Adult Role Model/Mentor Program***

At what point after your child's hearing loss was identified, did you first learn about the Lifetrack D/HH Adult Role Model/Mentor Program?

What made you want to participate in this program? [PROBE FOR: What made it seem like a good fit for your child/family?]

What did you think you might get out of it? What were the specific needs you were trying to meet by participating in this program?

Besides D/HH Adult Role Models/Mentors, what are some of the other ways your family, or other families you know, get this type of information or support?

What was your experience getting started in the program? [PROBE FOR: Was it easy? Were you nervous?]

What was your first meeting with your mentor like?]

How often did you meet with your mentor/for how long? [PROBE FOR: What frequency/duration would be ideal?]

Was there anything about the program that made it difficult your family to participate? [PROBE FOR: timing, staff/mentor characteristics, curriculum, communication mode options, accessibility and geographic availability, etc. as well as things about the family such as the child's other needs, other family responsibilities, jobs, other hardships, etc.]

Earlier I asked you what you wanted to get out of the program. Now I want to ask what you actually got out of it – what were the benefits to you and to your child?

**FOR PARTICIPANTS WHO WERE/ARE NOT INVOLVED IN THE LIFETRACK PROGRAM OR ANY OTHER MENTOR PROGRAM:**

***Reasons for not being involved with the Lifetrack D/HH Adult Role Model/Mentor Program***

*Facilitator to provide a description of the Lifetrack D/HH Adult Role Model/Mentor Program.*

If you have heard about Lifetrack or other mentor programs, did you think it sounded like something that was a good fit for your family? Why or why not?

Were there things that made it difficult for your family to participate in this program?

[PROBE FOR: timing, staff/mentor characteristics, curriculum, communication mode options, accessibility and geographic availability, etc. OR Things about your family such as your child's other needs, other family responsibilities, jobs, other hardships, etc.]

What kinds of benefits do you think children and families who participate in the D/HH Adult Role Model/Mentor Program experience, if any?

What are some of the drawbacks or negative experiences these children and families might have?

What are some of the ways your family, or other families you know, get information or support that might otherwise be provided by a mentor?

***Design a mentoring program to meet your family's needs***

What kind of D/HH Adult Role Model/Mentor Program would meet the needs of your child and family?

What kind of time commitment would be ideal? [PROBE FOR: frequency, duration]

How would you make sure the program reached families in all parts of MN, not just the Twin Cities?

How would you meet the needs of families who use various modes of communication and with different ranges of hearing loss? [PROBE FOR: cued speech, lip reading, cochlear implants, hearing aids, etc / Deaf, HH, unilateral, etc]

How would you support families of varying cultures, ethnicity, and/or language?  
Anything else?

***Develop a "sales pitch" to recruit other families like yours to participate***

If you were running this program and it was your job to try to get **every** family in Minnesota who has a young child who is D/HH to participate, what would your sales pitch be?

When would you tell families about this program?

How would you tell them about it – in-person, via mail, from a professional or another parent?

What about families who are initially reluctant to get involved – what kinds of additional outreach, if any, do you think might be helpful?

### ***Wrap-up***

Those are all the questions we have. Does anyone have any final comments with regard to helping us make recommendations for a D/HH Adult Role Model/Mentor Program to meet the needs of all families with young children who are D/HH in Minnesota?

Thank you very much for your time and participation!

\_\_\_\_\_ (Wilder staff) has your gift cards, so please don't leave until you have signed for your card and received it. I will stick around for a few minutes in case you have any additional questions or thoughts.



## Parent Focus Group Survey

1. Is your child's hearing loss unilateral or bilateral?  
<sup>1</sup> Unilateral (one ear)  
<sup>2</sup> Bilateral (both ears)
  
2. How severe is your child's hearing loss?  
<sup>1</sup> Mild  
<sup>2</sup> Moderate  
<sup>3</sup> Severe/Profound
  
3. What is your family's preferred/primary language for communicating with your child? **(PICK ONE)**  
<sup>1</sup> American Sign Language (ASL)  
<sup>2</sup> Spoken English  
<sup>3</sup> Other, please specify \_\_\_\_\_
  
4. What types of communication mode(s), tools, and assistive technologies do you use to communicate with your child? **(CHECK ALL THAT APPLY)**  
<sup>1</sup> American Sign Language (ASL)  
<sup>2</sup> Signed English  
<sup>3</sup> Pidgin Signed English (mixed with ASL)  
<sup>4</sup> Cued speech  
<sup>5</sup> Lip reading  
<sup>6</sup> Cochlear implants  
<sup>7</sup> Hearing aids  
<sup>8</sup> CART captioning  
<sup>9</sup> None of the above  
<sup>10</sup> Other, please specify: \_\_\_\_\_

## Parent Focus Group/Interview Consent Form

This is a consent form to participate in a needs assessment (research study) that is being conducted by Wilder Research on behalf of Lifetrack. Please read this entire form, ask any questions you have, and decide if you agree to participate – if so, sign at the bottom and return to the facilitator/interviewer.

### *Purpose of the research*

The purpose of this needs assessment is to better **understand the needs and preferences of families with young children (age 0-6) who are Deaf/Hard of Hearing (D/HH)** so Lifetrack, the Minnesota Department of Health (MDH), and the Minnesota Department of Human Services Deaf and Hard of Hearing Services Division (DHHSD) can improve the quality and sustainability of the existing D/HH Adult Mentor/Role Model Program and expand the program to better serve all families with young children (age 0-6) who are D/HH across Minnesota, with all types of hearing loss and who use various modes of communication.

### *Your participation*

We are asking for your one-time participation in this focus group/interview, which should take 1-2 hours. Your participation is **voluntary**. Your decision whether or not to participate, and your responses if you do participate, will not affect your relationship with Lifetrack, MDH, or any other project partner. **Refusal to participate will involve no penalty or loss of benefits to which you are entitled, and you may discontinue participation at any time without penalty or loss of benefits to which you are entitled.**

Your participation is also **confidential**. We will never use your name or any other identifying information in any reports. Only Wilder Research staff/consultants will see your identifying information. Your responses and the responses of other participants will be analyzed together to understand key themes and findings and make recommendations for program improvement and expansion. (We may use your comments in study reports as long as they do not identify you.)

IF YOU ARE PARTICIPATING IN A FOCUS GROUP: This group discussion will be facilitated by Wilder Research staff/consultants, who will review the ground rules for the discussion at the beginning of the group. You will be asked to participate in the discussion about your needs and preferences with regard to a D/HH Adult Mentor/Role Model Program. You are expected to stay for the duration of the focus group. At the end of the group, we will give you your gift card.

IF YOU ARE PARTICIPATING IN AN INTERVIEW: This interview will be conducted by a Wilder Research staff/consultant. You will be asked several questions about your child(ren) and family, including your needs and preferences with regard to a D/HH Adult Mentor/Role Model Program. After the interview is completed, we will give you your gift card (if in person) or send you your gift card (if by phone/Skype).

This is a qualitative research study where we are asking for you to tell us about your opinions and experiences only. No experimental methods will be used.

### *Risks to you*

One risk to you from participating in this research study is that we could accidentally reveal your personal information gathered during the discussion. Wilder Research uses data security best practices such as only giving access to electronic and paper records for the project to staff who are directly involved, and storing your identifying information, such as your name and address, in a separate file from your responses during the focus group/interview. In the unlikely event that your information is accidentally released, Wilder Research will notify you immediately.

The other risk to you is that you may feel uncomfortable answering the questions. The topic of the research study is somewhat sensitive: support needs for families who have young children (age 0-6) who are D/HH. However, our intent is to conduct the interview/focus group in a way that ensures all participants feel comfortable to express their true feelings and relevant experiences.

### ***Benefits to you***

At the end of the focus group/interview, you will receive a \$25 gift card as our way of saying thank you for your time. The only other benefit to you from participating in this study is that you may contribute information that will ultimately result in an improved D/HH Adult Role Model/Mentor Program and/or other programs or services that will better meet the needs of all families with young children who are D/HH in Minnesota. When, at some time in the future, a new program or service becomes available or the existing program is expanded and/or improved, we will be sure to let your family know.

### ***Who to contact for more information***

If you have questions about your participation in this research, please contact Sera Kinoglu from Wilder Research at 1-800-328-2972 or [sera.kinoglu@wilder.org](mailto:sera.kinoglu@wilder.org). For questions about your rights as a participant in this research, contact Peter Rode, Administrator of the Minnesota Department of Health Institutional Review Board, at 651-201-5942.

### ***Your consent***

I agree to participate in the research study described above on \_\_\_\_\_ (date).

Signed: \_\_\_\_\_

Printed name: \_\_\_\_\_

## Adults who are D/HH interview/focus group protocol, survey, and consent form

### D/HH Adult Focus Group Protocol

#### **Introduction**

Greetings! My name is \_\_\_\_\_ (name of facilitator) and this is \_\_\_\_\_ (introduce note takers, interpreters, etc.) We are from Wilder Research. Our company was hired by Lifetrack to do a needs assessment for families with young children (age 0-6) who are Deaf or Hard of Hearing (D/HH), which includes talking to adults who are D/HH about both your experiences as a child and any involvement you have had as an Adult Role Model/Mentor, formally or informally.

**Before we begin, I'd like for everyone to fill out this brief form about your hearing loss.**

First, let's review the consent form that describes the study and your participation, and then I'll give you a chance to ask questions.

#### *Instructions for facilitator:*

- Go over the main points (bolded text) and give them a chance to read the consent form (5 min.)
- Take and answer questions (or defer the questions to those listed on the consent form if you are not able to answer them).
- Get everyone's signed consent form before proceeding.

Now, let's quickly go over the ground rules for this conversation: *(list on flip chart)*

- Please participate actively and allow others to do so as well. Raise your hand when you want to talk and wait until you are called on by the facilitator.
- Be respectful of others' opinions and decisions.
- We'll keep your information confidential. Please do the same for each other.
- Eating during the discussion is fine.
- We will not be taking any official breaks, but we will end on time, at \_\_\_\_\_.
- The restrooms are located \_\_\_\_\_.
- Others?

Describe purpose of note taker and audio/video recording *(to use as back-up in case we miss anything in the notes – we want to record your thoughts accurately)* and ask everyone's permission to turn it on.

Agenda for the focus group *(list on flip chart)*

- Your characteristics and mentoring needs as a child
- Your experience with mentoring/role modeling
- Families' challenges to participating in mentoring programs
  - Program characteristics & accessibility
  - Family and child characteristics and needs
- Design a mentoring program to meet all families' needs
  - Develop a "sales pitch" to recruit families to participate

### ***Your characteristics and mentoring needs as a child***

By way of introduction, let's go around the room. Please say your first name, the type of your hearing loss (including if your parents also have a hearing loss), and at what age your hearing loss was identified.

Think back to the time when your hearing loss was first identified, or what you know about that time, if you were too young to remember. At that time...

What were your primary needs, either because of your hearing loss and/or other health conditions?

Did you or your parents ever consider having a D/HH adult as a role model or mentor? Did you ever have an adult who was D/HH who acted as a mentor and role model for you and your parents, either through a formal program or informally?

If yes... [PROBE FOR]

How did you originally meet your mentor?

How did you arrange the mentoring relationship?

How often did you meet with your mentor and over what period of time?

What kinds of things did your mentor help you with? What about your parents – what kinds of help did they specifically get from the mentor?

What was the main benefit to you from having a D/HH adult role model/mentor?

If no...

Why did you or your parents ultimately decide to not pursue a mentor or role model?

Were there things that prevented you or your family from getting involved with a D/HH adult as a mentor or role model?

Were there other types of support similar to a mentor relationship that your family found helpful?

What do you feel like you might have missed out on, if anything, because you did not have a D/HH adult role model or mentor as a child?

*Facilitator to provide a brief description of the Lifetrack D/HH Adult Role Model/Mentor Program, and emphasize age range being discussed. (If necessary, explain that it is tied to infant screening for this age range/funding)*

### ***Experience with role model/mentor programs or lack thereof***

*Facilitator to ask who in group does have experience with some type of formal mentor program.*

**For those that have had experience with a formal mentor program, how did you initially get involved?**

What needs of the children and families were you meeting by participating in a mentor program?

[PROBE FOR main benefits to children and families of having a mentor]

What kind of training did you have before meeting with families? [PROBE FOR opinion of training materials, missing pieces, etc]

What was most challenging about participating in the program? [PROBE FOR program timing, staff characteristics, curriculum, communication mode options, accessibility and geographic availability, etc]

**For those who have not had experience with a formal mentor program**, have you heard about such programs? Or, have you participated in any **informal mentoring?** (e.g., as a volunteer, through church, community, etc)

If so, was there anything about the program itself that made it difficult to participate? About your own schedule or interest? [PROBE FOR timing, curriculum, communication mode options, accessibility, geographic availability, etc]

What benefits do you think families might experience by having a mentor? [PROBE FOR ways they would receive that information or support without a mentor]

What kinds of benefits would someone experience by *being* a mentor?

What drawbacks or negative experiences do you think there might be for families who have a mentor?

### ***Design a mentoring program to meet all families' needs***

If you were designing a mentor program for families with young children (age 0-6), how would you reach out to families and get them oriented?

What kind of time commitment would be ideal? [PROBE FOR time per week/month, length of program]

How would you make sure you reached families in all parts of MN, not just the Twin Cities?

How would you meet the needs of families who use various modes of communication and with different ranges of hearing loss? [PROBE FOR cued speech, lip reading, cochlear implants, hearing aids, etc/Deaf, HH, unilateral, etc]

How would you support families of varying cultures, ethnicity, and/or language?

### ***Develop a "sales pitch" to recruit adults who are D/HH to participate as mentors***

What could a program coordinator do or say that would make *you* want to become a mentor? [PROBE FOR how to be contacted/recruited, information you would want, outcomes, etc]

Now thinking about it from the other perspective, if you were a program coordinator, what kinds of outreach would you do to inform families about mentorship who are otherwise reluctant to get involved?

### ***Wrap-up***

Those are all the questions we have. Does anyone have any final comments with regard to helping us make recommendations for a D/HH Adult Role Model/Mentor Program to meet the needs of all families with young children who are D/HH in Minnesota?

Thank you very much for your time and participation!

\_\_\_\_\_ (Wilder staff) has your gift cards, so please don't leave until you have signed for your card and received it. I will stick around for a few minutes in case you have any additional questions or thoughts.

## Adult Focus Group Survey

1. How old were you when your hearing loss was first identified?

age

2. Is your hearing loss unilateral or bilateral?

- <sup>1</sup> Unilateral (one ear)  
<sup>2</sup> Bilateral (both ears)

3. How severe is your hearing loss?

- <sup>1</sup> Mild  
<sup>2</sup> Moderate  
<sup>3</sup> Severe/Profound

4. What is your preferred/primary language? (PICK ONE)

- <sup>1</sup> American Sign Language (ASL)  
<sup>2</sup> Spoken English  
<sup>3</sup> Other, please specify \_\_\_\_\_

5. What types of communication mode(s), tools, and assistive technologies do you use?

**(CHECK ALL THAT APPLY)**

- <sup>1</sup> American Sign Language (ASL)  
<sup>2</sup> Signed English  
<sup>3</sup> Pidgin Signed English (mixed with ASL)  
<sup>4</sup> Cued speech  
<sup>5</sup> Lip reading  
<sup>6</sup> Cochlear implants  
<sup>7</sup> Hearing aids  
<sup>8</sup> CART captioning  
<sup>9</sup> None of the above  
<sup>10</sup> Other, please specify: \_\_\_\_\_

## Adult Focus Group/Interview Consent Form

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### *Purpose of the research*

The purpose of this needs assessment is to better **understand the needs and preferences of families with young children (age 0-6) who are Deaf/Hard of Hearing (D/HH)** so Lifetrack, the Minnesota Department of Health (MDH), and the Minnesota Department of Human Services Deaf and Hard of Hearing Services Division (DHHSD) can improve the quality and sustainability of the existing D/HH Adult Mentor/Role Model Program and expand the program to better serve all families with young children (age 0-6) who are D/HH across Minnesota, with all types of hearing loss and who use various modes of communication. As an adult who is D/HH, you will be asked about your experiences from the perspective of a mentor and/or role model for younger children who are D/HH, and about your experiences growing up as a child who is D/HH.

### *Your participation*

We are asking for your one-time participation in this focus group/interview, which should take 1-2 hours. Your participation is **voluntary**. Your decision whether or not to participate, and your responses if you do participate, will not affect your relationship with Lifetrack, MDH, or any other project partner. **Refusal to participate will involve no penalty or loss of benefits to which you are entitled, and you may discontinue participation at any time without penalty or loss of benefits to which you are entitled.**

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IF YOU ARE PARTICIPATING IN AN INTERVIEW: This interview will be conducted by a Wilder Research staff/consultant. You will be asked several questions about your experiences as an adult who is D/HH and your past experiences as child who is D/HH, including your needs and preferences with regard to a D/HH Adult Mentor/Role Model Program. After the interview is completed, we will give you your gift card (if in person) or send you your gift card (if by phone/Skype).

This is a qualitative research study where we are asking for you to tell us about your opinions and experiences only. No experimental methods will be used.

### *Risks to you*

One risk to you from participating in this research study is that we could accidentally reveal your personal information gathered during the discussion. Wilder Research uses data security best practices such as only giving access to electronic



and paper records for the project to staff who are directly involved, and storing your identifying information, such as your name and address, in a separate file from your responses during the focus group/interview. In the unlikely event that your information is accidentally released, Wilder Research will notify you immediately.

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### ***Benefits to you***

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### ***Your consent***

I agree to participate in the research study described above on \_\_\_\_\_ (date).

Signed: \_\_\_\_\_

Printed name: \_\_\_\_\_