A Qualitative Analysis of Early Identification of Pediatric Hearing Loss and Early Intervention Services for Families in Mongolia

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Abstract

A Qualitative Analysis of Early Identification of Pediatric Hearing Loss and Early Intervention Services for Families in Mongolia

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There are four equally important elements that must be in place in a continuum of care for successful outcomes in young children with hearing loss learning to listen and speak: a) early identification of hearing loss, b) family engagement, c) hearing technology, and d) access to local professionals with expertise in habilitation services (audiology, early intervention). The aim of this study was to understand the experience in Mongolia for those families who choose the listening and spoken language communication modality after their babies and young children are identified with hearing loss. The study had two objectives: 1) to elicit strengths and weaknesses in the current delivery of pediatric hearing health care services in Mongolia for children with hearing loss learning to listen and speak from newborn hearing screening to habilitation, and 2) to identify cultural, economic, and social enablers and barriers that motivate or demotivate families as they progress along the continuum of care. A qualitative study design was used. Semi-structured in-depth interviews were conducted with 26 individual Mongolian family members of babies and young children with hearing loss who either use hearing aids or cochlear implants or are in the process of obtaining such hearing technology. Focus group discussions and interviews were administered with 41 Mongolian medical professionals and therapists who provide pediatric hearing services to rural and urban populations and with four Mongolian government representatives. Thematic content analysis was applied to the data using inductive coding in the context of a grounded theory approach. Analysis revealed strengths and opportunity areas at each stage of care which contributed to varying family experiences in obtaining pediatric hearing health care services for their children with hearing loss. Results indicated that expanding existing pediatric hearing health care services and professional expertise beyond the capital of Ulaanbaatar, increasing awareness about pediatric hearing loss across Mongolian society, and providing additional financial aid to families would contribute to advancing pediatric hearing health care services in Mongolia. Investment in these areas would enable more of their children with hearing loss to access the essential support they need to learn to listen and speak and reach their potential.

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BACKGROUND

Overview of Pediatric Hearing Loss

Congenital hearing loss is one of the most common birth anomalies (Korver, et al, 2017) with a prevalence of .5 to 5 per 1,000 births worldwide (WHO, 2010). Left untreated, hearing loss can significantly and permanently impair the development of speech, language, and cognitive abilities in children. Untreated hearing loss reduces a child's educational potential which, in turn, can negatively influence his or her future employment opportunities and overall quality of life (Joint Committee on Infant Hearing, 2000). The World Health Organization (WHO) indicates that "in a broader context, untreated pediatric hearing loss affects the social and economic development of communities and countries" (WHO, 2016). In its report, *Global Costs of Unaddressed Hearing Loss and Cost-Effectiveness of Interventions,* the WHO specifies the costs associated with untreated pediatric hearing loss across different areas of society and the substantial dividends that could be derived via early identification and early intervention (WHO, 2017).

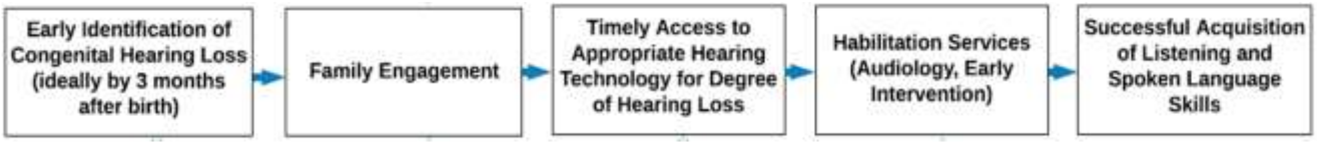
Systems within the human body develop during early childhood at different stages. Aural pathways in the brain that normally develop to enable listening and spoken language permanently convert to other uses if not utilized when the child is very young (Sininger, et al, 1999). Therefore, it is critical to identify hearing loss during the first years of life (Smith, 2008).

Significant advancements over the past several decades in hearing technology, specifically the advent of digital hearing aids and cochlear implants, have made it possible for more children with all degrees of hearing loss to access the sounds of speech that are needed to be able to learn to listen and speak (Lim and Simser, 2005).

Habilitation, which provide families with services, strategies and techniques to help their child with hearing loss develop listening and spoken language skills, have proven to be effective in combination with early identification and hearing technology to reduce the impact of deafness on a child's development. One research study reports that children with hearing loss who were identified by 3 months of age, fit with hearing technology, and enrolled into early intervention by 6 months of age had significantly better language and vocabulary than their peers who were identified and administered treatment at older ages (Yoshinaga-Itano, et al, 1998). Another study evaluated age of intervention as the predictor of language and found that early access to intervention led to enhanced language skills (Moeller, 2000).

As shown in Figure 1, there are four equally important elements that must be in place in a continuum of care for successful outcomes in young children with hearing loss learning to listen and speak: a) early identification of hearing loss, b) family engagement, c) hearing technology, and d) access to local professionals trained in habilitation (Joint Committee on Infant Hearing, 2000). The WHO reports that the majority of the 32 million children with hearing loss worldwide live in low and middle-income countries where these elements are limited, or not available at all, thus preventing them from achieving their full potential (WHO, 2016).

Figure 1. Continuum of Care for Children with Hearing Loss Learning to Listen and Speak



Components in the Continuum of Care for Children with Hearing Loss Learning to Listen and Speak

The following is a brief overview and definition of select services and technologies used at various stages within the continuum of care that are relevant to this research study and report.

Early Identification of Hearing Loss

Before the existence of universal newborn hearing screening programs, children were not diagnosed with hearing loss until nearly 2 years of age, or later, when speech and language were not manifesting as expected (Harrison, et al, 2003). As deafness is not visually obvious, there is a higher likelihood of late identification of congenital hearing loss without proactive testing (Yoshinaga-Itano, et al, 1998). Over 90% of babies born with hearing loss are born to parents of normal hearing, (Mitchell and Karchmer, 2004) who may have little knowledge about hearing loss. Today, it is possible to screen newborns for hearing loss as early as 24 hours after birth using physiologic methods (Lupoli, et al, 2013).

Otoacoustic Emissions (OAE) and Auditory Brainstem Response (ABR) are the two objective newborn hearing screening tests that are broadly used throughout the world (Yousefi, et al, 2013). OAE tests are simple to administer and can be completed in minutes. A probe is placed in the child's ear and a signal is presented. If a baby has normal hearing, the cochlea in the inner ear will respond to that signal and emit a vibration that echoes back to the middle ear. The OAE device picks up on that response and will record a "pass". If there is a possible hearing loss, there will be no response from the inner ear. The OAE device will indicate the child did not pass the screening test. In ABR testing, electrodes are placed on the child's head and a sound is presented through ear phones. Brain waves in response to that sound are recorded by the ABR and evaluated for hearing loss (ASHA, n.d.). ABR tests are more precise than OAE. However, they require more training and skill to interpret, more time to administer, and are more costly.

In a two-step screening process, OAE tests are administered first. If the baby passes the OAE test, no more testing is required. If the baby does not pass the OAE test, he or she is referred to an ABR test. ABR test results supersede OAE results, meaning if a baby passes ABR after not passing OAE, the ABR results are the confirmed diagnosis (ASHAa, n.d.).

An effective newborn hearing screening program includes a means for tracking patients across health facilities as they go through the process from initial screening at the birthing hospital to confirmation of diagnosis by a doctor and referral to habilitation services as needed (Neumann, et al, 2019). A *Tracking System* enables quality control and system-level management of the screening program as well as collection of epidemiological data (Neumann, et al, 2019).

Hearing Technology

A *Hearing Aid* amplifies sounds coming into the ear so that a person with hearing loss can more easily hear and process them acoustically. The more severe the hearing loss, the greater the level of amplification that is needed. However, there are limits to the amount of amplification a hearing aid can provide. For people with severe to profound hearing loss levels, a hearing aid becomes less effective in meeting their needs (NIDCDa, n.d.).

A *Cochlear Implant (CI)* is a surgical device that comprises of two parts – an external processor and an internal component that is surgically implanted under the skin. The cochlear implant transmits sound through electronic stimulus directly to the auditory nerve, thus bypassing the damaged middle and inner ear structures. A cochlear implant helps people with more severe hearing loss who cannot benefit from hearing aids be able to access sound, particularly the sounds of speech (NIDCDb, n.d.).

Habilitation Services

Habilitation encompasses *Audiology* and *Early Intervention* (which includes *Auditory-Verbal Therapy* and *Early Education*) and are essential for children with hearing loss in their developmental years. They help children access sound through hearing technology and learn to process those sounds to listen and speak (ASHAb, n.d.).

Audiology is the study of hearing, balance, and associated disorders. An audiologist (or audiology doctor) is trained in the management, diagnosis and treatment of hearing loss. They administer audiology tests, counsel patients, and fit hearing aids or cochlear implants as appropriate to address a person's level of hearing loss. Those who work with children are pediatric audiologists (Medical Net, n.d.). In many low- and middle-income countries there are no licensures in audiology. Instead, otolaryngologists (ENT doctors) are specially trained to provide audiological care.

Early Intervention delivers speech and language expertise in support of families of children with hearing loss (ASHAc, n.d.). *Auditory Verbal Therapy* specifically addresses listening and spoken language development in children with hearing loss with hearing aids or cochlear implants. A child with a significant hearing loss has the equivalent listening age of a newborn baby on the day he or she is fit with hearing technology (Lim and Simser, 2005). The child has to go through the same developmental stages as a baby with typical hearing before he or she can begin to listen and speak. It takes time for that process to unfold and the later it starts, the less likelihood for success. With the support of auditory-verbal therapy professionals and the commitment of family members, that process can be accelerated (Lim and Simser, 2005). *Early Education Support* includes specialized preschool and kindergarten to help children with hearing loss prepare for mainstream schools.

The Country of Mongolia

Mongolia is a democratic nation situated in North Asia between Russia and China. It spans 604,000 square miles, making it the 18th largest country in the world based on land mass (UN World Population Review, 2020). It has a population of 3.2 million people --- and 71 million animals (National Statistics Office of Mongolia, 2020). According to UN World Population Review data, nearly three-quarters of the Mongolian population lives in or around a major city, most of which is concentrated in one place (UN World Population Review, 2020). Forty-seven percent, or 1.5 million people live in the capital of Ulaanbaatar, which is locally referenced as UB (National Statistics Office of Mongolia, 2020). The rural aimags (provinces) outside of UB are both expansive and sparsely populated. Each aimag is about three to four times the size of Switzerland and has an average population density of five people per square mile. Travel to and from UB and between aimags is covered mostly on unpaved roads that, combined with extreme weather conditions in the winter, (UB is the coldest capital in the world), can contribute to long journey times. Mongolia has 21 aimags divided into 331 soums or administrative subdivisions. There are also nine municipal districts in UB which are administrative units separate from the soums (Baker, et al, 2017).

Mining and agriculture are the leading industries in Mongolia (Heritage Foundation, 2020). The average annual salary is $4,728 (Erdenechimeg, 2017). About 30% of Mongolia’s population works in animal husbandry which has an average annual salary of $2,500 (Save the Children, 2017). Mongolia also has a long herding tradition and is home to some of the world’s last truly nomadic communities (Vanderklippe, 2017). There are 233,000 nomadic and herder households which own livestock and live on the country’s vast grasslands (National Statistics Office of Mongolia, 2020).

Religion and Spirituality

Mongolian Shamanism is one of the world's oldest forms of religion, dating back to early recorded history (Hesse, 1987). It was the country’s dominant spiritual practice until Lama Ondor Gegeen Zanabazar, Mongolia’s religious and political leader in the 17th century, advanced Tibetan Buddhism and it became widely adopted among Mongolians (Wallace, 2015). During Mongolia’s communist era between 1920 and 1990, spirituality and religion were suppressed. Temples were destroyed and lamas were executed in large numbers (Wallace, 2015). All forms of religion were revived when the country shifted to a republic in the early 1990s (Heissig,1980). Today, nearly 54% of Mongolians identify as Buddhist and at least 3% of Mongolians maintain Shamanistic rituals. The Kazakh ethnic group practices Islam (3%). About 40% of the population does not officially subscribe to any religious ideology (Grim, 2010).

Health Care System

Mongolia was a satellite state of the Soviet Union for 70 years (Gan-Yadam, et al, 2013). The Soviets introduced the country to Western medicine and a socialist health care system. The Mongolia government covered the costs of basic services, immunizations, and maternal and child care for all its citizens until the country's transition to democracy and a market-based economy in 1990 (Jigjidsuren, et al, 2013). The health care system has undergone several reforms since including the introduction of a private sector and health insurance. Basic government health services are still guaranteed to all citizens and modern health care services remain highly centralized in UB (Jigjidsuren, et al, 2013). Health care services are covered through: a) the central state budget, b) social health insurance, and c) out-of-pocket payments (Dorjdagva, et al, 2016). Traditional health treatments including Buddhist and Shaman rituals are still in practice as well (Gan-Yadam, et al, 2013).

Over 99% of all babies in Mongolia are born in health facilities, and 52% are born in UB (Center for Health Development, 2017). About 95% of those born in UB are birthed at the three public maternal hospitals and two district general hospitals. The remaining births occur at private facilities and a few at home (Center for Health Development, 2017). The National Center for Maternal and Child Health (NCMCH) in UB is the main tertiary care center for pediatrics in both UB and the entire country.

Pediatric Hearing Health Care

All hearing health care services, including pediatrics, are available exclusively in UB at public and private hospitals and private health facilities.

The Mongolia Ministry of Health issued a decree in 2014 to implement universal newborn hearing screening (Mongolia Ministry of Health decree 182). However, until 2016, NCMCH was the only public hospital in the country with the equipment and expertise to screen newborns for hearing loss. Between 2016 and 2018, with the support of the United States nonprofit organization, Global Foundation For Children With Hearing Loss, newborn hearing screening in the capital was expanded to include all three maternal hospitals and two district general hospitals in UB. Newborn hearing screening tests have been proactively administered to newborn babies at these facilities since late 2017 (Shonkhuuz, 2019). The NCMCH reports that over 33,000 newborns were screened in 2018 and about 100 had confirmed hearing loss that would require habilitation (Shonkhuuz, 2019).

The NCMCH indicated that the Mongolia Ministry of Health has adopted hearing screening protocols as recommended by their hospital into the standard of care for newborns. NCMCH ENT doctors provide training on use of the screening equipment and the screening process to medical residents and medical professionals across the city to ensure consistency in how screening tests are conducted.

Hearing aids and cochlear implants are available only in UB. Doctors report that the cost of one hearing aid ranges from $300 for a basic level device up to $2,000 for higher quality, advanced models. Hearing aids are sold only at private hospitals and clinics. No public hospitals offer hearing aids. However, the Mongolia Welfare Labor Center provides a limited supply of basic level hearing aids at no cost to low-income families that are then fit by a private clinic. Health insurance provides a one-time subsidy to support the purchase of the first set of hearing aids. Hearing aids typically need to be replaced about every five years (Allen, 2002).

The Mongolia government subsidizes 70% of the cost of cochlear implants and related surgery for children. Families are responsible for the rest. Their cost ranges between $2,500 to $3,500 per ear depending on the device and surgery location, the equivalent of a full year average salary for rural citizens and up to 74% of the average annual salary for urban dwellers. Cochlear implant technology and corresponding surgical and mapping support are provided by both private and public hospitals in UB.

Study Aims

The advent of newborn hearing screening in Mongolia will likely contribute to earlier identification of hearing loss and heighten the potential for timely treatment. However, these developments are only useful if families are aware of the impact of hearing loss on their child's development and are able to access pertinent habilitation services and support in timely fashion.

The intent of this qualitative study is to understand the family experience in Mongolia for those who choose the listening and spoken language modality for their children who are deaf or hard of hearing. This study aims to achieve two inter-related objectives: to elicit strengths and weaknesses in the current delivery model of early identification and habilitation services, and also to identify cultural, economic, and social enablers and barriers that motivate or demotivate families along the continuum of care.

This study will yield information that could support future policy efforts to enhance and expand early identification and habilitation services for young children with hearing loss in Mongolia. Our findings will also contribute to existing literature about pediatric hearing health programs in low- and middle-income countries. While this study's focus is on hearing loss, the broader emphasis on understanding the family experience in addressing a health challenge may be relevant to other pediatric conditions in Mongolia.

METHODOLOGY

Study Design

For this exploratory qualitative study, we conducted semi-structured in-depth interviews (IDIs) and focus group discussions (FGDs) with family members and professionals in Mongolia about services for children with hearing loss in their country. The IDIs and FGDs were carried out at health facilities and government offices in the capital of Ulaanbaatar (UB) between September and November 2019. The study was approved by the Institutional Review Boards at the University of Washington and the Mongolia National Center for Maternal and Child Health.

Sampling Method

Stratified purposive sampling was used to identify potential study participants. This sampling method applies an intentional selection of participants with knowledge about a specific topic to maximize variation captured in experiences (Patton, 2002). Since pediatric hearing care services are centered in UB, we wanted to identify any potential differences in care experienced by families who live in the capital compared with those who live in the rural countryside areas. Additionally, we wished to identify any differences in family experiences based on the age of the children. Because hearing screening was implemented at all public birthing hospitals in UB in 2017, children with hearing loss who were two years of age or younger were likely to have received the tests if born there. Children older than two years of age were not likely to have received newborn hearing screening tests regardless of where they were born. Thus, we recruited family members who had children with hearing loss within these two age groups. Our approach helped to ensure that we captured a broad range of family perspectives with regards to their engagement with hearing health services for their young children with hearing loss.

Hearing health care professionals recruited to this study included ENT doctors specialized in audiology, nurses, and medical residents, all based in UB who provide hearing health care to babies and young children with hearing loss. We also sought the input of ENT doctors based in the countryside who work with families outside of UB. Therapists who provide auditory-verbal therapy and early intervention services to young children with hearing loss wearing hearing technology were recruited from UB facilities. Inclusion of professionals representing a variety of roles and responsibilities was intended to gain feedback valuable to the refinement and deployment of early identification and habilitation services in Mongolia. Other similar research studies confirmed that our approach would capture a diverse range of viewpoints and achieve thematic saturation, whereby no new information would be gained by additional interviewing (Sandelowski, 1995).

Recruitment and Enrollment Process

Research assistants

Three Mongolian study assistants were recruited to comprise the research team. All IDIs and FGDs were carried out using a semi-structured interview guide with interpreting support from one of the three study assistants at each session. The study assistants each transcribed verbatim into English and Mongolian the audio-recordings for the sessions in which they were directly involved. Transcripts and translations were housed in cloud storage, accessible only to the research team.

Family Members

Family members were eligible for inclusion in the study if they: 1) were the primary caregiver for their child with hearing loss, 2) were seeking, or had sought, habilitation services for their children, 3) were at least 18 years of age, and 4) were willing and able to provide consent.

Family members were recruited for interviews at the hospital facilities in one of three ways:

1. At the end of their child's audiology or auditory-verbal therapy appointment, family members were informed of the study by a Mongolian medical professional. If they were interested to participate, the IDI was conducted either on the spot or at a later scheduled time.
2. Mongolian medical professionals notified family members of the study via telephone. Interviews were then arranged with parents who expressed interest to take part.
3. Family members were encouraged to share information about the study with other families whom they thought might be interested to participate. Those families could contact their medical professional for further details and to arrange the IDI.

The Mongolian study assistant or a Mongolian health professional at the hospital collected signed consent forms prior to the start of in-person IDIs. Consents for IDIs conducted remotely via video conferencing (ie Facebook Messenger) were managed by the Mongolian health professional.

Professionals

Mongolian medical and educational professionals were eligible to participate in the FGDs if they: 1) had experience working with children with hearing loss, 2) were at least 18 years of age, and 3) were willing and able to provide Mongolian consent. Government personnel were eligible if they: 1) had experience working in newborn health policy and/or disability support at the national or provincial level, 2) were at least 18 years of age, and 3) were willing and able to provide consent.

The Mongolian study assistants managed recruitment of professionals to the study. If interested to participate, a time was scheduled to conduct the FGD or IDI with them. Consent forms were collected prior to the start of the session.

All consent forms for both family and professional IDIs and FDGs were delivered to the NCMCH for storage. No consent forms or personal identifying information were recorded by, or shared with, me as the UW researcher. All sessions were audio-recorded.

Payment

Family members were issued a small stipend as token of appreciation for their participation in the study. Those who traveled from rural areas were each given 10,000 tugriks (about $4) while locally-based families were given 5,000 tugriks (about $2). Mongolian professionals were each offered 5,000 tugriks for their participation, however most of them declined payment.

Positionality

It is important to consider positionality in global health work as the perceptions, identities, biases, and values that researchers and participants bring to a specific study can influence both the depth of information that is provided and how that information is interpreted. Lusambli, et al. points out that “positionality is not a unitary concept, but a multidimensional process, in which a researcher may be closely positioned to the participants on some aspects and not on others" (Lusambili, et al, 2020). Being sensitive and aware of various influences, both positive and negative, and adjusting for them as possible, can contribute to a richer experience for everyone involved and result in a more productive study.

The NCMCH kindly provided us with a private room to conduct the family interviews in the hospital. The doctors issued me a freshly-ironed white doctor's coat and urged me to wear it for professional stature (even though I am not a physician) among the families. While I appreciated the gesture and found humor in it, I was a bit wary about this misrepresentation. I also reflected on whether the white coat might exacerbate any shyness that the families might already have in discussing the sensitive topic of hearing loss in their children in a hospital environment and with a foreigner guest who did not look like them or speak their language. Most of the families were indeed a bit formal when they came into the room. To help address this, we started off the interviews with casual conversation about their children's personalities, interests, and hobbies before we proceeded with the research questions from our interview guide. It was interesting to contrast the in-person interviews in the hospital with those conducted via video conferencing with families speaking with us from their homes in the countryside. The latter were dressed informally and in a more familiar environment. They were more comfortable from the start of the interviews and they were quicker to begin sharing their experiences.

I myself was born with a severe hearing loss and use a hearing aid and a cochlear implant. When some of the families we interviewed learned of my hearing loss, any inhibition they might have had being in the presence of a foreigner in a white coat seemed to immediately be put to rest. They sometimes asked me questions about my own life experience and marveled at my ability to communicate well via spoken language. I was sometimes able to share brief personal stories about growing up with hearing loss that related to their own children. They visibility relaxed into more casual conversation as they recognized that I might be able to emphasize with some of their and their children's circumstances.

Data analysis

All translated transcripts were imported into Atlas.ti software. We then applied a thematic content analysis to the data using inductive coding in the context of a grounded theory approach. Two types of coding were applied to the transcripts. Descriptive coding "summarizes in a word or short phrase the basic topic of a passage of qualitative data" (Saldana, 2016). The identification of topics was helpful for drawing out key strengths and weaknesses in the system of care. InVivo coding "prioritizes and honor the participant's voice" (Saldana, 2016). It helped us to elicit human influences that enabled or discouraged care. Because In Vivo coding uses the direct language of the participants, it provided rich, personal reflections on the more systematic elements that Descriptive coding presented.

After the coding was complete, the resulting codes were analyzed for similar concepts. Codes were then sorted together and compared across transcripts to identify a network of related themes. This multi-level, iterative process ensured that the quality of data interpretation was maintained.

RESULTS

Participants in the Study

Family Members

Semi-structured IDIs were conducted with 26 individual family members of babies and children with hearing loss who either use hearing aids or cochlear implants or are in the process of obtaining such hearing technology. Eighteen of these IDIs took place at NCMCH, EMJJ Hospital, and Dunn early intervention center. Eight were conducted by video conferencing exclusively with parents who live in the rural areas. Eleven of the interviewees had children with hearing loss between 0-2 years of age, 11 had children with hearing loss between 2.5 – 5 years of age, and four had children with hearing loss older than 5.

Thirteen of the 26 IDIs were conducted with family members who live in UB. The remaining interviewees came from nine different aimags outside of UB: Arkhangai, Bayan-Ulgii , Bulgan (2), Darkhan-Uul, Khovd (2), Orkhon(2), Ugiin-Nuur, Uvs, and Zavkhan (2).

Professionals

Six focus group discussions (FGDs) were carried out with 41 total Mongolian medical professionals, therapists, and residents who provide pediatric hearing services to rural and urban populations. These engagements took place at NCMCH, EMJJ Hospital, First Central Hospital, and Third Central Hospital.

One FGD of two people and two interviews were conducted with four personnel representing the Ministry of Health, Ministry of Disability and Social Welfare, and Ulaanbaatar Public Health Department at their respective government offices in UB.

Table 1 (see Appendix) profiles the study population represented in the IDIs and FDGs.

Research Findings

As previously mentioned, successful outcomes for children with hearing loss learning to listen and speak require a continuum of care that starts with early identification of hearing loss and progresses to timely provision of hearing aids and/or cochlear implants and access to habilitation services by qualified professionals. From the analysis of the FGDs and IDIs, a conceptual model (Figure 2 in Appendix) was created to demonstrate the barriers and enablers at each step in this continuum of care. These are presented in detail in the following sections of this report.

I. Newborn hearing screening

Screening in Ulaanbaatar

Several ENT doctors indicated that the newborn hearing screening program is leading to earlier identification of hearing loss in babies born in UB. *"Many babies are being diagnosed thanks to the newborn hearing screening. We are busier now. The results are starting to show" (ENT doctor, UB).*

Parents whose children benefitted from newborn hearing screening expressed appreciation for the service. A parent who gave birth in UB said, *"Of course, it was hard to get the diagnosis but we are happy to have found out early and we got hearing aids without wasting time".* Another reflected that their family, "*did not know anything about the newborn hearing screening. They did the eye and hearing tests before we left the hospital. That was great because we would not have known about the hearing loss if it was not for that testing" (Parent, UB).*

The NCMCH doctors informed us that over 33,000 babies were screened per year in 2018 and again in 2019 at the five hospitals in UB. They explained that the high volume of births and a typical hospital release for mothers of 24 hours after delivery requires that adequate staffing is in place to ensure that every baby undergoes a hearing screening test. No new hires have been made specifically to support the newborn hearing screening program. Instead, medical residents and nurses have been tasked with conducting hearing screening tests at each public maternity hospital in addition to their mandated job duties. The medical residents and doctors expressed a need for more human resources that could be dedicated to screening program execution and oversight. One opined, *"We residents perform newborn hearing screenings. But I think that there should be health care assistants or health specialists to do the newborn screening as part of their job" (Medical resident, UB).*

There is a high rate of turnover with medical residents as they cycle through their program which leads to an additional need for ongoing training and quality control. Several medical residents indicated that additional training would be useful to provide better service for the families. *"The doctors do not have* *enough time to train us. They are always tied-up...the screening is not included in the curriculum of the [residency] program. If the screening cannot be put into the curriculum, maybe we could teach the next round of residents ourselves" (Medical resident, UB).*

Another medical resident in UB expressed*:*

"At first, we had no idea about the hearing screening device. We are given a one-time lecture about the device and how it works. Next day we have practice training in which we learn how to perform the hearing screening. After that we start to perform the hearing screening by ourselves. I don't think we had enough training. We learnt it by ourselves."

While the medical residents do not diagnose hearing loss, they felt they would benefit from some training on how to counsel parents about what a "do not pass" screening result means. *"It is hard to inform the parents that your child did not pass a screening test. I worry that the mother will think her child is deaf. Therefore, we need to provide good information after the baby fails the test" (Medical resident, UB).*

Screening Outside of Ulaanbaatar

Newborn hearing screening is currently available only in UB. That leaves the remaining 48% of Mongolian births born outside the capital each year without access to this important test. *"All babies are supposed to get the newborn hearing screening with no discrimination. But, in Mongolia only children born at maternity hospitals in Ulaanbaatar get screened" (ENT doctor, countryside).*

Many doctors and parents we interviewed felt that the newborn hearing screening program should be expanded nationwide. One parent from the countryside said, "*I think it's crucial to provide hearing screening devices for the hospitals in the provinces. Then the children can get identified earlier and start treatment earlier. Early identification can affect children's speech and language development."*

The countryside doctors expressed enthusiasm for acquiring the appropriate equipment so they could administer OAE and ABR tests. One doctor commented:

“There is no screening device in the countryside. We tell the parents to go to the maternity hospital in Ulaanbaatar a month after birth to get the testing done. Due to financial problems or being a nomad living far from the city, some parents don’t go. As a result, the children with hearing loss are being identified too late. Is there any possibility of providing hearing screening devices to the hospitals in provinces?”

The countryside doctors indicated they already have some knowledge about how to administer screening tests which could help with quickly assimilating such screening into their existing protocol. One such doctor explained, *“We cannot do the screening without equipment in the countryside but we know how to do it. During residency, we saw how screenings were done while on shifts at the National Center for Maternal and Child Health and the First Maternity Hospital. We have conducted screening ourselves at that time” (ENT doctor, countryside).*

Because of the lack of newborn hearing screening in the aimags, hearing loss tends to only be revealed at older ages when a child is not developing speech and language as expected. Late identification of hearing loss reduces opportunities to address it (Yoshinaga-Itano, et al, 1998). Interviews with families whose children were born outside of UB indicated that late identification of hearing loss was a common reality. *“I have met numerous parents who say I have never heard about hearing loss or hearing screening… because they live far in the countryside. They found out about it when they came to UB” (Parent, countryside).* A parent described a typical situation:

“We did not know about my daughter’s hearing loss at first. We thought she would start talking sometime. Then one day she was playing with her baby sister and we called them. That’s when our younger daughter turned around but our older did not. I said to my wife I think our older daughter has a hearing problem and we talked about what to do. We took her to the aimag [province] hospital, but there was no equipment to determine it. I decided to take her to the city [UB] myself. We got to the city and went to NCMCH. I saw the speech therapist first and explained that our daughter is approaching 3 years old. I asked what the reasons would be for not speaking. After all the tests it was revealed that there was almost no hearing” (Parent, countryside).

One of the ENT doctors in UB explained:

“Countryside people live far from UB and their children are usually diagnosed late due to the distance. It is a different situation for people who live in the city. They have instant access. Most children from countryside

usually come late. When we ask why they come later, it is because they observed something wrong or situations where their child does not say a single word."

While public hospitals outside of UB do not currently have the equipment to administer newborn hearing screening or audiological tests, some pediatricians and ENT doctors in the countryside do have basic knowledge of pediatric hearing loss and the importance of timely identification. When families notice something is wrong and come to them with concerns about their children's hearing, they said they are able to recognize the signs and know where to refer families in UB for services. One parent explained:

"He never turned around when we called his name. Usually a child would know his name by 1.5 years of age. He only reacted when he saw us head on. So we decided to get help from the aimag [province] hospital and a private pediatric hospital. They both said that it seems like he is not hearing. Go to the city immediately and get the hearing tests done" (Parent, countryside).

However, knowledge about pediatric hearing loss among countryside doctors is variable. A few countryside doctors indicated they do not feel prepared to answer parent questions about hearing loss issues in their children. *"My knowledge on hearing and detecting on hearing loss is not well updated" (ENT doctor, countryside).*

Parents are aware that the hearing health services are only available in the capital. Some bypass their local pediatrician and ENT doctor entirely to save time and go directly to UB to address hearing concerns in their children. A countryside doctor explained the situation and the fragmented care that results: *"Patients have learned that they can only get treatment and help at the National Center for Maternal and Child Health in UB and that there is no available service for them in the countryside. So, knowing that, they would not come to the countryside doctors. They only come to us to get the forms to extend their child's government monthly disability allowances" (ENT doctor, countryside).*

Tracking

NCMCH trialed a tracking software program for two years which networked the maternal hospitals in UB involved in the newborn hearing screening program. NCMCH leadership is currently exploring a permanent solution to the tracking needs now that the trial period has expired. In the meantime, the hospitals have migrated to a low-cost, paper-based process. The doctors we interviewed opined that a computerized, national tracking system and database for newborn hearing screening across Mongolia would be most effective. One doctor suggested that, *"The hearing screening would be even better if we had a joint computer database for patients that the hospitals can share. For example, if we could track the test results, patient history, and visits over time at individual patient level" (ENT Doctor, UB).*

II. Family Engagement

Counseling at Diagnosis

After confirmation of hearing loss, emotional support and guidance for families is essential to ensure that parents are able to move pass their grief and provide children with timely services (Roush and Harrison, 2002). *"The younger the baby, the harder the parents take the news" (ENT doctor, UB).* Many parents we interviewed reflected on the feelings of grief, denial, guilt, and confusion they experienced when the diagnosis of hearing loss was confirmed in their children. One parent in UB said, *"I was shattered when I heard the diagnosis*." Another parent shared, "*At the beginning it was very difficult. After learning about it, I cried a lot. Emotionally, it was difficult" (Parent, UB).*

Some parents placed blame on themselves or on others for their child's hearing loss. *"I was sad to hear she needs hearing aids. I kept thinking why did my child turn out like this? We don't have family history of this and it is my fault because I delivered her prematurely" (Parent, countryside).* Another parent reflected, *"I asked my husband what sins he has committed that our son is like this. He said don't talk about that kind of thing" (Parent, UB).*

Disbelief was a common reaction and could lead to a delay in seeking further support. *"We had a hard time believing. I asked what the reasons are and they said it could be genetic or I had a viral infection when pregnant. We could not understand it. We don't have any family history of deafness and I did not have any problems when I was pregnant" (Parent, UB).*

One ENT doctor shared, "*Most of the time, it is very hard for the parents to hear that their child has a hearing loss. Some don't believe it when they hear. They listen to all the information and then come back again later. They bring other family members and ask to meet again" (ENT doctor, UB). Another doctor said, "Some parents come back a day or two after consulting with their families. There are others who wait a year to come back" (ENT doctor, UB).*

The ENT doctors are instrumental in helping parents overcome the initial shock of learning their child has a hearing loss. A parent expressed her gratitude for the support: *"The doctor explained everything calmly….she told me the bad news in a positive way" (Parent, UB).* ENT doctors educate the families about the condition and the possible options to address it. They indicate they provide support and answer questions. For example:

"They ask why their child has a hearing loss, the reason. Is there a way to become healthy, is there a way to not wear hearing aids and get better? Will they get better with hearing aids? Is there medicinal treatment? Is this treatable if we go to another country? Would the hearing get worse over or better? Can their child go to a normal school?" (ENT doctor, UB).

However, ENT doctors in the public hospitals expressed they have an average of less than 30 minutes per patient, which is insufficient to provide adequate counseling. A doctor explained the difficulty in providing moral support and essential information in such a short time frame, *"We do not have much time per appointment and do not have time to talk a lot. Thus, I should be clear and concise. I usually explain the condition and what to do next. That's what I tell. I do not have much time to discuss" (ENT doctor, UB).* Some ENT doctors engage in task-sharing to accommodate the counseling needs of their patients. One doctor explained how her hospital manages the need:

> *"Some people have more questions and others less. We try to spend enough time and answer all the questions. Some parents are very chatty by nature and ask everything in detail one by one. We work as a team. If one of us has a long patient appointment, the others can take care of the next patient so they don't have to wait as long" (ENT doctor, UB).*

Family Engagement After Diagnosis

The doctors we interviewed expressed that parents usually do not have much general knowledge about early child development and how language progresses. This knowledge is helpful for understanding the urgency to address hearing loss in their children. *"I think there should be an educator who gives health education. The doctors cannot pay attention to everything. There is a social worker in each hospital but it is impossible to reach everybody" (Nurse, UB).* An ENT doctor commented on the significant learning curve that parents face in understanding the permanent implications of hearing loss on their child if they fail to act quickly:

> *"We have to educate parents about hearing loss very well. Otherwise parents delay the interventions for a while thinking that their child is still young and will learn to talk on their own. We have to tell parents that a child has to be hearing to prevent delays in learning to talk. Parents have to make sure the child with hearing loss wears the hearing technology all the time. Because of lack of information and knowledge, the parents lose the opportunity to help their child learn to listen and talk" (ENT doctor, UB).*

Another ENT doctor shared a similar reflection:

> *"The parents are not aware of consequence of no early interventions and that is a real danger. They do not understand that there is a challenge of having a child with hearing impairment later if they do not do anything to help the child at young age. They think the child is still young and there is time. Later, when the child is 5 or 6 years old they realize suddenly that their children are going to school. Because of that they start worrying about their child" (ENT doctor, UB).*

Some parents expressed regret or anger later for their own delay in taking action. *"We wasted time in making a decision and just recently got the hearing aids in both ears when he was about 2.5 years old" (Parent, UB).* An ENT doctor explained:

> *"When a baby is diagnosed with hearing loss, there is not any significant change in the baby's behavior. The baby still sleeps, still cries, still gets the breast milk. So no one takes it seriously. Parents come back*

2-3 years or more later and say their child does not listen. They get upset or angry when they learn that they have lost time to help their child. They say "why did you not tell us that earlier?" (ENT doctor, UB).

Doctors also shared there are misconceptions that hearing aids and cochlear implants will fully resolve hearing loss. *"Even the parents who are wanting the CI surgery badly have not done any research. They just think the surgery will make everything good as new" (ENT doctor, UB).* The ENT doctors have to explain that hearing technology is not a cure for hearing loss, but rather are tools to help their child overcome a permanent condition to have a chance to learn to hear and speak. *"We have to explain everything – how the human hears, how hearing technology works, how hearing works. We do a lot of counseling" (ENT doctor, UB).*

All the parents we interviewed wished for their children with hearing loss to learn to listen and talk. When we asked the parents where they sought information to help their child achieve that goal, they consistently mentioned their ENT doctors based in UB as their primary source. *"The UB doctor gave us all the medical information about hearing loss. We visited the hospital several times to get advice on hearing aids. We followed the advice of the doctor" (Parent, countryside).* Another parent shared: *"When I asked about further steps to take, the doctors said that we needed her to wear hearing aids as soon as possible. It was diagnosed early so her state could improve. That is why we immediately began collecting money for the hearing aids" (Parent, UB)*. The parents expressed great trust and respect for their doctors. *"I truly believe the doctors are doing everything they can for us" (Parent, countryside).*

Parents with higher levels of education also perused the Internet for information about hearing loss. *"The education level of parents is a major factor when it comes to understanding the situation. Parents who read or are a bit more educated will surf the Internet and read about hearing loss and come back to us" (ENT Doctor, UB).* Some parents sought out other parents of children with hearing loss to observe their children and learn about their family's experience. *"My husband and I went to the early intervention kindergarten in UB to see the children who already had a cochlear implant. I learned that deaf children can learn to talk from the doctors" (Parent, countryside).* Social media such as Facebook groups were not a popular source of information about hearing loss due to the perception that the information provided there is unreliable. *"If* *the information is from professional sources, I believe in it. Facebook usage in Mongolia is too much. I find the information on Facebook to be false. I don't trust it" (Parent, countryside).*

Some families indicated in their interviews that they wished that they had been provided more information about where to get early intervention services and support after their child was fit with hearing aids and cochlear implants. One parent commented, *"Doctors should have guided us and told us about the early intervention services available and then I would have gone to them for my child" (Parent, UB).* Parents felt that the ENT doctors tended to focus on the medical condition of hearing loss and hearing technology:

"Before the surgery, I was searching the hospital websites. They encouraged getting the CI surgery. But there was no information about aftercare or what to expect after the surgery, no advice to parents on how to interact with their child. At that time, I thought that was lacking. The doctors tell us that 30% of the success of the child is from the device and 70-80% of the work depends on the parents working with their child. But there is nothing in writing about what that 70-80% is. No pamphlets or anything" (Parent, countryside).

Extended Family Influence and Support

The ENT doctors indicated that extended family can greatly influence parental response to their child's hearing loss and the decisions they make to help their child. A doctor described what happens: *"The entire family is involved in decision making. Mongolians pick up the phone and start calling relatives and say our child has a problem" (ENT doctor, UB).* Another doctor expressed, *"Parents go home and explain that their child has been diagnosed with hearing loss. The grandparents might interject and say, "That's nonsense! Our grandchild hears perfectly. Don't say that sort of nonsense!"" (ENT doctor, UB).*

Given their involvement, it is important that accurate information is conveyed to all family members about the child's situation. This can be challenging when the parents are the messengers and they are still learning and processing the diagnosis themselves. A doctor explained, *"The person who saw us has the most* *knowledge and other family members not so much. Of course, the parents probably do explain to the family members but not at our level. It also depends on how well the person giving the information to others understand it themselves" (ENT Doctor, UB).*

Parent experiences indicated that reactions from family members about hearing loss in their child can be mixed. One parent expressed positive support, "*The cochlear implant surgery was a lot of money for us. My son's both grandparents helped us financially" (Parent, countryside)*. Another parent shared, *"We called our relative who works at the Ministry of Health and told her about our situation. She recommended we get the cochlear implant done" (Parent, countryside).* In contrast, a lack of family support can add stress to an already upsetting situation. *"My husband left us because of our children's hearing loss and now I am a single mom" (Parent, UB).* Another parent shared, *"My husband was upset and did not want to know about it. Sometimes he drinks to help him forget things and release his feelings. It was difficult for our parents and my family was worried" (Parent, UB).*

Traditional Religion and Spiritual Healing

Both parents and doctors shared that some families look to religious and spiritual leaders for guidance and support in addressing their child's hearing loss. One parent shared the comfort she found: *"We will go to the lama. We want to have a blessing from the lama [for the CI surgery] and ask the lama to guide our way. My mom wants to do this since my child is going to have a surgery" (Parent, UB).* Another parent shared, *"The lama told us that we should follow the doctor. The lama would do his best to support us" (Parent, UB).*

Traditional medicine practices are sometimes perused as well. *"After finding out, we took her to all of them – lamas and shamans. We even took her to a waterfall in Bayan-Ulgii known for helping children with spasms and hearing loss because of its cold and hard drop. We tried everything that was supposed to work" (Parent, countryside).*

The advice that religious and spiritual leaders offer can sometimes contradict medical recommendations and affect timely intervention for the child. One family shared such an outcome:

“The doctors told us that my child needs a cochlear implant. My husband and I went to a shaman when we returned from UB. The shaman said your child is fine. You just gave her an unsuitable name. She will be fine and able to hear when you change her name. We believed in that shaman. We changed our daughter’s name to one given by the shaman. We lost two years. There was no improvement in her hearing after two years so we decided to go back to the hospital and we did the CI surgery” (Parent, countryside).

An ENT doctor shared another example of contradiction: *“In some cases, parents might say we went to this monk and he said our child had been startled which caused the hearing problem. It should go away on its own soon. There is no need for treatment” (ENT doctor, UB).*

III. Timely Access to Hearing Technology

Cost of Cochlear Implants and Hearing Aids

The cost of hearing technology was expressed as a major barrier for some families once they make the decision to proceed with helping their children with hearing loss be able to hear and speak. The availability of government subsidies and health insurance for hearing technology in Mongolia is unique and commendable for a lower middle-income-country (LeClair and Saunders, 2019). However, the remaining cost is still a sudden and significant expense for families to afford. *“There are a lot of financial problems. There is some help from social welfare for the hearing aids. The cochlear implant is very expensive. Even though the welfare office does give some support, the out of pocket expense is still high” (ENT doctor, UB).*

It takes time to source funding for hearing technology whether through personal savings, tapping a friends/family network for loans, or seeking government support. That means precious time is lost in a child’s development. *“Parents have the problem of not being able to afford the hearing aids they need. There are a lot of children who haven’t got the hearing aids due to financial reasons” (ENT doctor, UB).* A parent explained:

"We decided to have a cochlear implant. It has been a year already now since we have talked with the doctor. We were told that she can have a surgery at that time but we did not have enough money. We had to save. I take care of my children at home and my husband alone works. We collected some donations from our relatives and some friends beside our money" (Parent, UB).

One parent explained that while she appreciated the disability support to help finance their child's needs, it can be a slow process to secure it. *"We waited for the meeting for a long time, as it happens only once a month. They call the families one by one into a room and determine if we qualify for social welfare" (Parent, UB).*

Some families wondered why the public hospitals did not provide hearing aid services. A parent commented, *"If it was possible to get the hearing aids from the public hospitals, I would. It would be much cheaper" (Parent, UB).*

In spite of the financial challenges, the families that we interviewed demonstrated determination and resolve in getting the hearing technology needed to help their child hear. *"In order to get a cochlear implant for my daughter, my husband and I sold our car, apartment, and raised the rest of the money from charity. Now we live in a ger with our relatives. We knew that we have to make sacrifices for our child. We can get all of them back by working hard" (Parent, UB).* A parent expressed, *"Of course, there are financial challenges but we will find a way to make her healthy and develop normally" (Parent, countryside).* Another parent reflected:

"We had to come up with the 2.9 million tugriks [$1,000] for the hearing aid and when we came to get it, the price had gone up to 3.5 million tugriks [$1,260]. Then we took out a loan for 700,000 tugriks [$260] because we knew we had to get the hearing aid. The doctor said there are cheaper aids but because your child's hearing loss is on the more severe side you should get this one. We lost some time because of money. But it is important to get it for our child to hear" (Parent, UB).

Ongoing Costs Associated with Hearing Technology

Parents also need funds to cover ongoing expenses related to their child's hearing technology such as repairs, replacement parts, ear molds, programming/mapping services, and batteries. One parent described the difficulty of financing these costs:

> *"It is necessary for us to buy batteries. Every month we buy a box of batteries which costs 60,000 tugriks [$21 USD]. Then there is cord that stick from outside with magnet. It is very fragile especially in winter. It breaks down in winter. We have already changed it three times since CI surgery. It is a challenge for us because it is expensive. The cord costs 600,000 tugriks [$216 USD]" (Parent, countryside).*

Families indicated that they can apply their child's government disability allowance towards any of these hearing-related expenses. The amount they receive depends on the province in which they live but generally averages about $100 per month. A parent explained, *"The disability allowance that my child receives every month is spent on the battery of the child's hearing aids and traveling from my town to Ulaanbaatar to get services" (Parent, countryside).*

Hearing Technology Repairs

Children with hearing loss need to wear their hearing aids or cochlear implants all waking hours if they are to develop listening and spoken language (Walker, et al, 2013). Parents expressed that long wait times for hearing technology repairs are a hindrance to achieving this objective. One parent explained, *"He wore the CI for five months after the surgery. It was starting to sound like he was saying things, but the device kept breaking so we sent it to Australia for repairs. It takes very long to come back" (Parent, countryside).* Another parent indicated how the duration of time without access to sound can stunt her child's progress:

> *"When our child didn't have the hearing aid for months due to repair, he forgets how to hear and all the things he learned. He has to start over from beginning. In September, he went with his dad and got the repaired hearing aid. He can now hear again. The doctors said if he had worn it for the whole time while it was broken, he should already be speaking by now" (Parent, countryside).*

There is also a shortage of loaner devices at the hospitals for the children to use while their own devices are being repaired. A parent relegated, *"When the CI breaks then it takes forever to get fixed. We have had* *a loaner one time. But we couldn't get it the other times as they said it was used for other children" (Parent, countryside).*

IV. Habilitation Support

Location of Services

Frequent audiology appointments are necessary to monitor a child's hearing ability and hearing technology over time. The introduction of behavioral audiometry tests as the child gets older enable a more precise measurement of hearing and are important for ensuring that hearing aids and cochlear implants are optimally fit (American Academy of Audiology, 2012). New earmolds are needed every 2-3 months to accommodate hearing aid users' growing ears (Mroz, 2019). Auditory-verbal therapy sessions ideally occur on a weekly or bi-weekly basis with a qualified therapist who coaches the family on developmental strategies and activities to help their child progress. Daily sessions at specialized early education programs prepare children with hearing loss for mainstream schools.

In Mongolia, such habilitation services are entirely centered in UB. Families in the countryside reported that they are challenged by the distance and time away from work and other obligations to travel regularly to the capital, particularly for the more frequent auditory-verbal therapy appointments. A parent in the countryside explained, *"One of the biggest difficulties we have now is going for the speech therapy appointments. If we lived near UB, I would take my child to speech therapy more frequently. My husband and I live and work in the countryside so it is difficult for us to travel to UB."*

One parent commented, *"I personally think that getting online speech therapy is necessary. I come there to UB from 1000 km for 30-minute speech therapy appointment" (Parent, Countryside).*

A medical resident commented, *"If both countryside parents are employed, there is not time for the parents to go to the ENT doctor with their child. It is almost impossible to get several days off from work. In order to book an appointment and parents have to come to the hospital in person early in the morning."*

As a consequence, the countryside children have irregular access to habilitation services. A parent explained, *“There is no service for hearing loss at all in my town. We were in UB just a few weeks ago. We have discussed with the doctor to come to UB every 2-3 months for audiology and auditory-verbal therapy” (Parent, countryside).*

A few countryside parents indicated that families sometimes split up for a period of months to stay with other relatives or at a short-term residence in UB to obtain a concentrated period of support for their child:

“My mother takes care of my other son in our hometown. She takes him to school and everything. Here in UB, I live with my son with hearing loss to take him to the Dunn early intervention kindergarten. My hometown is 220 km away. They visit on the weekends.” (Parent, UB)

Parent Education

The therapists felt that, in spite of their consistent efforts to inform, parents do not always understand the role of auditory-verbal therapy in achieving successful outcomes for their children. *“That is why we need to educate people earlier about child development. Otherwise they will not understand as parents, no matter how many times we tell them about it” (Therapist, UB).*

Parents sometimes think that the hearing technology is enough and the child will develop on their own. Others get discouraged by the perceived slow progress in their child’s development as they go through the stages to learn to listen and speak. *“At first when we got the hearing aid, we had very little knowledge and thought it would work and she would start speaking. We lost almost two years. After we found out that we need auditory-verbal therapy, we have been going consistently. It was so wrong for us to think that getting the hearing aid was the end of it” (Parent, UB).*

Some parents indicated they are aware of their responsibility to follow developmental plans and activities as provided by their therapist if they want their children to progress. One parent explained, *“The speech therapist said we should not just leave the children after getting the hearing aids or CI. We must work with them continuously and therapy is a must. We should not expect the aids will do. They are only there to help* *him hear" (Parent, UB).* However, parents sometimes indicated that work and other life commitments make it difficult to commit the necessary time at home to work with their child. This was a particular challenge for those in the countryside. For example:

"We had the surgery in November and stayed in UB until end of June. During that time, we went to therapy regularly. When we came back to Khovd, our therapist in UB kept telling us don't stop practicing the strategies. I promised our therapist and left. When we got home, the work had piled up and we worked long hours. It was hard to do it" (Parent, countryside).

Another parent shared similar thoughts, *"If the parents don't work, our lives stop. We have spent all our money in UB for habilitation services and had to return to our hometown because we had to go back to work for money. So, we cannot spend the necessary time to do therapy with our children when at home." (Parent, countryside).* A therapist elaborated*, "Most of the challenges are in the countryside. Both parents need to work so there is no one to put in the required amount of time and effort with the child which means less results" (Therapist, UB).*

Cost of Habilitation Services

There is a cost associated with most habilitation support. Doctors shared with us that audiology and auditory-verbal therapy services are provided at no cost to families at public hospitals. Private clinics and hospitals offer audiology services for a fee. A government official reported that there are no public early intervention kindergarten programs for children with hearing loss available in the country. This is a challenge for working parents who need a place for their child to go while they earn income to support the family. The private Dunn early intervention kindergarten is currently the only location in the country that offers both therapy and kindergarten services for children with hearing loss. It charges families an annual fee. A doctor suggested that the fees are a challenge: *"I think parents can be slow to get therapy services for their child due to the financial costs" (ENT doctor, UB).*

Government personnel explained that the disability subsidy from the Mongolian government can be applied to offset costs associated with habilitation services. This subsidy is determined by a specialized team of doctors in each province who meet once a month to evaluate applicants. Children and parents are eligible until the child turns 16. Some parents indicated that the government officials and doctors who make the subsidy decisions are not always informed about ongoing habilitation expenses required to help their children succeed. One parent described her experience: *"When we visit the committee, the local doctors at the aimag [province] and soums [districts] and the social welfare office do not have in-depth knowledge of hearing loss and do not look at it seriously. They make decisions on who is included and excluded from support. They are not aware of the needs of children with hearing loss like they are in UB" (Parent, countryside).*

As a result, families have to advocate with local officials that even though their child can speak, he or she still has a hearing loss and that there are ongoing costs associated with helping their child succeed. One parent was successful after such an effort: *"I have an understanding with my local doctors that I can get the social welfare until my child is 16. When my other child got the cataract surgery, he no longer qualified for welfare money. I explained to our doctors that even though this child got the CI, without it he would not hear so he should receive the welfare money until he is of age" (Parent, countryside).*

Yet, there were some instances where disability support was terminated after a period of time because the child with hearing loss began to talk. One parent explained, "*Both of us used to receive the disability monthly allowance. My child received 174,000 tugriks [$63] and as a caretaker I used to receive 70,000 tugriks [$25]. After 3 years of the CI, they excluded us from the support. We are no longer getting it" (Parent, countryside).* Another parent said, *"We do not receive the disability money anymore. It is because they think he got better" (Parent, countryside).*

Human Resources

The professionals currently providing habilitation services to children with hearing loss in UB are proficient in their specialties and have the respect of the families. There also are not enough of them to meet the demand. Families expressed that long wait times at public hospitals in UB for appointments with current ENT doctors and therapists make it challenging for working parents to get necessary services for their children. *"The UB public hospitals are packed and the appointment times are not available for a month or sometimes two months out" (Parent, UB).*

Countryside parents indicated a desire for ENT doctors and therapy professionals at hospitals outside of UB so they have more proximate access to support and care. *"It is difficult for us to travel so far to come to UB. It will be helpful if there are doctors or specialists closer. It would be very helpful if there was a kindergarten for children with hearing loss in our area. It can give an opportunity for parents to work" (Parent, countryside).*

Another parent asked:

"What about the children who live 1000 or 1500 km away from UB? Those parents say there is no improvement in their children. It is because the parents do not know how to work with their kids. They don't visit the speech therapist or doctor for follow-up appointment. It is so important to have speech therapists and audiologists in the hospitals in the small towns" (Parent, countryside).

A therapist observed:

"Children in the countryside need local professionals at least in the aimag [province] centers. Having a therapist and audiology doctor there would make all the difference. It would be much easier for families to travel to the aimag centers rather than the capital. The families have hard time finding jobs in the city. They spend their savings to come to UB for a while to get services. Then leave to go back to the countryside after a week or a month of a few therapy sessions" (Therapist, UB).

Parents indicated that additional early intervention centers for children with hearing loss, particularly in the provinces, would be useful. *"There needs to be more special education facilities from the government and it would help if they were differentiated by disabilities. The government should provide public kindergartens for different levels of hearing loss" (Parent, UB).*

There are no degree programs in either audiology or speech pathology which is one contributing factor to the limited number of qualified professionals in these fields to serve the country. A therapist reported, *"There are no teachers prepared as speech therapist in Mongolia. There is new degree of special education at the Teachers University that started this year. But this is not speech therapy specifically and is designed more for children with developmental disabilities. Our speech therapists have to get education in other ways, sometimes going to other countries."*

A government representative in UB observed, *"There is a need for capacity building of ENT doctors and other medical specialists….in general, doctors nationwide are not trained well enough on hearing loss, especially family doctors and soum doctors. Primary care doctors have some small knowledge".*

Community Bias and Stigma

Families and doctors expressed that limited understanding about hearing loss has contributed to bias and stigma that can leave families feeling frustrated. They felt that if there was more knowledge at all levels of society about pediatric hearing loss and how it can be addressed through timely interventions, the journey would be made easier for them and the children. A parent commented, *"Public education is vital. There is not enough outreach or information in society about hearing loss. It is important that the general population understand" (Parent, UB).* Another parent indicated a similar view and how it affects her personally: "*Not many people in Mongolian society are positive about the subject of disability. People say the child is not normal. Even relatives say things like she gives birth to sick children. They have a pretty negative perception so I hide my son's hearing aids with hats* (Parent, countryside)."

Families suggested that community health workers, welfare officers, and social workers could be trained to provide basic information about hearing loss to the aimag communities. *"I think it would be effective if we use the welfare officers in the aimags [provinces] for increasing awareness. They are required to give training each month or quarter to the public. If one of them was about early intervention or screening and the possibility of normal development for hearing loss, then the public will receive the information better because they respond better to an official than a letter or just any person" (Parent, UB).*

Some parents expressed interest in being involved with sharing their experience and knowledge with newer parents of children with hearing loss in their local areas. *"I really like to share what I learned or know when I meet parents with children with hearing loss who don't know what to do. I tell them what opportunities their children have" (Parent, UB).*

There was an indication that families sometimes feel an uncomfortable spotlight from the community at large. *"People ask why did we get such an expensive CI surgery. Sometimes I used to get angry. People do not understand why I am trying my best to help my child hear and speak" (Parent, UB).* A doctor shared, *"With regards to hearing aids, the social perception has gotten better but not like glasses. People think of hearing aids as being for old people and are surprised to see them on a 3-month-old baby. They ask the parent is this even ok?" (ENT doctor, UB).* Another parent commented, "*A lot of people get shocked when I say my children have hearing loss but have cochlear implants and can hear very well now" (Parent, UB).*

Parents explained they have to be advocates for their children with hearing loss as they prepare them for inclusion in the education setting. One parent described her experience trying to enroll her child into mainstream kindergarten. *"I tried to send my daughter to the state kindergarten with hearing children. But the teachers were advising me to send my child in a special kindergarten instead. This even though I told them that my child has a cochlear implant and she can hear and say some words" (Parent, UB).*

A parent suggested, *"It would be helpful to have a pamphlet to give to normal school teachers about hearing loss. It should at least provide information about how to handle the devices or how to interact with children with hearing loss" (Parent, UB).* Another parent concurred, *"More training for teachers on hearing loss topics would be good. My opinion is that the normal school teachers lack awareness on this matter" (Parent, UB).*

There were a few stories about kind people in the community who emphasized with the family situation. They helped the parents and made a difference for them and their children:

“One day my son’s teacher in the normal kindergarten in my hometown said he is doing well. I will take good care of your son so you better go back to work. I am already back to work now. In order to get speech therapy treatment for my son, I used to have to go to UB. It was difficult for my family to be split between two places. I have decided instead now to send my child to the normal kindergarten where he can interact with his peers and have the support of this teacher” (Parent, UB).

DISCUSSION OF RESULTS

There are three overall indicators for how well a family and their child with hearing loss are likely to progress through the continuum of care in Mongolia: 1) their accessibility to professional expertise and services, 2) their financial wherewithal for hearing technology and habilitation, and 3) the level of awareness and understanding within their support system for pediatric hearing loss. Each of these areas are elaborated in this section.

I. Accessibility to Professional Expertise and Services

Location of residence was a significant differentiator in accessibility to expertise and services in the continuum of care. Families in the countryside are negatively affected by the fact that such expertise and services are all concentrated in UB. Newborn hearing screening should be offered at the aimag hospitals to be consistent with the country’s emphasis on health equity. Closer proximity to subsequent habilitation services would allow families to engage more regularly with professionals and other families of children with hearing loss. The localized support system would be motivating for parents and would help with greater understanding about their child’s hearing loss. All of this would result in a stronger continuum of care for rural families and improved outcomes in their children.

Expansion of Newborn Hearing Screening

Most of the babies born in the countryside are birthed at the 21 provincial hospitals. There are also six tertiary level regional diagnostic centers across the country. Building capacity at these provincial and regional health centers to administer OAE and ABR tests would cover about 83% of the babies born outside of UB. A computerized tracking system connecting all participating hospitals for oversight at NCMCH would help with patient management and program evaluation. The implementation of these elements would be a big step forward towards ensuring that all newborns in Mongolia are screened at birth for hearing loss, regardless of where they are born.

Extending Habilitation Services

The Mongolian medical community is to be commended for their commitment to newborn hearing screening and habilitation services in UB. They work hard in the face of limited resources. The parents we interviewed often expressed their satisfaction on the quality of services rendered. The challenge now is to continue to develop the skills of current professionals in UB while extending their expertise to areas outside of the capital so that families in the countryside can more easily obtain the local support they need to help their children progress.

Training and Professional Development

To address the need for more professionals in ear and hearing care, some ENT doctors and therapists suggested that Mongolia would benefit from an accredited degree program in audiology and speech language pathology (which is a precursor to specialization in auditory-verbal therapy). Such an academic program would increase awareness of these fields with prospective students in Mongolia and create a local pipeline of future professionals. Currently, Mongolian ENT doctors and therapists travel to South Korea, Russia, and other locations to obtain such specialized education.

Beyond the professional sector, community health workers, welfare officers, and social workers could be trained to provide basic information about hearing loss to the aimag communities. Likewise, current parents of children with hearing loss could potentially be trained and empowered to share their knowledge and experiences with parents of newly identified children to expand the information available to families.

The Global Foundation For Children With Hearing Loss has provided in-country training programs in audiology and auditory-verbal therapy to Mongolian doctors, teachers, and therapists in UB since 2017. The Global Foundation employs a “train the trainer” model whereby its accredited audiology and auditory-verbal therapy professionals, mostly from the United States, travel to Mongolia to teach a curriculum to the same Mongolian doctors, teachers, and therapists over time to enhance their knowledge and support their practice. The organization also provides parent education sessions. Those who attend the Global Foundation training programs are ultimately prepared to share their learning with others in Mongolia to make the benefits repeatable and sustainable.

Telehealth

Given the vast terrain and widely spaced population centers that make up the Mongolia countryside, telehealth could be a useful mechanism for extending training to professionals outside of UB. Introductory concepts in ear and hearing care could be introduced to increase awareness among pediatricians and ENT doctors. Should the countryside hospitals acquire audiological equipment, training could expand to include audiology. Mongolia had success with a telemedicine network, supported by the Luxemburg government and the UN Population Fund, that enabled consultation on patient care between maternal health specialists in UB and countryside doctors working in the provincial hospitals (Jenkins, et al, 2015). The concept has been proven and could be applied to hearing health care as well.

Telehealth tools are also being used in several countries including Australia and the United States (Constantinescu, 2012; Galvan et al, 2014) to scale individual auditory-verbal therapy services between therapists and parents across urban and rural contexts. Therapists coach parents at their homes through an Internet connection on strategies and activities to carry out with their child. This approach could be a valuable offering to enable parents in the countryside to stay connected with, and learn from, their UB therapists on a more regular basis.

Early Intervention Facilities

The Mongolian government provides mainstream kindergarten education at no charge to families. In addition to fixed location facilities, the public education system offers mobile teachers who visit homes for individual instruction and a ger kindergarten program which serves groups of families in transportable gers. These programs help to meet the unique educational needs of young children living in rural areas and in nomadic families (World Bank, 2017). Perhaps these kindergarten programs could be expanded to include children with hearing loss as well. For instance, a mobile teacher with appropriate training could provide individual therapy sessions at the homes of families of children with hearing loss living in specific region. The current ger kindergarten program could include children with hearing aids and cochlear implants. Children with hearing loss benefit from interaction with typically hearing peers and the typically hearing children learn empathy and awareness about hearing loss from those with the hearing aids and cochlear implants.

In recent years, the Mongolia government has increased investment in mainstream preschool and kindergarten programs through its "Sustainable Development Vision 2030 program." The goal to strengthen early childhood education so that every child is enrolled in pre-school and kindergarten education facilities. It is a well-funded program supported by the government and private donors. The World Bank reports that "mainstream preschool and kindergarten education in Mongolia is free. In terms of both expenditure as a percent of GDP (1%) and as a percentage of total public expenditures on education (24%), Mongolia spends more on preschool education compared to other middle-income countries, including advanced OECD economies" (World Bank, 2017). Government officials could potentially be encouraged to include early intervention programs for children with hearing aids and cochlear implants in the Sustainable Development Vision 2030 program so these children too have the government-funded, early education support they need to be prepared to join mainstream schools by first grade.

II. Financial Wherewithal

Hearing Technology

Hearing technology is essential for a child with hearing loss to be able to learn to listen and speak. It is also a costly investment. Mongolian families are fortunate to have financial aid from the government and insurance for hearing technology, a rare benefit in lower income countries. To further support families, no-interest payment plans for hearing aids could potentially be offered to help children get hearing aids faster without creating additional financial burden. Seeking donations of used, but functioning hearing aids and cochlear implant processors could support a repository of loaner devices to keep a child hearing and progressing in their language development while their own technology is sent for repairs. Loaner devices could also be issued on a short-term basis to children who ultimately need a cochlear implant but whose parents need time to save money for the device and surgery. The children could get some benefit from the hearing aids in the meantime.

Longer term, the government could consider negotiating a bulk purchasing contract to supply quality hearing aids to families in need through the public hospital system. Such sourcing would require a corresponding investment in human resources, training, and additional audiology equipment to support hearing aid fittings. However, the upside is that a child could be diagnosed with hearing loss and provided immediate hearing aid services in the same public hospital instead of being referred out to private clinics for that care. NCMCH already provides cochlear implant surgery and mapping services so it may be appropriate to add hearing aids to their offering of services.

III. Community Support

The ultimate goal of early identification and early intervention is to successfully integrate children with hearing loss into mainstream schools and society at large (Yoshinaga-Itano, et al, 1998). Such assimilation does not occur in a vacuum, however. Parents are working to address hearing loss in their children but felt that greater awareness and understanding at all levels of society about hearing loss in young children and the possibility for them to learn to listen and speak would be helpful for acceptance and for removing barriers.

The families and professionals we interviewed had many ideas on this topic. They suggested working with the Ministry of Health and Public Health departments to create a national educational campaign about hearing loss, perhaps tied in with the international May 3 World Hearing Day. They recommended video and social media messages, featuring interviews with doctors and families of successful children on television news television, and short segments on the informational marquees in the hospital waiting rooms. Informational pamphlets could also be produced for new parents as part of the hearing screening test process and to families after confirmation of hearing loss in their children.

Parents and professionals alike agreed that no matter the medium, awareness efforts for hearing loss would help with making timely decisions and reduce some of the stigma and misinformation that families face. Families also need to be informed of communication options for their child with hearing loss and where to go for appropriate intervention services to support whatever modality they ultimately choose. For families who choose listening and spoken language, this means audiology support and enrollment into auditory-verbal therapy and early intervention programs. Advocacy with government officials on the local and national levels would help to strengthen and expand existing hearing health services as well.

Study Limitations

The families who participated in our interviews are currently in the system of care. A follow up study that locates and interviews families of children with hearing loss who have never pursued services or have dropped out of the system may be useful for additional perspectives.

This study specifically focused on understanding the enablers and barriers that families of children with hearing loss learning to learn to listen and speak. Our study did not include families who chose sign language or other communication modalities for their children. The services and support that those families need and the corresponding enablers and challenges they experience are likely somewhat different and thus were out of the scope of this particular study.

Conclusion

Four equally important elements must be in place in a continuum of care for successful outcomes in young children with hearing loss: a) early identification of hearing loss, b) family engagement, c) hearing technology, and d) access to local professionals trained in habilitation. Our discussions with professionals and families in Mongolia indicated that the country has laid a basic, if limited, foundation of early identification and habilitation services and expertise. Analysis of the data indicates that an investment in expanding these benefits beyond the capital of UB along with increased awareness about pediatric hearing loss across Mongolian society, and additional financial support for families are opportunity areas. Addressing these areas would contribute to advancing pediatric hearing health services so that more children with hearing loss in Mongolia can learn to listen and speak and reach their full potential.

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APPENDIX

Table 1. Study population that engaged in the interviews and focus groups

PROFESSIONALS				FAMILIES		
	Medical professionals and residents	**Early intervention Therapists**	**Government personnel**	**Family members of children with hearing loss (HL) 0-2 years of age**	**Family members of children with hearing loss (HL) 2.5-5 years of age**	**Family members of children with hearing loss (HL) 5+ years of age**
Count and Location of Workplace/ Residence	• 10 medical professionals based in UB • 20 medical professionals based in provinces • 8 residents based in UB	3 based in UB	4 based in UB	• 6 living in UB • 5 living in provinces	• 5 living in UB • 6 living in provinces	• 2 living in UB • 2 living in provinces
Gender	40 women 5 men			23 women 3 men		
Age of Participant	≥18 years	≥18 years	≥18 years	≥18 years	≥18 years	≥18 years
Inclusion	Experience working with children with hearing loss	Experience with children with hearing loss using hearing technology	Knowledge of government newborn health policy and/or disability support	Currently receive or have received audiology/therapy/early intervention services for their children with HL and Have babies or children with HL using, or in process of obtaining, hearing technology to learn to listen and speak		

Figure 2. Conceptual model