Access to Healthcare in Nepal for People who are Hard of Hearing

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Client leaning to hear during a reception interaction

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I would like to express my great appreciation to my advisor, Dr. Ruth Warick, President of the International Federation of Hard of Hearing People (IFHOH). Dr. Warick guided me and provided various documents for literature reviews and advised on the methodology for the study and all phases of its implementation, including the preparation of this report. I thank her for her immense support and for making it possible for me to complete this Fellowship.

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Neeta Keshary
Fellow, Access to Healthcare
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## Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>CBS</td>
<td>Central Bureau of Statistics</td>
</tr>
<tr>
<td>CI</td>
<td>Cochlear Implant</td>
</tr>
<tr>
<td>COVID</td>
<td>Corona Virus Disease</td>
</tr>
<tr>
<td>COVID-19</td>
<td>Corona Virus Disease of 2019</td>
</tr>
<tr>
<td>CRPD</td>
<td>United Nations Convention on the Rights of Persons with Disabilities</td>
</tr>
<tr>
<td>dB</td>
<td>Decibel</td>
</tr>
<tr>
<td>DID</td>
<td>Disability Inclusive Development</td>
</tr>
<tr>
<td>GDP</td>
<td>Gross Domestic Product</td>
</tr>
<tr>
<td>GoN</td>
<td>Government of Nepal</td>
</tr>
<tr>
<td>HA</td>
<td>Hearing Aid</td>
</tr>
<tr>
<td>HDI</td>
<td>Human Development Index</td>
</tr>
<tr>
<td>HI</td>
<td>Humanity and Inclusion</td>
</tr>
<tr>
<td>HLPF</td>
<td>High Level Political Forum</td>
</tr>
<tr>
<td>IDA</td>
<td>International Disability Alliance</td>
</tr>
<tr>
<td>IDS</td>
<td>Institute of Development Studies</td>
</tr>
<tr>
<td>IDS</td>
<td>Disability Inclusive Development Nepal</td>
</tr>
<tr>
<td>IFHOH</td>
<td>International Federation of Hard of Hearing People</td>
</tr>
<tr>
<td>NFDN</td>
<td>National Federation of Disabled Nepal</td>
</tr>
<tr>
<td>SDA</td>
<td>Sustainable Development Agenda</td>
</tr>
<tr>
<td>SDG</td>
<td>Sustainable Development Goals</td>
</tr>
<tr>
<td>SHRUTI</td>
<td>National Association of the Hard of Hearing and Deafened Nepal</td>
</tr>
<tr>
<td>UN</td>
<td>United Nations</td>
</tr>
<tr>
<td>UNDP</td>
<td>United Nations Development Program</td>
</tr>
<tr>
<td>VNR</td>
<td>Voluntary Review Process</td>
</tr>
<tr>
<td>WB</td>
<td>World Bank</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
</tr>
</tbody>
</table>
Executive Summary

Health professionals lack knowledge and understanding of the communication and access needs of hard of hearing persons. This finding arose from a study of the hearing health access of hard of hearing persons in Nepal. Eleven hard of hearing persons shared their perceptions for this qualitative study that was completed from March 2021 to June 2021, under the auspices of the International Federation of Hard of Hearing People and the International Disability Alliance.

Other significant findings from the study are that communication barriers impede the access of hard of hearing persons to accurate information during their medical visits. Health providers were found to be unaware of communication strategies for interacting with hard of hearing persons and to be unaware of the range of available accommodations. The interactions at reception services were particularly problematic given that these tend to be noisy environments. Even a simple thing like making a medical appointment was a huge challenge for hard of hearing persons; many of them got someone else to do it for them, depriving them of their own independence.

Most persons who are hard of hearing do not have their own medical doctor and, therefore, their access to healthcare is through a hospital or clinic. These environments were found to be noisy environments, making communication even more difficult.

The study found that access to health for people who are hard of hearing was not prioritized during the COVID pandemic, as many hard of hearing could not visit a hospital to deal with an ear infection and other ear health-related issues. Respondents to the study reported not being able to obtain hearing aids or cochlear implants, thus affecting their ability to hear during the pandemic. Even getting batteries for hearing devices was a problem.

The widespread use of face masks during the COVID pandemic and the requirement for social distancing also created additional barriers for hard of hearing persons. The hard of hearing participants in the study reported that they could not understand what had been said about their health, as they could not lip read due to opaque face masks.

Most respondents taking part in the study had their hearing loss detected when they were older and, consequently, their use of hearing aids or cochlear implants also lagged behind. This calls for early intervention and hearing screening programs for persons of all ages, with rehabilitation being a key component resulting from the identification of persons with hearing losses.

One of the fundamental problems in Nepal is that hearing losses from mild to moderate levels (30dB to 64dB) are not recognized as a disability by the government. Due to the lack of recognition, many hard of hearing persons are excluded from being provided with accommodations and access to healthcare. A key recommendation of the report is for governmental recognition of hard of hearing persons with mild to moderate hearing losses.

Other recommendations in the report call for training for health professionals and staff about hearing loss, the development of resource materials for professionals, improvements in the acoustical environment of hospitals and medical facilities, the early identification of hearing loss accompanied by appropriate rehabilitation, and the establishment of protocols for accessible communication in risk-adverse situations. A concluding recommendation calls for a recognition of the role of hard of hearing persons and their organizations in creating awareness about hearing loss and their accessibility needs.
Introduction

During the past two years, from 2020 into 2022, the COVID-19 pandemic wrought major changes in the everyday lives of every citizen on the planet. It impacted hugely on the access to healthcare services of hard of hearing persons. A survey conducted for international hard of hearing organizations during the pandemic revealed that the use of covered masks, social/physical distancing and restrictive practises impacted negatively on many hard of hearing persons (Warick & Tang, 2020). Even during the best of times, persons who are hard of hearing often face barriers to access to healthcare services due to a lack of accessibility and communication challenges. Yet, there is little documentation of the impact of the COVID pandemic and the access to healthcare services experienced by hard of hearing persons in developing countries. To rectify this gap, a study was undertaken about the accessibility and communication issues faced by hard of hearing persons in Nepal during the pandemic. The study was undertaken from March to June 2021. This document is a report of the findings.

The study was undertaken by Neeta Keshary as the Fellow on Hearing Access to Healthcare for the International Federation of Hard of Hearing People (IFHOH) and the International Disability Alliance. Her position commenced mid-January 2021, and continued to the end of to September 2021, under the supervision of Dr. Ruth Warick, President of IFHOH. Dr. Warick also served as primary editor for this report.

Dr. Ruth Warick

Ms. Neeta Keshary
Country Fact and Figures

Nepal is a landlocked country which lies between India and China. It is relatively remote with landscape ranging from plains in the south, and hilly and mountainous regions in the north. The climate is diverse and ranges from tropical to high-altitude.

People of Nepal are called Nepalese. Nepali customs can usually be linked to Hindu, Buddhist or other religious traditions. There are ten religious categories reported in the census 2011. Hindu is followed by 81.3 percent (21,551,492) of the population followed by Buddhism (9%; 2,396,099), Islam (4.4%; 1,162,370), Kirat (3.1%; 807,169), Christianity (1.4%; 375,699), Prakriti (0.5%; 121,982), Bon (13,006), Jainism (3,214), Bahai (1,283) and Sikhism (609)\(^1\).

According to the United Nations Development Program Human Development\(^2\) 2019, Nepal ranks 147 out of 189 countries, which is two spots better than in the previous year. Nepal acquired a rating of 0.579 on the Human Development Index (HDI) in 2018, which places the country in the medium Human Development category.
According to the national population census of 2011, Nepal’s population stands at 26,494,504, of which 513,321 (1.94 percent of the national population) live with some kind of disability (CBS, 2011a)\[4\]. However, another survey conducted by the Government of Nepal in 2011 states that 3.6 percent of people have some kind of disability (CBS, 2011b)\[5\]. Among the latter group of persons with disabilities, physical disabilities constitute 36.3%, followed by blindness/low vision (18.5%), deaf/hard of hearing (15.4%), speech problem (11.5%), multiple disabilities (7.5%), mental disability (6%), intellectual disability (2.9%) and deaf-blind (1.8%).

The census figures are quite low as compared to the disability prevalence claimed by the World Health Organization and the World Bank\[6\], both of whom estimate that persons with disabilities represent 15 percent of the world’s population, of whom 80 percent live in developing countries. Hence, the actual number of persons with disabilities in Nepal can be conjectured as being much more than the above official numbers, possibly because people do not want to disclose their disability.
Policy Review

Disability rights are included in two major pieces of legislation: the Constitution of Nepal (2015) and the Act relating to the Rights of Persons with Disabilities (2017). The latter legislation assigns national-level responsibility for persons with disabilities to the Ministry of Women, Children and Senior Citizens and the National Disability Direction Committee. At the village and municipality levels, disability coordination committees are expected to be responsible for implementing disability rights.

The Constitution of Nepal of 2015 guarantees human rights and fundamental freedoms to all citizens. As a result, different measures have been identified to end all forms of discrimination against persons with disabilities, and to promote meaningful participation and full accessibility of healthcare. More specifically, the Constitution also declares that every citizen shall have the right to free basic health services[7] from the state and no one shall be deprived of any emergency health services. Article 35 of the constitution further states that every citizen shall have the right to basic health services and necessary therapy services, including speech therapy and occupational therapy, from the state free of cost as provided in the law for the persons whose annual income is less that the income prescribed. Article 42 of Nepal’s Constitution states that citizens with disabilities shall have the right to live with dignity and honor, recognizing the diversity of their identity, and to have equal access to public services and facilities.

The Constitution of Nepal also declares that healthcare is a fundamental right. Under Article 35(2), it states that every person shall have the right to get information about his/her medical treatment. Similarly, Article 35(3) says that every citizen shall have equal access to health services.

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) recognizes that the rights of people with disabilities to fundamental health services and reasonable accommodation need to be ensured (UN General Assembly, 2007)[8]. The Government of Nepal ratified the CRPD in 2010; its Article 25 on Health refers to equal access to health services for persons with disabilities, but other articles of the CRPD are also relevant for healthcare, including Article 9 on Accessibility that calls for accessibility and refers to accessibility in the provision of information, facilities, and services. Article 26 is also relevant, referring to habilitation and rehabilitation. It also discusses training of staff and the promotion of assistive devices and technologies for persons with disabilities.

The CRPD Committee is mandated to monitor a State’s compliance with their obligation under the Treaty[9]. This Committee is the body of independent experts which monitors the implementation of the Convention by States Parties. All States parties are obliged to submit regular reports to the Committee on how the rights are being implemented. The Committee examines each report and makes suggestions and general recommendations on the report as it may consider appropriate and shall forward these to the State Party concerned. The Committee also reviews shadow reports submitted by the disability community in drafting its own report.

Nepal’s Government submitted its report to the CRPD Committee in January 2018, and a consortium of disabled people’s organizations submitted a shadow report to the CRPD committee in 2017[10].
Among the issues raised was the need to ensure barrier-free communication for persons with hearing disabilities in hospitals, and to recognize persons are hard of hearing in keeping with World Health Organization standards. Currently only persons with a loss of 60 decibels or greater are recognized by the Government as having a disability, whereas WHO defines disabling hearing loss as greater than 40dB in the better hearing ear in adults, and 30dB in the better hearing ear in children\[11\].

The CRPD Committee released its observations of the consortium’s shadow report in 2018\[12\]. The Committee expressed concerns that persons with disabilities have limited access to comprehensive health and rehabilitation services, particularly in rural and remote areas. The committee recommended that the State should develop measures to ensure comprehensive access to health services for persons with disabilities, and also to strengthen the provision of comprehensive community-based rehabilitation services.

In 2015, Nepal, as a member of the UN, signed the 2030 Sustainable Development Agenda (SDA). The SDA sets out 17 goals that define globally sustainable development goals (SDG) for 2030. SDG Goal #3 relates to universal health coverage, including financial risk protection, access to quality essential healthcare services, and access to safe, effective, quality and affordable essential medicines and vaccines for all, including persons with disabilities.

The Voluntary Review Process\[13\] is a reporting mechanism established by the UN to measure SDG progress. Reviews are country-led and serve as a basis for regular reviews by the high-level political forum (HLPF), under the auspices of the UN Economic and Social Council. Nepal has been reviewed twice through the Voluntary National Review process. The second VNR report on Jun, 2020\[14\], discussed challenges to ensure access to each and every citizen of Nepal to health services, especially for marginalized communities. The report discussed access to quality of health services as being crucial for the safety of human lives. Additional findings were that COVID-19 poses serious threats to the achievements on quality of health to-date, and that health services are quite expensive, and thus are not affordable by all citizens.

COVID Policy in Nepal

According to a rapid needs assessment conducted by Humanity and Inclusion, *An inclusive response to COVID-19 in Nepal*\[15\], the COVID-19 situation is an extreme health crisis in Nepal. It worsened social inequalities, with a multiplied negative impact on persons with disabilities. The report considers that persons with disabilities faced major barriers to protect themselves and their family from COVID-19, as well as barriers to getting accessible information on health, and access to healthcare services and social support. It also explained that persons with disabilities are at higher risk of contracting and developing severe cases of COVID-19, as the infection worsens existing health conditions. Persons with disabilities are also at higher risk of being discriminated against when seeking care and support, along with a higher risk of isolation.

According to the article\[16\], *Rapid Assessment of Covid-19 Related Policy Audit in Nepal*, the Government of Nepal developed a number of policies and guidelines, and adopted different strategies to control COVID-19. However, the guidelines were beyond the understanding of the general population. It also found that government policies and guidelines had not considered the accessibility needs of persons who are hard of hearing.
Situation Analysis Regarding Access to Healthcare in Nepal for People who are Hard of Hearing

The Act regarding the Rights of Persons with Disabilities, 2017[17] in its Chapter 7 on health, rehabilitation, social security and recreation, states that the State shall make necessary provisions to remove the access barriers for persons with disabilities to hospitals. The Act does not adequately reference persons with hearing disabilities, and as a result, many hard of hearing people are not included in disability categories[18] and have not been provided disability identity cards to get services. According to an article about COVID on the IDA website, many persons who are hard of hearing could not access needed information and health services adequately due to not having proper access to captioning, note-takers, sign supporters, visual display, and communication support services in Nepal[19].

According to ‘Living Conditions among People with Disabilities in Nepal: A National Representative Study’ more than 40% respondents reported that they did not receive health services even though they needed it[20].

The Institute of Development Studies (IDS) has prepared Situational Analyses (SITANs)[21] where it is reported that persons with disabilities experienced stigma, prejudice, and marginalization, which excluded them from daily life. Persons with disabilities have more health issues as they have limited access to healthcare and rehabilitation services. Furthermore, it reports that there are many barriers in healthcare and treatment/rehabilitation centers, such as, lack of accessible health information, negative attitudes, and lack of understanding of disability by health workers.
Research Design and Methodology

Research Design

The study focused on the experiences and perceptions of hard of hearing persons in Nepal in accessing healthcare services during the COVID-pandemic period. The focus of the study was on the impact of their hearing disability on accessing healthcare services during a twelve-month period, from March 2020 to June 2021. The study considered whether the accessibility needs of hard of hearing persons were met, and if not, the challenges that were faced. Their perceptions of the knowledge and understanding of healthcare providers was an important element of the study.

A literature review was undertaken of relevant sources as reported in the literature review section of this report. The data and information were collected through the following organizations: the International Disability Alliance (IDA), the International Federation of Hard of Hearing People (IFHOH), and SHRUTI, the hard of hearing peoples’ organization in Nepal. The data sources were from three district levels in Nepal: Kathmandu, Rupandehi, and Chitwan.

Based on the review, a semi-structured questionnaire was developed. Hard of hearing respondents
were selected through SHRUTI and its networks. Three participants were interviewed in person and eight participants were provided the questionnaire by electronic means; they returned completed responses in writing.

For purposes of this study, hard of hearing persons were those who self-identified as being hard of hearing. The definition of hard of hearing by the International Federation of Hard of Hearing People is as follows:

“Hard of hearing usually refers to persons with varying degrees of hearing loss who communicate primarily by spoken language. A hard of hearing person may use hearing aids and/or cochlear implants and may supplement residual hearing with assistive listening devices”[22].

Data Analysis
The data collected from the questionnaires was entered and tabulated in a Word document. Tables were prepared on the demographic information and various responses, as shown in this report. For the open-ended questions, the answers of the respondents were grouped according to keywords and analyzed for common themes.
Findings

Demographic Profile of the Respondents

Seven of the 11 survey respondents were from Kathmandu and the rest were from other parts of Nepal. Seven respondents were female and four respondents were male. Eight of the respondents had completed university at an undergraduate level, and two of them had completed postgraduate education. One respondent’s highest level of completed education was at the high school level.

The survey questionnaire was provided in English. Explanations and interactions were provided in the Nepali language. As per any request from respondents, terminology that they found difficult to understand was explained in the Nepali language.

Five of the respondents identified as being indigenous persons. Their mother tongue is other than Nepalese. Due to a language barrier, two respondents who live outside of Kathmandu were assisted in completing the questionnaire by friends who spoke Nepali. The other three indigenous participants had sufficient grasp of the Nepalese language to complete the questionnaire on their own.
The employment status of the respondents was mixed. Four respondents were students and four were employees. One respondent was self-employed in his own business, having retired from salaried work. Another respondent was unemployed.

Regarding marital status, nine respondents were single and only two respondents were married.

Five respondents were between the ages of 26 to 35 years. The next largest age group was 18 to 25 years; four respondents were in this category. One respondent was between 36 to 45 years old and one respondent was above 56 years old. The following table summarizes the demographic profile of the respondents.

**Table 1. Demographic profile of the respondents**

<table>
<thead>
<tr>
<th>Demographic profile</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>4</td>
</tr>
<tr>
<td>Female</td>
<td>7</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
</tr>
<tr>
<td>High School</td>
<td>1</td>
</tr>
<tr>
<td>Undergraduate</td>
<td>8</td>
</tr>
<tr>
<td>Postgraduate</td>
<td>2</td>
</tr>
<tr>
<td><strong>Residence</strong></td>
<td></td>
</tr>
<tr>
<td>Kathmandu (capital city)</td>
<td>7</td>
</tr>
<tr>
<td>Nepal (excluding Kathmandu)</td>
<td>4</td>
</tr>
<tr>
<td><strong>Employment</strong></td>
<td></td>
</tr>
<tr>
<td>Student</td>
<td>4</td>
</tr>
<tr>
<td>Employee</td>
<td>4</td>
</tr>
<tr>
<td>Self-employed</td>
<td>1</td>
</tr>
<tr>
<td>Retired from employment</td>
<td>1</td>
</tr>
<tr>
<td>Unemployed</td>
<td>1</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>9</td>
</tr>
<tr>
<td>Married</td>
<td>2</td>
</tr>
<tr>
<td><strong>Age Group</strong></td>
<td></td>
</tr>
<tr>
<td>18-25 years old</td>
<td>4</td>
</tr>
<tr>
<td>26-35 years old</td>
<td>5</td>
</tr>
<tr>
<td>36-45 years old</td>
<td>1</td>
</tr>
<tr>
<td>46-55 years old</td>
<td>-</td>
</tr>
<tr>
<td>56 above years old</td>
<td>1</td>
</tr>
</tbody>
</table>
Hearing Status

All respondents reported having a bilateral hearing loss. Five of them reported a moderate hearing loss; three, a severe hearing loss; and three, a profound loss.

The age of onset of the hearing loss varied considerably, with only two persons reporting having the hearing loss identified before they turned one year old. As shown in Table 2, the age of discovery of the hearing loss ranged from childhood up to early adulthood for most of the other participants. Five persons were aware of the cause of their hearing loss: ear infection, contaminated water, ear damage, pneumonia and premature birth.

Most respondents reported not having other family members with a hearing loss. Two persons reported another sibling has a hearing loss and one reported a parent having a hearing loss.

Table 2. Hearing loss and functioning

<table>
<thead>
<tr>
<th>Hearing Functioning</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bilateral</td>
<td>11</td>
</tr>
<tr>
<td>Moderate</td>
<td>5</td>
</tr>
<tr>
<td>Severe</td>
<td>3</td>
</tr>
<tr>
<td>Profound</td>
<td>3</td>
</tr>
<tr>
<td>Less than one year</td>
<td>2</td>
</tr>
<tr>
<td>1-5 years old</td>
<td>-</td>
</tr>
<tr>
<td>6-10 years old</td>
<td>2</td>
</tr>
<tr>
<td>11-15 years old</td>
<td>3</td>
</tr>
<tr>
<td>16 to 20 years old</td>
<td>3</td>
</tr>
<tr>
<td>21 to 25 years old</td>
<td>1</td>
</tr>
</tbody>
</table>
Access to Hearing Devices

Nine of the respondents used hearing devices and only two respondents did not use any type of hearing device, although one of them had used a hearing aid infrequently for less than two months. (She did not continue to use it because she felt she could not understand speech even with its use.) Among those using hearing devices, six respondents wore hearing aids and two persons wore cochlear implants. In addition, one person used both a cochlear implant and a hearing aid.

Use of a hearing aid was reported to be fairly late, with only one person reporting its use before age 10 years. Five persons reported wearing hearing aids between 11 to 20 years old and four of them used hearing devices after 21 years old.

Regarding the method of communication, nearly three-quarters of respondents stated they preferred the communication by speech/oral means including listening and lip reading. One person used both sign language and speech together, and another used a mixture of gestures and body language. Two respondents reported using a combination of written and oral communication. Results are shown in Table 3.

Table 3. Access to hearing devices and communication types

<table>
<thead>
<tr>
<th>Access to Hearing Device</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Usage of hearing devices</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>9</td>
</tr>
<tr>
<td>No</td>
<td>1</td>
</tr>
<tr>
<td>Stopped using devices</td>
<td></td>
</tr>
<tr>
<td>Hearing Aid</td>
<td>6</td>
</tr>
<tr>
<td>Cochlear Implant</td>
<td>2</td>
</tr>
<tr>
<td>Bone Conductive</td>
<td>-</td>
</tr>
<tr>
<td>Combination of HA and CI</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>-</td>
</tr>
<tr>
<td>Age when started using hearing device</td>
<td></td>
</tr>
<tr>
<td>Less than 10 years old</td>
<td>1</td>
</tr>
<tr>
<td>11 – 20 years old</td>
<td>5</td>
</tr>
<tr>
<td>More than 21 years</td>
<td>4</td>
</tr>
<tr>
<td>Types of communication</td>
<td></td>
</tr>
<tr>
<td>Speech/Orally/Listening</td>
<td>8</td>
</tr>
<tr>
<td>Sign language &amp; Speech Mix</td>
<td>1</td>
</tr>
<tr>
<td>Gesture Sign and Body Language</td>
<td>1</td>
</tr>
<tr>
<td>Speech and Writing on Paper</td>
<td>2</td>
</tr>
</tbody>
</table>
Access to Healthcare in First Language

In Nepal, there are 123 languages, spoken as mother tongue, according to the national census 2011. Nepali is spoken as mother tongue by 44.6 percent of the total population[24]. Remaining nationals speak in other languages such as Maithili, Bhojpuri, Tharu, Tamang, Newar, Bajjika, Magar, Doteli, and Urdu. Nepal has a diversity of ethnic groups according to a national census conducted in 2011 - there are 126 caste/ethnic groups.

A research question was framed around whether respondents can communicate with their health provider in their own first language. Nearly two-thirds of respondents reported that they were able to get health services in their first language. When accessing health services in a hospital, clinic, and audiology center, eight of the respondents stated that they could access health services in their first language. The other three respondents reported that they do not usually access health services in their first language. Two of these respondents were indigenous persons living in rural areas. As a result, they experienced barriers in communicating directly with health providers. To overcome difficulties, they required friends or other staff to act as translators.

“We could not understand detailed explanations on our medical situation in our language; we felt like a fool about own medical condition”

Reported one of respondent on difficulties in access to healthcare in her first language

Table 4. Access to health services in respondents’ first language

<table>
<thead>
<tr>
<th>Access to health service</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>8</td>
</tr>
<tr>
<td>No</td>
<td>3</td>
</tr>
<tr>
<td>Most of the time</td>
<td>7</td>
</tr>
<tr>
<td>Sometimes</td>
<td>1</td>
</tr>
<tr>
<td>Not usually</td>
<td>3</td>
</tr>
</tbody>
</table>

Those respondents who reported language barriers expressed that they had difficulties understanding their health professional, communicating with them, and having access to accurate information as shown in Table 5.

Table 5. Language Barriers to health services

<table>
<thead>
<tr>
<th>Barriers on getting information</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Difficulties communicating with health professionals</td>
<td>4</td>
</tr>
<tr>
<td>Difficulties accessing accurate and comprehensive health information</td>
<td>3</td>
</tr>
<tr>
<td>Difficulties understanding what is being communicated by doctors and other health professionals</td>
<td>5</td>
</tr>
<tr>
<td>No barriers experienced as person is often accompanied by someone</td>
<td>1</td>
</tr>
</tbody>
</table>
Health Status

Nearly half of the surveyed hard of hearing persons had health issues in the past 12 months, (all during the COVID pandemic). Many of them reported having ear infections. One person reported being infected with COVID-19.

Eight persons reported requiring medical care; the remaining three respondents did not require any medical care for their health condition. Most reported having a moderate condition; none reported a serious condition. Two persons reporting a moderate condition were hospitalized for 1 to 5 days.

Among those requiring medical care, seven persons stated that they were satisfied with the medical care they received, giving a satisfactory rating on a five-point scale; another four persons were not satisfied, giving a dissatisfied rating.

Table 6. Health condition of respondents and their healthcare during the pandemic

<table>
<thead>
<tr>
<th>Health Condition during Pandemic</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Issues in health condition</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>5</td>
</tr>
<tr>
<td>No</td>
<td>6</td>
</tr>
<tr>
<td><strong>Infected by COVID</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>1</td>
</tr>
<tr>
<td>No</td>
<td>10</td>
</tr>
<tr>
<td><strong>Requirement of medical care during 12 months (pandemic)</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>8</td>
</tr>
<tr>
<td>No</td>
<td>3</td>
</tr>
<tr>
<td><strong>Impact on health condition</strong></td>
<td></td>
</tr>
<tr>
<td>Mild</td>
<td>2</td>
</tr>
<tr>
<td>Moderate</td>
<td>6</td>
</tr>
<tr>
<td>Serious</td>
<td>-</td>
</tr>
<tr>
<td>Very Serious</td>
<td>-</td>
</tr>
<tr>
<td><strong>Hospitalization</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>2</td>
</tr>
<tr>
<td>No</td>
<td>8</td>
</tr>
<tr>
<td><strong>Duration of hospitalization</strong></td>
<td></td>
</tr>
<tr>
<td>Less than one day</td>
<td>-</td>
</tr>
<tr>
<td>1-5 days</td>
<td>2</td>
</tr>
<tr>
<td>6 to 14 days</td>
<td>-</td>
</tr>
<tr>
<td>Longer</td>
<td>-</td>
</tr>
<tr>
<td><strong>Level of satisfaction on medical care</strong></td>
<td></td>
</tr>
<tr>
<td>Very Satisfied</td>
<td>-</td>
</tr>
<tr>
<td>More than satisfied</td>
<td>-</td>
</tr>
<tr>
<td>Satisfied</td>
<td>7</td>
</tr>
<tr>
<td>Unsatisfied</td>
<td>4</td>
</tr>
<tr>
<td>Very Unsatisfied</td>
<td>-</td>
</tr>
</tbody>
</table>
Access to Health Services

Four respondents reported getting health information from their health facility; four through the internet; and five from family members.

Most respondents did not have their own family doctor; very few have a doctor whom they regularly visit. Most respondents reported going to a hospital or a clinic for checkups and care. Some respondents explained that they did not have direct access to a doctor. They noted that it is easy to book an appointment in a private clinic. They said it was more complicated to get an appointment at a hospital which required that they register with the outpatient department first. Only one person reported having private medical insurance. Most reported relying on publicly-financed facilities, i.e. hospitals or clinics.

The following table summarizes the respondents’ information on access to healthcare.

Table 7. Respondents’ Information on Access to Health Services

<table>
<thead>
<tr>
<th>Access to Health Service</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Way of getting information on health situation</td>
<td></td>
</tr>
<tr>
<td>From own health facility</td>
<td>4</td>
</tr>
<tr>
<td>From Internet</td>
<td>4</td>
</tr>
<tr>
<td>From family members and others</td>
<td>5</td>
</tr>
<tr>
<td>Respondent themselves</td>
<td>3</td>
</tr>
<tr>
<td>Medical insurance</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>1</td>
</tr>
<tr>
<td>No</td>
<td>10</td>
</tr>
<tr>
<td>Public</td>
<td>-</td>
</tr>
<tr>
<td>Private</td>
<td>1</td>
</tr>
<tr>
<td>Access to medical care</td>
<td></td>
</tr>
<tr>
<td>Public hospital</td>
<td>7</td>
</tr>
<tr>
<td>Private hospital or clinic</td>
<td>3</td>
</tr>
<tr>
<td>Private nursing home</td>
<td>1</td>
</tr>
<tr>
<td>Private medical shop</td>
<td>1</td>
</tr>
</tbody>
</table>
During the first 12 months of the pandemic, eight persons visited a doctor, nurse, clinical officer or audiologist to access health services. All were in-person visits except for one respondent who accessed the services by phone. Frequency of visits was less than 5 times for five people, while for three persons it was between 6 to 10 times during the past 12 months. Regarding the reason for the visit to the health professional, six respondents visited for a check-up of their medical condition, four for follow-up for an existing medical condition, and a few consulted about a new medical condition.

Table 8 shows the access to existing health services for the hard of hearing respondents during the pandemic.

Table 8. Access to existing health services for hard of hearing

<table>
<thead>
<tr>
<th>Access to Health Service</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Have own doctor</strong></td>
<td></td>
</tr>
<tr>
<td>Yes, regular doctor</td>
<td>1</td>
</tr>
<tr>
<td>No, go to clinic or hospital</td>
<td>9</td>
</tr>
<tr>
<td>Do not have access to doctor</td>
<td>1</td>
</tr>
<tr>
<td><strong>Visited health professionals during 12 months period</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>8</td>
</tr>
<tr>
<td>No</td>
<td>3</td>
</tr>
<tr>
<td><strong>Types of visits</strong></td>
<td></td>
</tr>
<tr>
<td>In-person</td>
<td>8</td>
</tr>
<tr>
<td>By both telephone and in person</td>
<td>1</td>
</tr>
<tr>
<td><strong>Frequency of visits</strong></td>
<td></td>
</tr>
<tr>
<td>1-5 times</td>
<td>5</td>
</tr>
<tr>
<td>6-10 times</td>
<td>3</td>
</tr>
<tr>
<td>More than 10 times</td>
<td>-</td>
</tr>
<tr>
<td><strong>Reasons for visits</strong></td>
<td></td>
</tr>
<tr>
<td>Only checkup of medical condition</td>
<td>6</td>
</tr>
<tr>
<td>Follow up of existing medical conditions</td>
<td>4</td>
</tr>
<tr>
<td>New medical conditions (audiology condition)</td>
<td>3</td>
</tr>
</tbody>
</table>
Attitude/Interactions

The attitude of health professionals toward hard of hearing patients was found to be mixed. During their healthcare visit, most respondents stated that they informed the health provider about their hearing loss. Most of the respondents also reported that there were changes in communication after letting health professionals know about their hearing loss. Four of the respondents said that the health professionals started to speak a little slower while facing them. Some also said that the health professional started to communicate in writing. A few hard of hearing respondents said that the doctor used their assistant to communicate with them and, sometimes, a family member (if present).

One of the respondents reported “Most of the doctors requests us to accompany with family member or friends. They do not want to do conversation with repeatedly even mentioning that I cannot hear clearly. It made me discomfort while visiting doctors.”

Regarding the question whether hard of hearing spoke with medical staff such as a doctor, nurse, clinical officer or audiologist by themselves directly or through another party, five of the respondents stated that they spoke to medical staff themselves, one of them communicated in writing online, and the remaining three did not directly speak to the health professional as their family member attended with them. Of those who spoke to a doctor or health provider directly, three cited the use of writing in paper or on a small board. Table 9 summarizes the interactions with health professionals. Note: responses are by eight participants, as not all participants in the study had recent contact with a healthcare provider.

Table 9. Interaction with health professionals

<table>
<thead>
<tr>
<th>Type and method of engagement</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Spoke with medical staff on own</strong></td>
<td></td>
</tr>
<tr>
<td>Yes, in person</td>
<td>5</td>
</tr>
<tr>
<td>Yes, but online</td>
<td>1</td>
</tr>
<tr>
<td>No, a family member attended with me</td>
<td>2</td>
</tr>
<tr>
<td><strong>Method for communication</strong></td>
<td></td>
</tr>
<tr>
<td>Communicated orally</td>
<td>2</td>
</tr>
<tr>
<td>By speaking slowly and clearly</td>
<td>8</td>
</tr>
<tr>
<td>Communicate by writing on paper or small board</td>
<td>3</td>
</tr>
<tr>
<td>Accompanied by family or friend</td>
<td>4</td>
</tr>
</tbody>
</table>
Impact of the Pandemic on Communication with Health Professionals

Throughout the pandemic, the wearing of masks was required of health professionals. Four respondents reported that health professionals were wearing face masks during their visit. In addition, two health providers also wore face shields. In two cases the health professionals took off the mask for easier communication. When face masks were worn, all of the hard of hearing respondents reported difficulties understanding the doctor, nurse or clinical officer. Two respondents did not understand at all when health professionals used masks. The following table summarizes the communication during the pandemic with health professionals by those responding to this question in the survey.

*Table 10. Communication with health professionals*

<table>
<thead>
<tr>
<th>Communication</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health professionals and use of masks</td>
<td></td>
</tr>
<tr>
<td>Yes, covered</td>
<td>4</td>
</tr>
<tr>
<td>Yes, but transparent</td>
<td>-</td>
</tr>
<tr>
<td>Yes but mask lifted</td>
<td>2</td>
</tr>
<tr>
<td>Yes, wore mask and face shield</td>
<td>2</td>
</tr>
<tr>
<td>No mask but a face shield</td>
<td>-</td>
</tr>
<tr>
<td>No mask nor face shield</td>
<td>-</td>
</tr>
<tr>
<td>Patients’ level of understanding with health professionals using masks</td>
<td></td>
</tr>
<tr>
<td>Fully understand</td>
<td>-</td>
</tr>
<tr>
<td>Mostly understand</td>
<td>-</td>
</tr>
<tr>
<td>Half understand</td>
<td>1</td>
</tr>
<tr>
<td>Partially understand</td>
<td>5</td>
</tr>
<tr>
<td>Not understand at all</td>
<td>2</td>
</tr>
</tbody>
</table>
Due to the pandemic, six of the respondents found that the health official maintained physical distance and found that this increased difficulties in communication. Among the respondents who visited healthcare professionals, three of them responded that the physical distance extremely affected communication; three of them found communication moderately affected; and one of them found communication somewhat affected. One respondent reported being slightly affected in the communication.

Nearly half of the hard of hearing persons responded that they could not hear and understand what the health professionals were saying, and nearly two-thirds of the respondents said that they could not lip read as the health professionals were using a face mask. One respondent said that the acoustic environment was challenging. Some of the respondents also stated they could not understand when the doctor was in next room, behind a glass, using a microphone.

Responses of the participants were mixed about methods of communication with doctor, nurse, and clinical officer. Among eleven respondents, only eight of them had visited a health professional. Out of these eight persons, only two respondents who had mild/moderate hearing loss could communicate orally at a pace similar to that of hearing persons. Another respondent communicated by speaking slowly. In addition, three of the respondents also wrote on paper or on a small board, and the remaining four were accompanied by a family member.

Three of the respondents reported that communication with health professionals was improved when using a face shield without wearing face mask. However, four of the respondents reported that use of the face shield did not improve communication, and one of them said that it made communication worse. This latter response was attributed to light being reflected on the face shield and sound blockage while also maintaining physical distance. Although the person could hear sound, comprehension and understanding was limited. Note: responses were not given by all participants as some did not experience health professionals’ use of clear face shields.

Contact with Support Staff

Almost three-quarters of respondents said that they had difficulties booking medical appointments due to their hearing loss. Nearly two-thirds had someone else book appointments for them. Two persons used the mail to make bookings and one booked in person.

In terms of communication with reception staff, only a few persons reported communicating orally. A few cited communicating by writing in a notebook. Almost half reported that their accompanying family member or friend took care of the communication for them. All of the respondents reported difficulties with medical reception services, such as being unable to hear when called upon for their appointment or being unable to understand the staff person. Only one hard of hearing person reported using an amplifying device at the registration and cashier desk but found it was ineffective due to background noises. No provision for use of a sign language interpreter, captioner, or note-taker was reported.
Accommodations

Only two of the hard of hearing persons who visited hospital or medical services were satisfied regarding the accommodation provided, and six of them were unsure with the accommodation provided in the medical office. Contributing to the unsatisfactory ratings was a noisy acoustic environment. Another factor was that the lack of knowledge on the part of doctors and other medical staff about how to communicate with hard of hearing patients.

Respondents found that only Ear, Nose and Throat specialists were aware about the needs of hard of hearing people, as they often speak clearly and slowly. Table 11 reports the respondents’ view of the difficulties in coordinating at health services.

Table 11. Difficulties in coordinating with supporting staff at health service center

<table>
<thead>
<tr>
<th>Coordination with supporting staff</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Difficulties in booking health services</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>6</td>
</tr>
<tr>
<td>No</td>
<td>2</td>
</tr>
<tr>
<td>Types of booking appointments</td>
<td></td>
</tr>
<tr>
<td>Booked in person</td>
<td>1</td>
</tr>
<tr>
<td>Booked by email</td>
<td>2</td>
</tr>
<tr>
<td>Had someone else book for me</td>
<td>4</td>
</tr>
<tr>
<td>Communication at the service desk/reception</td>
<td></td>
</tr>
<tr>
<td>Communicate orally</td>
<td>1</td>
</tr>
<tr>
<td>Communicate by writing in notebook</td>
<td>2</td>
</tr>
<tr>
<td>Communicate by sign language</td>
<td>-</td>
</tr>
<tr>
<td>Accompanied by family or friend</td>
<td>4</td>
</tr>
<tr>
<td>Never had communication with reception</td>
<td>1</td>
</tr>
<tr>
<td>I was asked to be accompanied by family members /friends</td>
<td>3</td>
</tr>
<tr>
<td>Other form of communication</td>
<td>-</td>
</tr>
<tr>
<td>Difficulties to communicate at medical services</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>8</td>
</tr>
<tr>
<td>Could not hear when, I was called.</td>
<td>3</td>
</tr>
<tr>
<td>Could not understand speech of explanations or questions from the staff</td>
<td>-</td>
</tr>
<tr>
<td>Rate of satisfaction with the accommodation provided in medical office</td>
<td></td>
</tr>
<tr>
<td>Very satisfied</td>
<td>-</td>
</tr>
<tr>
<td>Satisfied</td>
<td>2</td>
</tr>
<tr>
<td>Unsure</td>
<td>6</td>
</tr>
<tr>
<td>Dissatisfied</td>
<td>-</td>
</tr>
<tr>
<td>Very dissatisfied</td>
<td>-</td>
</tr>
</tbody>
</table>
All the persons surveyed responded that they needed more assistance in their communication at medical facilities. More than half of the respondents felt it would be beneficial to have their hearing loss listed on their medical record book or chart, including the types of hearing devices such as hearing aids and cochlear implants they wore. Nearly two-thirds of the respondents said that the medical staff should supplement verbal information with a written account; they stated medical staff should speak clearly to facilitate lip-reading. Nearly half of the respondents expressed the need for a captioner or note-taker, and for a visual display such as signboards and materials to support the communication. A few respondents supported the use of assistive technology such as an FM system. A third of the respondents said that they needed to be accompanied by a family member or friend.

One of the respondents reported that the attitude of doctors was negative. He said "It would be different, if they need someone to assist us. Because they view us as disabled that we don't understand anything. Most doctors show aggressive attitude. They tend to care less about hard of hearing people. Mostly they won't think about providing accessibilities for us. Most doctors say with shouting, "Come again with friends or parents." The following table summarizes communication solutions by respondents.

Table 12. Need of communication solution in health sector as per respondents

<table>
<thead>
<tr>
<th>Need of communication solution</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Requires statement about your hearing loss in your medical chart</td>
<td>6</td>
</tr>
<tr>
<td>Uses hearing devices (HA or CI)</td>
<td>6</td>
</tr>
<tr>
<td>To be accompanied by family members, etc.</td>
<td>4</td>
</tr>
<tr>
<td>Requires a captioner or note-taker</td>
<td>5</td>
</tr>
<tr>
<td>Needs information written down by the doctor, nurse, clinical officer or other staff in the medical office</td>
<td>7</td>
</tr>
<tr>
<td>Needs doctors and other staff to speak clearly and for lip-reading</td>
<td>7</td>
</tr>
<tr>
<td>Uses of assistive listening or amplification devices</td>
<td>3</td>
</tr>
<tr>
<td>requires a visual display such as signboards and materials</td>
<td>5</td>
</tr>
<tr>
<td>Sign board which shows details of health services</td>
<td>5</td>
</tr>
<tr>
<td>Use of an assistive or amplifying device at the registration desk</td>
<td>2</td>
</tr>
<tr>
<td>Speech (with lip reading)</td>
<td>7</td>
</tr>
<tr>
<td>Visual supports (signboard)</td>
<td>5</td>
</tr>
</tbody>
</table>
Access to Health Services during the COVID Period

Regarding the experience of hard of hearing respondents in interactions with doctors, nurses, clinical officers, and the healthcare system, six of the surveyed hard of hearing persons said there were no changes on the interaction with health professionals and staff. A quarter of the respondents reported that communication had worsened during the pandemic compared to the pre-COVID period.

Regarding the impact of coronavirus on access to health services, one person reported that the impact was severe. Respondents were divided between considering the impact moderate and the pandemic not having an impact on them. Yet, when respondents spoke about the impact on use of hearing aids and cochlear implants during the pandemic, the situation appeared to be worse.

The most affected service was access to audiology services. Seven persons reported that they could not access audiology appointments because of a long lockdown. Three persons reported that they could not access hearing aids or cochlear implants. The two cochlear implant users reported being unable to get their devices mapped according to their hearing needs, thus being unable to use their cochlear implants well.

In addition, one person could not continue speech therapy. Two persons could not remove wax from their hearing aid, and five persons could not access batteries for their hearing aid and cochlear implants.

A telling response was that half of respondents reported not feeling safe in a disaster due to barriers to communication. They were also uncertain whether they would be able to access health services.

The summary of the finding on access to health services during the COVID period is summarized in Table 13.
### Table 13. Access to health services during the COVID period

<table>
<thead>
<tr>
<th>Access to health during COVID</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Much improved communication</td>
<td>-</td>
</tr>
<tr>
<td>Improved communication</td>
<td>-</td>
</tr>
<tr>
<td>No change</td>
<td>6</td>
</tr>
<tr>
<td>Worse communication</td>
<td>5</td>
</tr>
<tr>
<td>Much worse communication</td>
<td>-</td>
</tr>
<tr>
<td>Reasons: Due to the use of mask and shield by medical personnel</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Impact of COVID on health services</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Severe</td>
<td>1</td>
</tr>
<tr>
<td>High</td>
<td>3</td>
</tr>
<tr>
<td>Moderate</td>
<td>3</td>
</tr>
<tr>
<td>Low</td>
<td>1</td>
</tr>
<tr>
<td>Not at all</td>
<td>3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Effect on Audiology services</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>9</td>
</tr>
<tr>
<td>No</td>
<td>2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Type of impact</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Could not access audiology appoints</td>
<td>7</td>
</tr>
<tr>
<td>Could not access hearing aid/ cochlear implant</td>
<td>3</td>
</tr>
<tr>
<td>Could not do mapping</td>
<td>2</td>
</tr>
<tr>
<td>Could not continue speech therapy</td>
<td>1</td>
</tr>
<tr>
<td>Could not remove wax from hearing aid</td>
<td>2</td>
</tr>
<tr>
<td>Could not access hearing aid / cochlear batteries</td>
<td>5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Feel safe in communication if any pandemic or disaster arises</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>-</td>
</tr>
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<td>No</td>
<td>4</td>
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<tr>
<td>Don’t know</td>
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Recommendations

As a result of this study, recommendations are framed dealing with issues of attitudes, accommodations, the acoustical environment, responding to COVID-19 pandemic barriers, and the status of persons who are hard of hearing in Nepal.
RECOMMENDATION ONE:

Recognition of Hard of Hearing Persons

That the Nepalese government recognize hard of hearing persons who have a hearing loss in accordance with the definition of the World Health Organization and based on their experienced barriers due to hearing loss.

RECOMMENDATION TWO:

Training of Health Professionals and Staff

That health professionals and staff be required to attend attitudinal awareness training programs as well as learn about the communication and accommodation needs of hard of hearing persons. Accommodation needs to include the use of hearing aids, cochlear implants, technical devices such as FM or loop systems and, where appropriate, and the provision of a captioner (i.e. a trained person who provides verbal information in a text format).

RECOMMENDATION THREE:

Develop Toolkits

That the Government and its Ministry of Health and Population work together with the hard of hearing community of Nepal to develop a handout for professionals about hearing access and communication, to be shared with all healthcare workers in the country.

RECOMMENDATION FOUR:

Acoustical Environment

That hospitals and medical clinics take measures to reduce the noise level of their environments and to adopt Universal Design principles for accessibility that would benefit all persons, not only hard of hearing persons. For example, they should provide display boards, information maps, and written information, as well as use carpet, curtains, and soundproof materials in reception areas, examination rooms, and other healthcare rooms.
RECOMMENDATION FIVE:

**Early Identification, Hearing Screening and Rehabilitation**

That the Government establish programs for the early identification and intervention regarding hearing loss, and for hearing screening for persons of all ages. As part of these programs, those who are identified as having a hearing loss should then receive rehabilitation services at no cost.

RECOMMENDATION SIX:

**Information during Risk-Adverse Situations**

Protocols for accessible communication should be established for risk and humanitarian emergencies, which was the case during the COVID pandemic. Accessible communication measures should include hotlines, text messages, and warning systems. Every relevant broadcast should be captioned as well as supported with sign language interpretation. In addition, funding programs should be instituted to support citizens during such times.

RECOMMENDATION SEVEN:

**Role of Hard of Hearing Persons and their representative Organizations**

Recognition of the important role of hard of hearing persons and their representative organizations in building an inclusive and accessible society that attends to the healthcare needs of its citizens should be backed by support for their advocacy work. They can be partners in informing all segments of society about the communication and accessibility needs of hard of hearing persons.
Conclusion

Valuable information was obtained about the experiences and perceptions of hard of hearing persons in Nepal about their access to healthcare in this qualitative study. While the findings are not generalizable due to the research methodology for the study, the information obtained can inform the work that needs to be done to make hearing healthcare accessible for hard of hearing persons in Nepal.

The study found that people who are hard of hearing often face barriers in accessing healthcare in Nepal, whether living in the capital city or in different districts of the country. However, persons in rural areas for whom the Nepali language is not their mother tongue experience additional barriers. Most of these persons are indigenous people. Because of their hearing loss and language issues, they face double barriers to accessing healthcare services.

Many hard of hearing persons experience difficulty communicating with health providers and in accessing accurate information during their medical visits. The lack of knowledge among healthcare providers regarding the needs of hard of hearing persons represents a formidable barrier in healthcare services. Many hard of hearing persons reported that there was a lack of knowledge and understanding of their communication and access needs. Some persons also went further to cite attitudinal barriers, including negative reactions and a lack of respectful communication.

Most of the hard of hearing persons taking part in this study do not have their own medical doctor, and therefore, they access healthcare through a hospital or clinic. Health providers were found to be
unaware of communication strategies for interacting with hard of hearing persons and to be unaware of the range of available accommodations. The interactions at reception services were particularly problematic given that these tend to be noisy environments. Even a simple thing like making a medical appointment was a huge challenge for hard of hearing persons; many of them got someone else to do it for them, a blow to their independence.

The health service sector such as hospitals, clinics, and nursing homes were found to be noisy environments, making communication even more difficult. In this respect, applying Universal Design principles to create a barrier-free environment that benefits everyone, including hard of hearing people, is desirable. Because of both the noisy environment and the lack of reasonable accommodation for people who are hard of hearing, most of the hard of hearing respondents in this study reported that they could not communicate with staff at health services desks/reception areas. As a result, their ratings of satisfaction overall were below average regarding information received and services provided. Given these findings, their fundamental rights to access information and healthcare is threatened.

The widespread use of face masks during the COVID pandemic and the requirement for social distancing also created additional barriers for hard of hearing persons. Most people who are hard of hearing could not understand what was being said about their health and could not communicate directly themselves during the COVID pandemic, as they could not lip read due to using facial masks and were not provided written information.

One of the findings from the report is that, generally, respondents had their hearing loss detected when they were older and their use of hearing aids or cochlear implants also lagged. This calls for early intervention and hearing screening programs for persons of all ages, with rehabilitation being a key component.

As noted in the literature review, a fundamental problem in Nepal is that hearing losses from mild to moderate (30dB to 64dB) are not recognized as a disability by the government. Due to the lack of recognition of many hard of hearing persons, they are excluded from being provided accommodations and access to healthcare. This lack of access continued during the pandemic. Until government policy changes, the needs of persons with hearing loss will continue to be unmet and their exclusion will continue to exist in Nepalese society.

Finally, it is noted that this study was undertaken by persons with hearing loss from the non-profit sector. This underscores the important role that the voluntary sector of hard of hearing persons’ organizations have in bringing to light issues affecting the human rights of individuals. Such organizations are important sources of information and support for individuals as well as for the community and governments. They can truly ensure that solutions to problems are undertaken in the spirit of the CRPD of Nothing about us, without us.
End Notes


Bibliography


INFORMED INTERVIEW CONSENT

SURVEY ON POST COVID-19 EFFECT ON HARD OF HEARING IN ACCESS TO HEALTH SERVICES

Project Description:

The International Federation of Hard of Hearing People (IFHOH), in partnership with International Disability Alliance (IDA), is attempting to identify the various challenges faced by hard of hearing persons in accessing health, and the impacts of COVID-19 on access to health of persons with disabilities, particularly hard of hearing persons. Hard of hearing is defined as a person who has a hearing loss and communicates mainly by spoken language.

I have been appointed as a Health Fellow to interview hard of hearing persons about their experiences in accessing health services and will prepare a report of my findings which will inform IFHOH and IDA in their policy work.

All those participating in interviews will have their identity remain anonymous. You will not be identified in the report about interview results.

The recordings and recording-transcripts (or copy of notes taken) will be kept anonymous, without any reference to your identity, and your identity will be concealed in any reports written from the interviews.

If I participate, what does it involve?

You would be interviewed for 60 to 90 minutes. Interviews will be through questionnaire/taped/videotaped.

What will I get?

The opportunity to share your view that will help to analysis on access to health and suggestions to removing barriers to the policy makers in future.

Will responses be private?

Absolutely! Pseudonyms will be used. All raw data will be secured.
**Procedure:**

I would like to record the interview, if you are willing, please feel free to say as much or as little as you want. You can decide not to answer any question, or to stop the interview any time you want. The tapes and transcripts will become the property of project. There are no known risks associated with participation in this study. If you agree to join this study, please sign your name on the following page.

**Confidentiality:**

Your identity will be concealed in any reports written from the interviews. No publications or reports from this project will include identifying information on any participant without your signed permission, and after your review of the materials. If you agree to join this study, please sign your name on the following page.

Thank you for your attention and consideration.

Sincerely Yours,

Neeta Keshary Bhattarai,
Nepal
IFHOH Inclusive Health Project Fellow

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The International Federation of Hard of Hearing People (IFHOH), established in 1977, is an international, non-governmental organization, registered in Germany. IFHOH represents the interests of more than 460 million hard of hearing people worldwide. IFHOH has over 40 national member organizations from most regions of the world. IFHOH and its regional networks work to promote greater understanding of hearing loss issues and to improve access for hard of hearing people. IFHOH has special consultative status with the United Nations Economic and Social Council (ECOSOC), affiliation with the World Health Organization, and membership in the International Disability Alliance.
INFORMED CONSENT FOR INTERVIEWS
IFHOH Inclusive Health Project

I, ____________________________, agree to be interviewed for the project entitled (INCLUSION WORKS PROJECT) which is being led by Neeta Keshary (SHRUTI- National Association of the Hard of Hearing and Deafened Nepal) and IFHOH (International Federation of Hard of Hearing)

I certify that I have been told of the confidentiality of information collected for this project and the anonymity of my participation; that I have been given satisfactory answers to my inquiries concerning project procedures and other matters; and that I have been advised that I am free to withdraw my consent and to discontinue participation in the project or activity at any time without prejudice.

I agree to participate in one or more electronically recorded interviews for this project. I understand that such interviews and related materials will be kept completely anonymous.

I agree that any information obtained from this research may be used in any way thought best for this study.

_____________________________  Date ____________________________
Signature of Interviewee

If you cannot obtain satisfactory answers to your questions or have comments or complaints about your treatment in this study, contact:

Neeta Keshary,
President

SHRUTI (National Association of the Hard of Hearing and Deafened, Nepal)
Dhumbarahi, Kathmandu, Nepal
Tel. 9849-501-416
Email: ntkeshary@gmail.com
Hello, my name is Neeta Keshary and I am a Fellow for the INTERNATIONAL FEDERATION OF THE HARD OF HEARING PERSONS AND INTERNATIONAL DISABILITY ALLIANCE. I am conducting a survey of hard of hearing about their experiences in health service situation during the COVID-19 period and post-COVID period. The interview will take about 60 to 90 minutes. The identified person's identity will not be disclosed and will remain strictly anonymous. If you wish not to answer a question or wish to stop the interview, please let me know. May I start now?

__________________________________________________________

YES, PERMISSION IS GIVEN                                      NO, PERMISSION IS NOT GIVEN

__________________________________________________________

Interviewer's name and ID code

Day/Month/Year of Interview  _____ / _____ / 2021
General Information (GI) of Hard of Hearing

→ GI1. Hard of Hearing’s:
  First Name: ____________________________________________________________
  Last Name: ____________________________________________________________

→ GI2. What is your last educational level?
  □ Basic Level
  □ High School
  □ Undergraduate Degree
  □ Postgraduate Degree
  □ PhD
  □ Informal Education

→ GI3. What is your gender?
  □ Male
  □ Female
  □ Other
  □ Prefer not to say

→ GI4. What is your employment status?
  □ Student
  □ Employee
  □ Self-employed
  □ Not in the paid labor force
  □ Retired from employment
  □ Other – please specify __________________________________________________
GI5. What is your marital status

- Single
- DeFacto Relationship
- Married
- Divorced
- Prefer not to say

GI6. What is your age group?

- 18 to 25 years
- 26 to 35 years
- 36 to 45 years
- 46 to 55 years
- 56+ years
- Prefer not to say

GI7. Do you receive healthcare in your first language?

- Most of the time
- Sometimes
- Not usually

If you do not receive healthcare in your first language, what types of barrier do you face?

- Difficulty in communicating with health professionals
- Difficulty to access accurate and comprehensive health information
- Difficulty to understand what is being communicated to me by doctors and other health professionals
- No barriers experienced as I often accompany with others
- Other, please specify
## Information on Hearing Loss and Functioning

### HL1. What is your status of hearing loss?

- [ ] Unilateral
- [ ] Bilateral
- [ ] Mild (_______dB)
- [ ] Moderate (_______dB)
- [ ] Severe (_______dB)
- [ ] Profound (_______dB)
- [ ] Total loss
- [ ] Don’t Know dB
- [ ] Other – please specify _______________________________________________________

### HL2. Do you know when did your hearing loss occurred?

- [ ] Yes
- [ ] No

### HL2. At what age was your hearing loss revealed?

__________ Years old

### HL4. In addition to your hearing loss, do you have a family member with a hearing loss?

- [ ] Yes
- [ ] No

### HL5. Please specify if the family member have hearing loss.

- [ ] Spouse
- [ ] Parent
- [ ] Grandparent
- [ ] Sibling
- [ ] Child
- [ ] Other – please specify the relation ______________________________________________
HL 6. Do you know what the cause of hearing loss is?

- Yes
- No

If yes, please specify ____________________________

HL 7. Do you use assistive hearing devices?

- Yes
- No

HL 8. If you use hearing devices, please mark below which you use.

- Hearing aid
- Cochlear Implant
- Bone Conductive
- Combination of the above
- None of above
- Other – please specify ____________________________

HL 9. If you do not use hearing devices, would you please explain the reason? (Please mark that apply)

- Not suitable for me
- I don’t hear even using it
- I cannot pay it
- It will damage my hearing
- I feel shy to use it.
- People will know I am deaf
- I can understand as I can lip-read
- Not necessary for me right now
- Other – please specify ____________________________
HL10. At what age did you start using hearing devices?

__________ Years old

HL11. How do you usually communicate with people?

☐ Speech only/Listening/Lip-reading
☐ Sign language and speech together/a mixture
☐ Sign language only
☐ By using gesture sign/natural body language
☐ Cued speech
☐ Other – please specify ________________________________

HL12. Have you had any issues in your health conditions in the past 12 months?

☐ Yes
☐ No
If yes, please specify __________________________________________

HL13. Did you come down with the COVID virus during the past year?

☐ Yes
☐ No

HL14. Did you require medical care during the past year for any health condition?

☐ Yes
☐ No

HL15. How would you rate impact of the condition?

☐ Mild
☐ Moderate
☐ Serious
☐ Very serious
HL16. Were you in the hospital for any of the above conditions?

- Yes
- No

HL17. If you answered Yes to HL16, how long were you in the hospital?

- Less than one day
- 1-5 days
- 6 to 14 days
- Longer (please specify)

HL18. In general, how satisfied are you with your medical care from your doctor nurse or other health professional?

- Very Satisfied
- More than Satisfied
- Satisfied
- Unsatisfied
- Very Unsatisfied

HL19. How do you get the information of your health situation?

- From my health facility
- From the internet
- From family members and others
- Mostly, I don’t know about my health situation
- Other – please explain _______________________________________________________

HL20. Do you have medical insurance?

- Yes
- No

If yes, what kind of coverage? Please specify ________________________________________
HL21. Where do you get medical care from?

☐ The public health system
☐ The private health system

HL22. Where do you get medical care?

☐ Public hospital
☐ Private hospital or clinic
☐ Private Nursing Home
☐ Medical Shops
☐ Other – please specify ______________________________________________________
Information on Health Services with Doctor/Nurse/Clinical Officer

HS1. Do you have your own doctor?
- Yes, regular doctor
- Yes, family doctor
- No, go to a clinic or hospital
- Do not have access to Doctor
- Other – please specify ______________________________

HS2. In the last 12 months, have you met with a doctor, nurse or clinical officer?
- Yes
- No

HS3. If you answered yes to meeting a doctor, nurse or clinical officer, how did you meet?
- In person physically
- Online or social media
- By telephone
- Other – please specify ______________________________

HS4. How often did you meet with a doctor, nurse or clinical officer in last 12 months?
- 1 to 5 times
- 6 to 10 times
- More than 10 times

HS5. What was purpose of the meeting? (Indicate all that apply)
- Check up
- Existing medical condition (follow up)
- New medical condition
- Other – please specify ______________________________
**HS6. Did you inform your doctor, nurse or clinical officer about your hearing loss?**

- Yes
- No

**HS7. Were there any changes in communication after you identified your hearing loss?**

- Yes
- No

**HS8. If you answered Yes to question HS7, what kind of support did doctor, nurse or clinical officer provided after knowing you have hearing loss?**

- Started to speak slowly and facing to you
- Started to communicate with writing
- Used speech to text services through app in mobile
- Used sign language
- Used assistant to communicate with you
- Nothing any of above, please specify ________________________________

**HS9. Did you speak with medical staff (doctor, nurse, clinical officer) on your own?**

- Yes in person
- Yes but on line
- No, a family member attended with me
- No, a friend attended with me
- No – I had a sign language interpreter
- No, I had a captionist
- No, I had an oral assistant
- Other – would you please explain ________________________________
HS10. How did you communicate with your doctor, nurse or clinical officer?  
(Check as many that apply)

- Communicate orally
- By speaking slowly and clearly
- Communicate by writing in paper or small board
- Assisted through nurse/staff
- Assisted by sign language interpreter
- Communicate by using sign language or gesture and body language
- Accompanying by family or friends
- I used to be explain after returning back from hospital
- Other communication methods, would you please explain _________________________

HS11. Did the doctor, nurse or clinical officer wear a mask?

- Yes – covered
- Yes but transparent
- Yes but lifts the mask up for me
- Yes wore a mask and a face shield
- No mask but a face shield
- No mask or face shield

HS12. If the doctor, nurse or clinical officer wore a mask (but no face shield), to what extent could you understand the doctor?

- Fully Understand
- Mostly Understand
- Half Understand
- Partially Understand
- Not understand at all

HS13. Did the doctor, nurse or clinical officer stay at a physical distance from you during the meeting?

- Yes
- No
HS14. If the doctor, nurse or clinical officer stayed at a physical distance during the meeting, did the distancing affect communication?

- Not at all affected
- Slightly affected
- Somewhat affected
- Moderately affected
- Extremely affected

HS15. If there were difficulties in understanding, would you please explain the difficulties you faced?

- Could not hear and understood
- Could not read lips as using facemask
- Challenging acoustic environment
- Other – please specify _______________________________________________________

HS16. If you responded yes to the doctor, nurse or clinical officer using a face shield without a mask (Question HS11), how did the use of the face shield affect communication?

- Improved communication
- No impact at all
- Made it worse

HS17. Did you experience any difficulty booking doctor, nurse or clinical officer’s appointments yourself by phone due to a hearing difficulty?

- Yes
- No

HS18. If you experienced difficulty booking by phone, how did you arrange to see your doctor, nurse or clinical officer?

- Booked in person
- Booked by email
- Had someone else book for me
- Other – please specify ______________________________________________________
**HS19. When you were at the medical office, how did you communicate at the service desk/reception?**

- [ ] Communicate orally
- [ ] Communicate by writing in notebook.
- [ ] Communicate by sign language.
- [ ] Accompanied family or friend
- [ ] Never had communicate with reception
- [ ] I was asked to accompany family/friends members, etc.
- [ ] Other form of communication, please specify ________________________________

**HS20. Did you have any difficulties to communicate at the medical service desk/reception?**

- [ ] Yes
- [ ] No because I have been accompanied by assistant, such as family/friend

If yes, would you please check all that apply

- [ ] Could not hear when, I was called.
- [ ] Could not understand speech of explanations or questions from the staff

**HS21. At medical examination and/or diagnosis, do you think that any assistance is necessary in communication with medical support staff?**

- [ ] Yes
- [ ] No

If Yes, Please select what you need and check all that apply

- [ ] Need to mention about your hearing loss in your medical chart
- [ ] Need to mention if using hearing devices HA or CI
- [ ] Need to be accompanied by family members, etc.
- [ ] Need to have a captionist or note-taker
- [ ] Need to have a sign language interpreter
- [ ] Need to have information written down by the doctor, nurse, clinical officer or other staff in the medical office
- [ ] Doctors and other staff need to speak clearly and for lip-reading
- [ ] Need use of assistive listening or amplification devices.
- [ ] Need a visual display such as signboards and materials
- [ ] Other, please explain ________________________________
HS22. To what extent do you feel medical and support staff are accommodating of your hearing disability? (Check all that apply)

- Sign board which shows details of health services
- Use of an assistive or amplifying device at the registration desk
- Provision of captioning and sign language
- Development of a sign indicating support for patients with hearing loss
- Speech (with lip reading)
- Sign language
- Visual supports (Signboard)
- Other, would you please explain?
- Extra supports are not necessary

HS23. Would you please rate of your satisfaction with the accommodation that provided in the medical office?

- Very Satisfied
- Satisfied
- Unsure
- Dissatisfied
- Very Dissatisfied

Please clarify the reason for your rating __________________________________________________________

HS24. Do you have any comments regarding the access to, audiology, speech therapy and other ear care services during the pandemic and after the pandemic?

______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
Access to health services during the COVID period

**CP1.** Compared to the period before COVID, what has been your experience with interactions with doctors, nurses, clinical officers and the health system? Please rate it below.

- □ Much improved communication
- □ Improved communication
- □ No change
- □ Worse communication
- □ Much worse communication

Please comment further about your response _______________________________________

**CP2.** What impact did the corona virus have on your access to health services?

- □ Severe
- □ High
- □ Moderate
- □ Low
- □ Not at all

**CP3.** Were audiology services impacted during COVID-19?

- □ Yes
- □ No

If you answered yes, would you please check below that applies?

- □ Could not access audiology appointments
- □ Could not access to hearing aid/ Cochlear
- □ Could not do mapping
- □ Could not continue speech therapy
- □ Could not remove wax from hearing aid
- □ Could not access hearing aid / Cochlear batteries
- □ Other – please specify ________________________________
CP4. Do you feel safe to communicate if there any pandemic or disaster arises to access to health?

☐ Yes
☐ No
☐ Don’t know
☐ Other – would you please explain? ________________________________

This questionnaire focused on visiting a doctor/medical office.

Do you have any comments regarding the access to, audiology, speech therapy and other ear care services during the pandemic and after the pandemic?

Any other comments?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

Thank you very much.