

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



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**Photo Front page cover:** 

Client leaning to hear during a reception interaction





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Neeta Keshary Fellow, Access to Healthcare

# **Table of Contents**

Acknowledgments	I
Abbreviations	/
Executive Summary	/
Introduction	
Literature Review	)
Country Fact and Figures2	)
National Data on Disability3	3
Policy Review4	ļ
COVID Policy in Nepal5	5
Situation Analysis Regarding Access to Healthcare in Nepal	_
for People Who are Hard of Hearing6	
Research Design and Methodology	
Research Design	
Data Analysis	3
Findings9	)
Demographic Profile of the Respondents9	)
Hearing Status11	
Access to Hearing Devices12	)
Access to Healthcare in First Language13	
Health Status14	ļ
Access to Health Services15	
Attitude/Interactions17	7
Impact of the Pandemic on Communication with Health Professionals18	
Contact with Support Staff19	)
Accommodations20	
Access to Health Services during the COVID Period22	<u>)</u>
Recommendations24	ļ
<b>Conclusion</b>	7
End Notes	
Bibliograghy31	
APPENDIX 1 - CONSENT FORM	
APPENDIX 2 - INTERVIEW GUIDE	

# **List of Tables**

Table 1. Demographic profile of the respondents	10
Table 2. Hearing loss and functioning	11
Table 3. Access to hearing devices and communication types	12
<b>Table 4.</b> Access to health services in respondents' first language	13
Table 5. Language barriers to health services	13
<b>Table 6.</b> Health condition of respondents and their healthcare during the pandemic	14
Table 7. Respondents' Information on access to health services	15
Table 8. Access to existing health services for hard of hearing	16
Table 9. Interaction with health professionals	17
Table 10. Communication with health professionals	18
<b>Table 11.</b> Difficulties in coordinating with supporting staff at health service center	20
Table 12. Need of communication solution in health sector as per respondents	21
<b>Table 13.</b> Access to health services during the COVID period	23

# **Abbreviations**

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

# **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

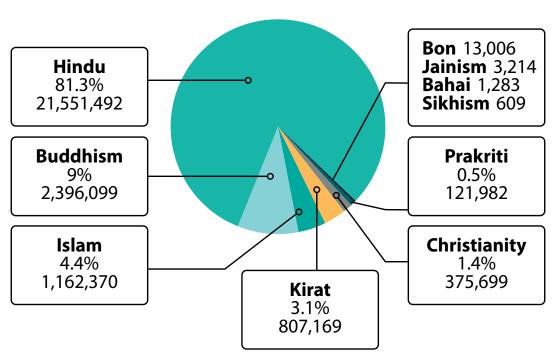
## **Literature Review**

## **Country Fact and Figures**

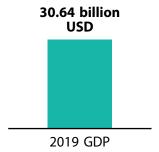
Nepal is a landlocked country which lies between India and China. It is relatively remote with landscape ranging from plains in the south, and hilly and mountainous regions in the north. The climate is diverse and ranges from tropical to high-altitude.

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].

#### Ten religious categories reported in the census 2011



According to the United Nations Development Program Human Development<sup>[2]</sup> 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 official data from the World Bank, the Gross Domestic Product (GDP) of Nepal was worth 30.64 billion US dollars in 2019. The GDP value of Nepal represents 0.03 percent of the world economy<sup>[3]</sup>.

## **National Data on Disability**

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)<sup>[4]</sup>. 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)<sup>[5]</sup>. 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%).

#### **National Data on Disability** Blindness/ Physical Disabilities Low Vision 36.3% 18.5% Deaf/hard of **Deaf-Blind** 1.8% Hearing 15.4% Intellectual Disability Speech 2.9% Problem 11.5% Mental Disability Multiple 6% Disabilities 7.5%

The census figures are quite low as compared to the disability prevalence claimed by the World Health Organization and the World Bank<sup>[6]</sup>, 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<sup>[7]</sup> 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<sup>[9]</sup>. 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<sup>[10]</sup>. 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<sup>[12]</sup>. 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<sup>[13]</sup> 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<sup>[14]</sup>, 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<sup>[15]</sup>, 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<sup>[16]</sup>, 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<sup>[17]</sup> 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<sup>[18]</sup> 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<sup>[19]</sup>.

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<sup>[20]</sup>.

The Institute of Development Studies (IDS) has prepared Situational Analyses (SITANs)<sup>[21]</sup> 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.







Patient receiving medical care

# 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.

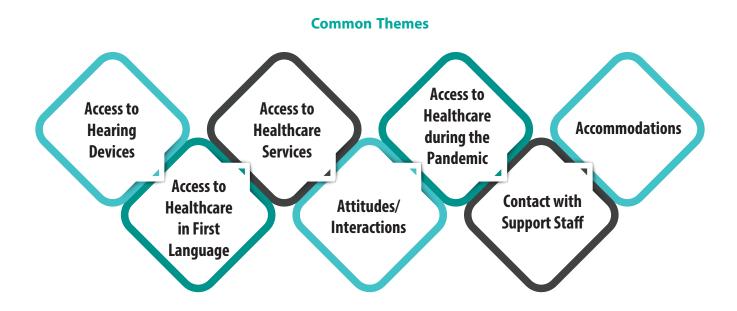
For purposes of this study, hard of hearing persons were those who self-identified as being hard of hearing. The definition of hard of hearing by the International Federation of Hard of Hearing People is as follows:



"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.





Private clinic reception being visited by a hard of hearing person



# **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<sup>[23]</sup> 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

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

## **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

Hearing Functioning		Number
	Bilateral	11
	Moderate	5
	Severe	3
Status of hearing loss Hearing loss revealed age	Profound	3
	Less than one year	2
	1-5 years old	-
	6-10 years old	2
	11-15 years old	3
	16 to 20 years old	3
	21 to 25 years old	1

## **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

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

## **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<sup>[24]</sup>. 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

Access to health service		Number
Access to health in first language	Yes	8
	No	3
	Most of the time	7
	Sometimes	1
	Not usually	3

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

Barriers on getting information	Number
Difficulties communicating with health professionals	4
Difficulties accessing accurate and comprehensive health information	3
Difficulties understanding what is being communicated by doctors and other health professionals	5
No barriers experienced as person is often accompanied by someone	1

## **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

Health Condition during Pandemic		Number
Issues in health condition	Yes	5
issues in nearth condition	No	6
1.6 . 11 .60//0	Yes	1
Infected by COVID	No	10
Requirement of medical care during 12 months	Yes	8
(pandemic)	No	3
	Mild	2
Impact on health condition	Moderate	6
Impact on health condition	Serious	-
	Very Serious	-
Hospitalization	Yes	2
riospitalization	No	8
	Less than one day	-
Duration of hospitalization	1-5 days	2
Duration of nospitalization	6 to 14 days	-
	Longer	-
	Very Satisfied	-
	More than satisfied	-
Level of satisfaction on medical care	Satisfied	7
	Unsatisfied	4
	Very Unsatisfied	-

### **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

Access to Health Service		Number
	From own health facility	4
	From Internet	4
Way of getting information on health situation	From family members and others	5
	Respondent themselves	3
	Yes	1
Medical insurance	No	10
	Public	-
	Private	1
	Public hospital	7
Access to medical care	Private hospital or clinic	3
	Private nursing home	1
	Private medical shop	1

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

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

## **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

Type and method of engagement		Number
	Yes, in person	5
Spoke with medical staff on own	Yes, but online	1
	No, a family member attended with me	2
	Communicated orally	2
Method for communication	By speaking slowly and clearly	8
	Communicate by writing on paper or small board	3
	Accompanied by family or friend	4

## 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

Communication		Number
Health professionals and use of masks	Yes, covered	4
	Yes, but transparent	-
	Yes but mask lifted	2
	Yes, wore mask and face shield	2
	No mask but a face shield	-
	No mask nor face shield	-
Patients' level of understanding with health professionals using masks	Fully understand	-
	Mostly understand	-
	Half understand	1
	Partially understand	5
	Not understand at all	2

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

Coordination with supporting staff		Number
Difficulties in booking health services	Yes	6
	No	2
Types of booking appointments	Booked in person	1
	Booked by email	2
	Had someone else book for me	4
	Communicate orally	1
	Communicate by writing in notebook	2
	Communicate by sign language	-
Communication at the service	Accompanied by family or friend	4
desk/reception	Never had communication with reception	1
	I was asked to be accompanied by family members /friends	3
	Other form of communication	-
Difficulties to communicate at medical services	Yes	8
	Could not hear when, I was called.	3
	Could not understand speech of explanations or questions from the staff	-
Rate of satisfaction with the accommodation provided in medical office	Very satisfied	-
	Satisfied	2
	Unsure	6
	Dissatisfied	-
	Very dissatisfied	-

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

Need of communication solution		Number
Types of assistance necessary in communication with medical support staff in examination and/or diagnosis	Requires statement about your hearing loss in your medical chart	6
	Uses hearing devices (HA or CI)	6
	To be accompanied by family members, etc.	4
	Requires a captioner or note-taker	5
	Needs information written down by the doctor, nurse, clinical officer or other staff in the medical office	7
	Needs doctors and other staff to speak clearly and for lip-reading	7
	Uses of assistive listening or amplification devices	3
	requires a visual display such as signboards and materials	5
Feeling medical and support staff are accommodating of hearing disability	Sign board which shows details of health services	5
	Use of an assistive or amplifying device at the registration desk	2
	Speech (with lip reading)	7
	Visual supports (signboard)	5

## **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

Access to health during COVID		Number
Experiences of access to health compared to the period before COVID	Much improved communication	-
	Improved communication	-
	No change	6
	Worse communication	5
·	Much worse communication	-
	Reasons: Due to the use of mask and shield by medical personnel	
	Severe	1
	High	3
Impact of COVID on health services	Moderate	3
	Low	1
	Not at all	3
Effect on Audiology services	Yes	9
	No	2
Type of impact	Could not access audiology appointments	7
	Could not access hearing aid/cochlear implant	3
	Could not do mapping	2
	Could not continue speech therapy	1
	Could not remove wax from hearing aid	2
	Could not access hearing aid / cochlear batteries	5
Feel safe in	Yes	-
communication if any pandemic or disaster	No	4
arises	Don't know	3



# 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.



Seeking medical help during the pandemic



# **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**

- GoN, Ministry of Foreign Affairs. Nepal Profile. Retrieved from https://mofa.gov.np/about-nepal/ nepal-profile/
- [2] UNDP. Inequalities in Human Development in the 21st Century, UNDP. Retrieved in December 2020, from <a href="http://hdr.undp.org/sites/all/themes/hdr">http://hdr.undp.org/sites/all/themes/hdr</a> theme/country-notes/NPL.pdf
- [3] WB. GDP – Nepal. The World Bank. Retrieved on May 2021, from https://data.worldbank.org/ indicator/NY.GDP.MKTP.CD?locations=NP
- [4] CBS (2011a) National Population and Housing Census. Kathmandu: Central Bureau of Statistics, National Planning Commission, Government of Nepal
- [5] CBS (2011b). Nepal Living Standard Survey 2010/2011. Kathmandu. Central Bureau of Statistics, National Planning Commission, Government of Nepal
- [6] World Health Organization (WHO) World Report on Disability 2011. The World Health Organization and the World Bank
- [7] Nepal Law Commission. Retrieved on May 2021 from <a href="http://www.lawcommission.gov.np/en/">http://www.lawcommission.gov.np/en/</a> archives/20819
- UN General Assembly. (2007). Convention on the Rights of Persons with Disabilities: resolution/ adopted by the General Assembly, 24 January 2007, A/RES/61/106
- [9] Committee on Rights of Persons with Disabilities. United Nation Human Rights. Retrieved from https://www.ohchr.org/en/hrbodies/crpd/pages/crpdindex.aspx in Aug, 2021
- [10] National Federation of Disabled Nepal (NFDN). (2017). Supplementary Information to the List of Issues in Relation to the Initial Report of the Federal Democratic Republic of Nepal on the Implementation of the Convention on the Rights of Persons with Disabilities (CRPD). UNCRPD
- [11] WHO, Deafness and hearing loss (2020). www.who.int/mediacentre/factsheets/fs300/en/
- [12] UNCRPD, Concluding Observations on the Initial Report of Nepal 2018, Retrieved from https:// digitallibrary.un.org/record/1483339#record-files-collapse-header in June, 2021
- [13] High Level Political Forum. United Nation Human Rights. Retrieved from https://www.ohchr. org/EN/Issues/SDGS/Pages/2020VoluntaryNationalReviews.aspx
- [14] National Review of Sustainable Development Goal. GoN, National Planning Commission. Retrieved from https://sustainabledevelopment.un.org/content/documents/26541VNR 2020 Nepal Report.pdf on Aug, 2021
- HI. (2020). Rapid Need Assessment An inclusive response to COVID-19 in Nepal. HI
- [16] Government of Nepal, Nepal Health Research Council, and Research November 2020 Rapid Assessment of Covid-19 Related Policy Audit in Nepal retrieved in June 2021 from http://nhrc. gov.np/wp-content/uploads/2021/02/Policy-audit-Report-Final-MD.pdf

- [17] Government of Nepal, The Act Relating to Rights of Persons with Disabilities, 2074 (2017), Retrieved in June 2021 from Nepal Law Commission – NLC
- [18] UNCRPD, Concluding observations on the initial report of Nepal 2018, Retrieved in June, 2021 from https://digitallibrary.un.org/record/1483339#record-files-collapse-header
- Cut from the World: Pandemic experience for hard of hearing persons in Nepal, IDA. Retrieved from https://www.internationaldisabilityalliance.org/nepal-covid19
- [20] SINTEF (2016).Living conditions among people with disabilities in Nepal. Retrieved in May 2021 from <a href="https://www.sintef.no/en/publications/publication/?
- IDS (2020). Disability Inclusive Development Nepal Situational Analysis June 2020, IDS. Retrieved in May 2021 from DID Nepal SITAN\_June 2020.pdf (ids.ac.uk)
- [22] Chupina, K. & Warick, R. (Eds). (2020) Inclusive Education Report: Realities Facing Hard of Hearing Learners in Nepal and Uganda. Available on the IFHOH website www.ifhoh.org
- Government of Nepal, Ministry of Foreign Affairs, Nepal Profile. Retrieve in July 2021 from https://mofa.gov.np/about-nepal/nepal-profile/
- [24] Government of Nepal, Ministry of Foreign Affairs, Nepal Profile. retrieve on July 2021 https:// mofa.gov.np/about-nepal/nepal-profile/

# **Bibliograghy**

Bradford, A. (2015). Nepal: Facts about Geology and Culture, Live Science. Retrieved on May 2021 from https://www.livescience.com/50734-nepal-facts.html

Central Bureau of Statistics (2011a). National Population and Housing Census. Kathmandu: Central Bureau of Statistics, National Planning Commission, The Government of Nepal.

Central Bureau of Statistics (2011b). Nepal Living Standard Survey 2010/2011. Kathmandu. Central Bureau of Statistics, National Planning Commission, Government of Nepal.

Chupina, K. & Warick, R.P. (Eds). (2020) Inclusive Education Report: Realities Facing Hard of Hearing Learners in Nepal and Uganda. Available on the IFHOH website www.ifhoh.org

Government of Nepal, Nepal Health Research Council (2020). Rapid Assessment of Covid-19 Related Policy Audit in Nepal, 2020. Retrieved from http://nhrc.gov.np/publication/rapid-assessment-of-covid-19-related-policy-audit-in-nepal/

Humanity & Inclusion. (2020). Rapid Need Assessment - An inclusive response to COVID-19 in Nepal. Humanity & Inclusion. Retrieved from <a href="https://www.fsnnetwork.org/sites/default/files/HI%20Rapid%20">https://www.fsnnetwork.org/sites/default/files/HI%20Rapid%20</a> Need%20Assessment%20-%20An%20Inclusive%20response%20to%20COVID-19%20in%20Nepal.pdf

International Disability Alliance (2020). Cut from the World: Pandemic experience for hard of hearing persons in Nepal. Retrieved from <a href="https://www.internationaldisabilityalliance.org/nepal-covid19">https://www.internationaldisabilityalliance.org/nepal-covid19</a>

Institute of Development Studies (2020). Disability Inclusive Development Nepal Situational Analysis June 2020. Retrieved from DID Nepal SITAN June 2020.pdf (ids.ac.uk)

Nepal Government (2015) The Constitution of Nepal, 2015, https://www.mohp.gov.np/downloads/ Constitution%20of%20Nepal%202072 full english.pdf

Nepal Law Commission. Act Relating to Right of Persons with Disabilities, Nepal 2074 (2017). Retrieved from http://www.lawcommission.gov.np/en/archives/20819

National Federation of Disabled Nepal (2017). Nepal Civil Society Supplementary Report on the Initial Report of the Government of Nepal on the Convention on the Rights of Persons with Disabilities (CRPD), Supplementary Information to the List of Issues in Relation to the Initial Report of the Federal Democratic Republic of Nepal on the Implementation of the Convention on the Rights of Persons with Disabilities (CRPD).

SINTEF (2016) Living condition among people with disability in Nepal. Retrieved from https://www. sintef.no/en/publications/publication/?publid=1431820

The World Bank Nepal (2021). Current GDP Nepal. Retrived from https://data.worldbank.org/indicator/ NY.GDP.MKTP.CD?locations=NP

United Nations Committee on the Rights of Persons with Disabilities (2018), Concluding Observations on the Initial Report of Nepal 2018. Retrieved from https://digitallibrary.un.org/record/1483339#recordfiles-collapse-header

United Nations Development Programme (201). Human Development Report 2020, The Next Frontier: Human Development and the Anthropocene Briefing note for countries on the 2020. Retrieved from http://hdr.undp.org/sites/all/themes/hdr theme/country-notes/NPL.pdf

United Nations General Assembly. (2007) Convention on the Rights of Persons with Disabilities: resolution/adopted by the General Assembly, 24 January 2007, A/RES/61/106.

United Nation Human Rights Committee on Rights of Persons with Disabilities. Retieved on Aug. 10, 2021 from <a href="https://www.ohchr.org/en/hrbodies/crpd/pages/crpdindex.aspx">https://www.ohchr.org/en/hrbodies/crpd/pages/crpdindex.aspx</a>

United Nation Human Rights. High Level Political Forum. Retrieved from <a href="https://www.ohchr.org/EN/">https://www.ohchr.org/EN/</a> Issues/SDGS/Pages/2020VoluntaryNationalReviews.aspx

United Nation. List of issues in relation to the initial report of Nepal. Committee on the Rights of Persons with Disabilities. Retrieved in August 2021 from https://digitallibrary.un.org/record/1483058/files/ CRPD C NPL Q 1 Add-1-EN.pdf

United Nations Nepal, (2020). COVID-19 NEPAL: Preparedness And Response Plan (NPRP), 2020. Retrieved from https://nepal.un.org/en/108408-covid-19-preparedness-and-response-plan-jan-2021

Warick, R. P. & Tang B. (2020). Global Report of COVID-19's Impacts on Hard of Hearing People. Retrieved from the International Federation of Hard of Hearing People www.ifhoh.org/positionpapers.

World Health Organization (2011). World Report on Disability 2011. Retrieved from the World Health Organization World report on disability 2011 (who.int)

World Health Organization, Deafness and Hearing Loss (2020). www.who.int/mediacentre/factsheets/ fs300/en/

# APPENDIX 1 - CONSENT FORM





### 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

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 <u>electronically recorded</u> 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:
<b>Neeta Keshary</b> , President
SHRUTI (National Association of the Hard of Hearing and Deafened, Nepal) Dhumbarahi, Kathmandu, Nepal Tel. 9849-501-416 Email: ntkeshary@gmail.com

# **APPENDIX 2 - INTERVIEW GUIDE**

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 a	nd ID code
Day/Month/Year of Interview	/ / 2021

## General Information (GI) of Hard of Hearing

<b>→</b>	GI1. H	lard of Hearing's:
	First Na	ame:
	Last Na	ame:
<b>→</b>	GI2. W	Vhat is your last educational level?
		Basic Level
		High School
		Undergraduate Degree
		Postgraduate Degree
		PhD
		Informal Education
<b>→</b>	GI3. W	Vhat is your gender?
		Male
		Female
		Other
		Prefer not to say
<b>→</b>	GI4. V	Vhat is your employment status?
		Student
		Employee
		Self-employed
		Not in the paid labor force
		Retired from employment
		Other – please specify

<b>→</b>	GI5. V	Vhat is your marital status
		Single
		DeFacto Relationship
		Married
		Divorced
		Prefer not to say
<b>→</b>	GI6. V	Vhat 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
<b>→</b>	GI7. D	o you receive healthcare in your first language?
		Most of the time
		Sometimes
		Not usually
	If y	ou do not receive healthcare in your first language, what types of barrier do you face?
		☐ Difficulty in communicating with health professionals
		☐ Difficult to access accurate and comprehensive health information
		☐ Difficult 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**

<b>→</b>	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		
<b>→</b>	HL2. I	Do you know when did your hearing loss	oc	curred?
		Yes		
		No		
<b>→</b>	HL2. /	At what age was your hearing loss revea	led?	
		Years old		
<b>→</b>	HL4. I	n addition to your hearing loss, do you	have	e a family member with a hearing loss?
		Yes		
		No		
<b>→</b>	HL5. I	Please specify if the family member have	he	aring loss.
		Spouse		
		Parent		
		Grandparent		
		Sibling		
		Child		
		Other – please specify the relation		

<b>→</b>	HL 6. Do you know what the cause of hearing loss is?
	□ Yes
	□ No
	If yes, please specify
<del>)</del>	HL 7. Do you use assistive hearing devices?
	□ Yes
	□ No
<b>→</b>	HL8. 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
<del>&gt;</del>	HL9. 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
	,

<b>→</b>	HL10.	At what age did you start using hearing devices?
		Years old
<b>→</b>	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
<b>→</b>	HL12.	Have you had any issues in your health conditions in the past 12 months?
		Yes
		No
	If y	es, please specify
<b>→</b>	HL13.	Did you come down with the COVID virus during the past year?
		Yes
		No
<b>→</b>		Did you require medical care during the past year for any health condition?
		Yes
		No
	111 45	Harry and describe the second of the second
<b>→</b>		How would you rate impact of the condition?
		Mild
		Moderate
		Serious
		Very serious

<b>→</b>	HL16.	Were you in the hospital for any of the above conditions?
		Yes
		No
<b>→</b>	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)
<b>→</b>	HL18.	In general, how satisfied are you with your medical care from your doctor nurse
-		ner health professional?
		Very Satisfied
		More than Satisfied
		Satisfied
		Unsatisfied
		Very Unsatisfied
<b>→</b>	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
<b>→</b>	HL20.	Do you have medical insurance?
		Yes
		No
	If y	res, what kind of coverage? Please specify

<b>→</b>	HL21.	Where do you get medical care from?
		The public health system
		The private health system
<b>→</b>	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

<b>→</b>	HS1. I	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
<b>→</b>	HS2. I	n the last 12 months, have you met with a doctor, nurse or clinical officer?
		Yes
		No
<b>→</b>		f you answered yes to meeting a doctor, nurse or clinical officer,
	nurse	or clinical officer, how did you meet?
		In person physically
		Online or social media
		By telephone
		Other – please specify
<b>→</b>	HS4. I	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
<b>→</b>	HS5. \	What was purpose of the meeting? (Indicate all that apply)
		Check up
		Existing medical condition (follow up)
		New medical condition
		Other – please specify

<b>&gt;</b>	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
>		f you answered Yes to question HS7, what kind of support did doctor, 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

(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
<b>→</b>	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
<b>→</b>		If the doctor, nurse or clinical officer wore a mask (but no face shield), at extent could you understand the doctor?
		Fully Understand
		Mostly Understand
		Half Understand
		Partially Understand
		Not understand at all
<b>→</b>		Did the doctor, nurse or clinical officer stay at a physical distance from you g the meeting?
		Yes
		No

7		eeting, did the distancing affect communication?
		Not at all affected
		Slightly affected
		Somewhat affected
		Moderately affected
		Extremely affected
<b>→</b>		If there were difficulties in understanding, would you please explain fficulties you faced?
		Could not hear and understood
		Could not read lips as using facemask
		Challenging acoustic environment
		Other – please specify
<b>→</b>	face s	If you responded yes to the doctor, nurse or clinical officer using a hield without a mask (Question HS11), how did the use of the face shield communication?
		Improved communication
		No impact at all
		Made it worse
<b>→</b>		Did you experience any difficulty booking doctor, nurse or clinical officer's ntments yourself by phone due to a hearing difficulty?
	_	
	Ц	Yes
		Yes No
<b>→</b>	□ HS18.	
<b>→</b>	□ HS18.	No  If you experienced difficulty booking by phone, how did you arrange to see
<b>→</b>	HS18.	No  If you experienced difficulty booking by phone, how did you arrange to see doctor, nurse or clinical officer?
<b>→</b>	HS18.	If you experienced difficulty booking by phone, how did you arrange to see doctor, nurse or clinical officer?  Booked in person

<b>→</b>	the service desk/reception?						
		Cor	mmunicate orally				
		Cor	mmunicate by writing in notebook.				
		Cor	mmunicate by sign language.				
		Acc	companied family or friend				
		Nev	ver had communicate with reception				
		I w	as asked to accompany family/friends members, etc.				
		Oth	ner form of communication, please specify				
<b>→</b>	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 y	es, v	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				
<b>→</b>			medical examination and/or diagnosis, do you think that any assistance ry in communication with medical support staff?				
		Yes					
		No					
	If Y	'es, F	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				
		$\Box$	Other place explain				

<b>→</b>	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
<b>→</b>		Would you please rate of your satisfaction with the accommodation that ded in the medical office?
		Very Satisfied
		Satisfied
	_	Unsure
		Dissatisfied
	_	Very Dissatisfied
Plea		ify the reason for your rating
i icu	se ciari	my the reason for your fating
<b>→</b>	HS24.	Do you have any comments regarding the access to, audiology, speech therapy
		ther ear care services during the pandemic and after the pandemic?

### Access to health services during the COVID period

<b>→</b>	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		
	Ple	ase comment further about your response		
<b>→</b>	CP2.	What impact did the corona virus have on your access to health services?		
		Severe		
		High		
		Moderate		
		Low		
		Not at all		
<b>→</b>	CP3. \	Were audiology services impacted during COVID-19?		
		Yes		
		No		
	lf y	ou 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		

	Do you feel safe to communicate if there any pandemic or disaster arises to sto health?			
	Yes			
	No			
	Don't know			
	Other – would you please explain?			
This questionnaire focused on visiting a doctor/medical office.				
Do yo	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 o	ther comments?			
,				







