STORY BOOK 2

Voice of our own

Stories of People who are

Hard of Hearing and Deafened

in Asia and the Pacific

Asia Pacific Federation of the Hard of Hearing and Deafened (APFHD)

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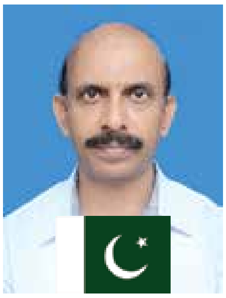
The movement

The movement of people who are Hard of Hearing and Deafened (HoHD) in Asia-Pacific (AP) was started in 2007 when a former trainee of APCD and IFHOHYP combined his learning on networking from APCD and knowledge on HoHD from IFHOYP, ALDA and IFHOH and started networking HoHD people in AP region. Initially it became a non-formal group, then formed ALDA-AP group, after that with the help of APCD it became a formal network when representatives from 10 AP countries founded **The Asia-Pacific Federation of the Hard of Hearing and Deafened (APFHD)** in March 2012 at the APCD Training Building, Bangkok, Thailand.

APFHD is the only network in the Asia-Pacific region to represent persons who are hard of hearing and deafened with an aim to protect and promote their rights. APFHD is a regional member of International Federation of the Hard of Hearing (IFHOH) People, and World Hearing Forum (WHF) of WHO.

Executive Committee of APFHD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MESSAGES

DR. RUTH WARICK

IFHOH / IDA

THE POWER OF STORIES

Transforming Experiences into Collective Action

I am inspired by the stories about experiences living with a hearing loss that were shared in this publication.

Many of the stories resonated with my own experience growing up as a child without hearing aids although I was born with a substantial hearing loss. I struggled in school in my early years, often did not hear, and experienced challenges and discrimination in the labour force. It was sheer determination and hard work that turned my life around. Plus it helped to get a hearing aid at age 11, then a second one at age 22 although two had been needed all along. It also helped that I became involved in the hearing loss movement in my early adulthood so was no longer alone in journeying through life as a hard of hearing person.

It is through sharing our voices about our experiences that we generate an understanding of what it means to have a hearing loss for ourselves and for those who do not have a hearing loss. By connecting with each other, we can begin to jointly identify solutions to the barriers encountered and to advocate for changes in our communities to make things better for everyone. Thus, the individual experience becomes transformed into a collective one leading to advocacy to change things for the better.

Dr. Ruth Warick
Immediate Past President,
IFHOH - International Federation of Hard of Hearing People

First Vice-President,
International Disability Alliance (IDA)

Mr. AVI BLAU

President of IFHOH

WISHING APFHD A GREAT SUCCESS

Coming back after a long break because of the pandemic

It is a great pleasure to write in this storybook 2 of APFHD. After a long break because of the pandemic, it is good to see this collection of stories by HOH persons telling us about their life.

IFHOH is a long-time supporter of APFHD and will continue to help as needed to make APFHD a viable and successful federation.

As a world-level organization, IFHOH represents HOH persons in organizations like the UN, WHO, ITU, IDA, and others. IFHOH way of maintaining the connection with HOH persons is by raising regional federations like the European Federation of Hard Of Hearing people - EFHOH, the Asia Pacific Federation of Hard of hearing and Deafened - APFHD, and in the future, maybe also an African federation of HOH persons.

Each federation represents national organizations in its region and helps the national organizations to make good connections with the HOH persons in the specific country.

We at IFHOH wish APFHD great success with this storybook and with all its actions.

Avi Blau
President -
IFHOH - International Federation of Hard Of Hearing People

MS. LIDIA BEST

President of EFHOH

EFHOH stand shoulder to shoulder with our friends in Asia-Pacific Region

Congratulations to Asia Pacific Federation of Hard of Hearing and Deafened team on developing this important Story Book!

Our stories need to be told whilst society and especially politicians need to understand rich diversity among our community.

All too often our specific needs, allowing us function in the society in a way that enables us to reach our full potential are ignored. Hearing aid, cochlear implants ,Hearing loops, and speech to text are still out of the reach of many people who require them.

I hope the book and this action will inspire and bring positive change in both society and policy development, leading towards more inclusive society for hard of hearing and deafened people.

EFHOH stands shoulder to shoulder with our friends in Asia Pacific Region.

Lidia Best CPACC
President
European Federation of Hard of Hearing People (EFHOH)

MR. AKIIE NINOMIYA

Ex. Executive Director APCD

“KIZUNA”

Solidarity between persons
a sense of unity and love

Kizuna is a Japanese word meaning a sense of solidarity between persons, a sense of unity and love.

In 1981, Disabled Peoples’ International was “born” in Singapore, the International Year of Disabled Persons by the United Nations. The motto was, “A Voice of Our Own.”

In 2005, the Asia-Pacific Development Centre on Disability (APCD) conducted a conference in Islamabad, Pakistan for The Community-based Self-Help Organization of Disabled People where I established “Kizuna” with Mr. Akram. After the conference, Mr. Akram appealed for a voice of persons with hard of hearing since sign language interpreters had been recognized by the Pakistan Government but persons with disabilities were not. Mr. Akram emphasised that the Conference should be centred around persons with disabilities and a “voice of our own” should be respected above sign language interpreters.

In 2008, the United Nations established the Convention on the Rights of Persons with Disabilities (CRPD) which clearly states that a “Voice of Our Own” is a human right.

In 2012, APCD organized the first Conference on the Hard of Hearing and Deafened where participants established the Asia-Pacific Federation of Hard of Hearing and Deafened, APFHD.

A “Voice of Our Own” should not be limited to communicating in sign language only but also through other means of communication since many hard of hearing and deafened persons do not use sign language. For this reason, “Nothing about us without us” promoted “Kizuna” among the hard of hearing and deafened persons in the Asia-Pacific Region.

I value “Kizuna” with Mr. Akram and APFHD.

Akiie Ninomiya,
Ex-Executive Director of APCD
EX - Chief Advisor - Japan International Cooperative Agency (JICA)

MR. PIROON LAISMIT

APCD Executive Director

Partner to empower emerging group of disabilities.

On behalf of the Asia Pacific Development Center on Disability (APCD), I'm delighted with the launch of Story Book 2 in 2023 published by the Asia-Pacific Federation of the Hard of Hearing and Deafened (APFHD). This inspiring collection of stories celebrates diverse experiences and achievements of people who are Hard of Hearing and Deafened.

It highlights the important work being done by APFHD and its partners to empower this emerging group of disabilities.

As the Secretariat of AFFHD since 2012, APCD is proud to be part of a network that dedicated to promote the inclusion and rights of people who are Hard of Hearing and Deafened in the Asia-Pacific region and beyond.

I congratulate the new executive board led by President Mr. Muhammad Akram and praise their commitment to empower friends who are Hard of Hearing and Deafened.

With this new booklet, I hope it inspire readers to learn more about the significant work done by APFHD to strengthen a more inclusive society. APCD looks forward to collaborating with APFHD and other stakeholders in the Asia-Pacific region to ensure the voices of people who are Hard of Hearing and Deafened are louder and valued.

Congratulations to all involved in bringing Story Book 2 to life!

Piroon Laismit,
APCD Executive Director

DR. RYUHEI SANO

Understadning about Hard of Hearing and Deafened in our region

Professor, Hosei University

I am pleased to get the announcement of this storybook by colleagues who are hard of hearing and deafened.

The nature of international networking has changed over time. The availability of the Internet, the use of smartphones and social networking services, and the worldwide popularity of COVID-19 have changed communication drastically. On the other hand, I believe that some things should not be changed. Even if there are differences of opinion and conflicts, it must be powerful to keep the relationships we have built up, to share the feelings and dignity we cherish as persons with disabilities, to recall together the days filled with pain and regret, and echo our courage jointly to take the next step.

I hope that the readers of this book will gain some hints and understanding about hard of hearing and deafened in our region.

Ryuhei Sano (Dr.)
Professor, Hosei University

Mr. Dominique Schlupkothen

All of us can learn from and be inspired by these stories from Asia-Pacific

Director - CBID, CBM

CBM's Vision is for an inclusive world in which all persons with disabilities enjoy their human rights and achieve their full potential. Working towards this Vision, CBM not only responds to the immediate needs of persons with disabilities, but also supports building inclusive systems, advocating for inclusive policies, and fostering partnerships that ensure persons with disabilities can equitably participate in society.

Despite many achievements, there is still a long way to go in creating awareness and understanding about the rights and needs of persons with disabilities. Societal views regarding disability often lead to discrimination, stigma and isolation. As a result, many persons with disabilities have connected experiences of social exclusion, poverty, violence and abuse, as well as limited opportunities to live a self-determined life.

In this Story Book, we read about how individuals who are hard of hearing or deafened, and live in different countries across the Asia Pacific Region have overcome the barriers they faced during different moments of their life. Examples illustrate the need to overcome barriers in education, health and in social environments. All of us can learn from and be inspired by the stories and experiences shared by the individuals in this book.

When looking at societal transformation towards inclusion, it is vital that these stories are heard and that people who are hard of hearing and deafened themselves contribute towards discussions, policy formulation and implementation. The most qualified people to raise awareness about being hard of hearing are people who are hard of hearing themselves. Their journeys are inspirational and provide positive role models for other people who are hard of hearing, for caregivers, families and close friends who can be important supporters on life's journey. Last not least, this book is an inspiring read for professionals working in the field and anyone interested in ensuring that inclusion truly means including all.

Mr. Dominique Schlupkothen
Director Community Based Inclusive Development, CBM

Sarna Shah

Bangladesh - South Asia

LIVING WITH HEARING LOSS

A story of a **Deafened** person from Bangladesh

I was born on 5th January, 1994 at a hospital in Dhaka, the capital of Bangladesh. We moved to a village in Gazipur district when I was 3, because living in the capital was expensive. Being the firstborn of my parents, I had a childhood full of joy and affection. I started my school in a local kindergarten at the age of 5. I had lots of friends in school and neighborhood. so far, so good.

I was 7 when I had meningitis. The world became totally silent around me within a few days. The doctor told my parents, “She will forget how to talk, because she won’t be able to hear anything. Only a cochlear implant can restore her hearing to some extent, but it’s not available in Bangladesh right now and it will be costly. For now, the best you can do is to talk to her. Talk to her and encourage her to speak so that she doesn’t forget how to talk.”

My father started his mission to “fix” me. My mother obeyed the doctors’ advice and kept talking to me. At first, it was small instructions with gestures like “eat, sleep, go, come, read, etc.” Soon the conversations were longer. I remember watching TV together with my family, I watched the silent pictures moving by and my mother or my aunts were interpreting what was happening for me. By then, father found out that “fixing me” was not affordable, so he also started supporting me in any way he could. He used the written communication method. I used to carry a notebook and pen, and loved the written communication because it let me understand everything, not only the summary.

Even though I was a talkative child, it took me 1 year to start speaking confidently again. It isn’t easy to talk back to a silent world. My family and friend’s support gave me the confidence, I knew I was heard, I was understood. Still, I was never confident to speak to strangers. I was kind of ashamed of my deaf voice.

As we were living in a village, there was no “deaf school” around. I resumed my schooling soon after recovering from meningitis, but couldn’t continue. It wasn’t easy for me when I couldn’t recognize the ever-known environment anymore, when I wasn’t able to connect with my dearest friends. I didn’t know how to continue; my teachers didn’t know either. I dropped out.

After 1 year, when I was able to lip-read well and could talk back perfectly, I resumed school. this time a bigger and most prestigious school in district, hoping that they will know what to do. But it turned out, they had no idea how to support a student with hearing disability properly, either. They didn’t even want to admit me, father had to take help from someone influential and advocate to the school management. He was successful, I got in.

I hated school, I had no friends, couldn’t understand what teachers were saying, couldn’t absorb the lessons at all. I sat in the classroom, looking at the clock, waiting for the classes to be over. Teachers tried their own ways to include me, they made me sit in the front row, asked my classmates to help me to understand homework, took special care of me when needed.

Sarna Shah ... *continued*

Still, not everything worked, they had 60 other children to take care. But I believe that they tried their best. If only they had knowledge about inclusive education!

Books were my best friends back then. It was the doorway by which I could connect with the outside world. I used to read a lot, everything I could find, books, newspapers, magazines, leaflets, paper packets in which street vendors sell snacks, anything I could find to read. These filled my silent world with words, sentences, and language. It took me 2years to understand that what was taught in the classroom was already in the books. And I love books! I started doing well in examinations, even without any extra support.

We lived in a village, and we didn't have cable TVs in there. The first time we had cable TV, I was 13. I found out an interesting thing, the subtitles! Till then I had to depend on other people to understand the contents going on TV. But with subtitles, I could understand everything by myself! The world became easier. Within a few more years, I discover internet and text messaging! The sense of independence was so overwhelming but still it came with its own problems, internet connections were too bad back then, most people were not (still are not) comfortable with text messaging. Recently, video calling and speech to text apps removed many barriers but of-course not all.

After graduation, I got an internship in Centre for Disability in Development (CDD) and after completing the internship I got a job as Technical Officer in a project aimed at including deaf children in mainstream education system. I was happy to get an opportunity to make a difference, no matter how small it was. Been trying to do that since then.

My life is as "normal" as it could gets, with lots of barriers to deal with. If I ever get sick, I have to wait for someone who can take me to the doctors, because the doctors don't have time or patience to communicate with me. I travel alone pretending to be a hearing person (I'm a pretty good lip-reader) but sometimes it can get messy, like missing my stoppage or boarding the wrong bus/train. Airports are kind of nightmares to me if I'm traveling alone, the officials can get really non-cooperative sometimes. I love going to movies but without any subtitle it's not so enjoyable to me. I like shopping, but in fixed price stores because I can't bargain properly. But these shops can be too expensive sometimes. And whenever I'm taking any online service like uber, online shopping or food delivery; I have to take support from someone else because delivery men/drivers would always call.

Photo 1:
Presenting her work at IDA Bridge Training in Nepal

Photo 2:
Meeting with persons with disability's self-help group.

Photo 3:
Facilitating a training on disability orientation

CHHIM Kim Hean

Cambodia - Southeast Asia

AN ENT DOCOTOR WITH HEARING LOSS

A story of a **Deafened** person from Cambodia

I am CHHIM Kim Hean, profoundly deaf, a founder of H.O.P.E Cambodia.

My H.O.P.E Cambodia works in cooperation with Doctor Alliance of Union of Youth Federation of Cambodia (DAUYFC) and Samdech Techo Voluntary Youth Doctor Association (TYDA) as well as Cambodian Red Cross (CRC) and Starkey Hearing Foundation (SHF) as Ear and Hearing Health Care Coordinator (EHC).

My organization provides free ENT Screening and Treatment for all residents at the fields and at H.O.P.E Cambodia Clinic Centers and when they are persons with hearing loss, they will get free hearing aids from Starkey Hearing Foundation (SHF). All hearing aid users always receive free screening and treatment as well as free aftercare service for their hearing aids.

My work is for hearing loss prevention especially for little children and orphans at poor communities and orphanage centers.

Hemendra Mistry

India - South Asia

COPING WITH DISABILITY

A story of a **hard-of-hearing** person from India

Dr. Hemendra Mistry, an Indian researcher who is hard of hearing, surmounted several obstacles to succeed in his academic career and win the Marie Curie Action Co-fund fellowship for his research on diversity. He refused to let his hearing impairment hold him back.

“I managed to finished all of my higher education in mainstream universities, despite having a moderately-severe hearing loss.”

Mistry has always been confident in his abilities and has never let his hearing impairment stand in his way. At the age of 17, he received a diagnosis of a disability in the form of bilateral sensorineural hearing loss, which led to five years of social withdrawal and multiple scholastic failures. Education in general universities can be seen as something that could hold back a moderately-severe hearing-impaired person. However, he has not let this define. He has successfully completed his higher studies, which include a Bachelor of Science (B.Sc.) in Chemistry, a Master of Arts (M.A.) in Sociology, a Master of Education (M.Ed.) with Teacher Education as a specialisation, and a Doctor of Philosophy (Ph.D.) in Education.

“Despite the fact that my social life was significantly impacted by the hearing problem, I still have a wide range of friends.”

The onset of the hearing loss left Mistry with the scary reality that he could permanently lose his hearing at any time. The scholastic setbacks he experienced in the early years of the development of his hearing impairment and the hostile home environment took a toll on his confidence, but he remained certain that he could overcome them, succeed, and make a positive contribution to society. Soon after the hearing impairment began, he lost his father. He had to work as a labourer to take care of his family's needs, which included a physically challenged sibling and an elderly mother, which prevented him from pursuing his dream of seeking higher education. However, the NCPEDP Post-graduate Scholarship was a huge aid and allowed him to resume his higher education.

"My participation in more than 50 academic forums (conferences, seminars, and workshops) and more than 50 publications sufficiently reflect my never-ending ambition to know more and more in the subject."

Due to his personal learning experiences in Mainstream institutions where he struggled with his hearing, Dr. Mistry developed a keen interest in inclusive education and has subsequently conducted extensive research on the topic. In his more than ten years of research experience, he has improved several qualities, including teamwork, leadership, the ability to complete projects on time, commitment, and collaboration.

Hemendra Mistry ... continued

As a result, he has been able to advance these and boost his confidence in his work as a hard-of-hearing researcher with hearing academics, where he has increased their awareness of hearing problems, taught them how to communicate with hearing-impaired people, and encouraged them to accept an invisible disability.

“I received the Dr. S. Radhakrinan Postdoctoral Fellowship, the ICSSR Postdoctoral Fellowship, and the UGC Research Fellowship from the Ministry of Education.”

Dr. Mistry has been employed as an independent postdoctoral scholar at the Maharaja Sayajirao University of Baroda, India, for the past six years. While there, he has had numerous opportunities to organise academic forums (seminars, conferences, and workshops) with other team members. These chances boosted his leadership abilities, self-assurance, organisational abilities, ability to collaborate well with large groups, and success in completing assignments.

“During my doctoral and postdoctoral level researches, senior professors found that I was a more courageous and self-assured researcher than other fellow hearing researchers.”

Dr. Mistry utilised the period that colleges were closed due to lockdown during the COVID-19 pandemic to publish research papers in journals, apply for international grants, and seek academic employment. Using a speech-to-text tool, the online interviews helped him hone his communication abilities even more. He was one of twenty candidates chosen by the University of Salamanca in Spain for the Marie Curie Action Co-fund fellowship after being rejected four fellowships.

“"I have the ability to work well in a team as well as finish academic and research activities on my own, without help."

Dr. Mistry has come this far in his academic career despite receiving numerous rejections as a result of hearing problems, and he is certain that he will be offered a permanent academic job in a university. He also serves on the boards of IASSIDD* and IFHOH as an Independent Associate Member. He has maintained contact with his friends for more than 15 years.”

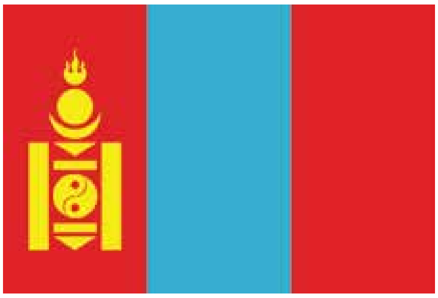
"Rejections are a part of life; embrace them with courage and strive hard to succeed."

Despite his impairment creating obstacles, Dr. Mistry is working very hard and says he appreciates the challenge of achieving goals. His passion, demonstrated by all of his accomplishments, is reflected in his higher education and research career. He is adamant that his hearing impairment won't prevent him from achieving his goals in life and that he will utilise it to his advantage by supporting other hard-of-hearing people.

"I give credit to my parents and teachers for my personal triumphs; without their help and persistence, I couldn't have progressed as far as I have."

* IASSIDD - International Association for the Scientific Study of Intellectual and Developmental Disabilities

Yumjirdulam Buyankhishig



Mongolia - East Asia

A TEACHER WITH HEARING DISABILITY

A story of a **hard-of-hearing** person from Mongolia

I am Yumjirdulam Buyankhishig, from Mongolia, I am married and living with my husband and 2 children. I am working with Ministry of Education and Culture as Sign Language Teacher and Interpreter. Same time I founded Deaf Club Mongolia.

In study at School No.29 for children with hearing disability, and did not felt any difficulty in school however I used to feel isolated from my peers from home to school and back.

I completed the special school in 1995 after obtaining 8 years of education. I studied at the evening shift school, which allowed working youths to get a general education diploma. It felt unusual on the first day as I shifted from special school to regular school. It was a completely different environment than I expected because some of the children were chewing gum, and some even played cards and held guitars while the teachers were teaching their lessons. I was very surprised because I had never seen such a thing and it was unforgettable how tired I was from the noise after school.

I would suggest that we need to create an accessible environment where children with hearing disabilities can have access to quality education, we also need to train and empower teachers so they can work with children with hearing disability. we also nee to improve children's learning environment and adaptive access due to rising demands

When it comes to communiate with family my husband is deaf so we use sign language to communicate. Our children have normal hearing but they are fluently in sign language too. In some cases, if I don't hear well after removing my hearing-aids, our children speak close to my ear.

Nowadays, the attitude towards the people with hearing disability in society has been changing positively. When I was communicating without a hearing aid in a public place, if I ask for something to be written down for me, people will write it down for me on a piece of paper. I also use my mobile phone to write or communicate in public. In addition, there have been instances where I communicated with others using body gestures. However, due to the negative attitude of a handful of individuals, there certainly have been cases where it was difficult to communicate in public.

It is complicated to watch TV. If I increase the volume to a level I can hear, the house becomes filled with loud noise. Our neighbors have appeared to come to terms with it. I am not able to understand important news on the TV when I am at home or go outside, so I only read captions or texts to understand the content. I don't have any problems hearing when I go to the cinema because the audio is loud and has subtitles. However, there have been times when the subtitles loaded too fast and I missed the information.

I usually receive my information, watch my favorite TV and shows, talk with friends, and have personal and business conversations through the Internet.

Yumjirdulam ... *continued*

Healthcare in hospitals depends on the attitude of doctors. Doctors are reluctant to communicate with a hearing impaired person, so they often ask the nurse to write on a piece of paper, or ask if there is someone accompanying the patient. Personally, I can access the option to communicate with healthcare providers and get medical services.

There is no access to assistive listening accommodations here. In case of hearing aids, in Mongolia, social welfare only provides 500,000 MNT (which is equal to $150) only once every 3 years. Modern, technologically advanced hearing aids are expensive. Purchasing them poses a great financial difficulty for many people. Purchasing hearing aids with credit is not accepted. In addition, meeting venues, theaters, schools, and kindergartens do not have noise canceling devices at all.

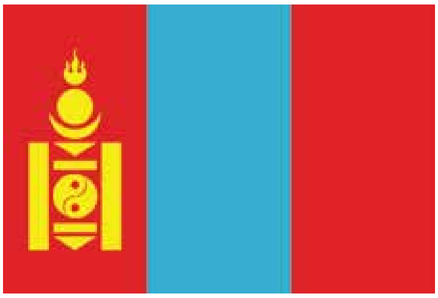
I don't need speech therapy. Only a few speech therapists are trained in our country. Schools and kindergartens do not make speech therapy accessible, and the methodology of working with children is poor. Demand has increased in recent years to empower speech therapist teachers and effectively provide services that reach the target children.

During parliamentary, presidential, and local elections, subtitles and sign interpreters are displayed on television and social media. However, the availability of information during the formation of a new government and the presidential inauguration following the election is insufficient. Government breaking news is delivered once a week with a sign language interpreter, but no subtitles are given. Access to sign language interpreters is available in court, but not available during preliminary hearings or investigations. There are no accommodations for the hearing impaired in many legal and political proceedings.

I personally aim to make society understand that not being able to listen is not a barrier to communication, and I work as a bridge between people with and without hearing. Hearing loss can sometimes make it difficult to hear at a normal level. Many people don't realize that I can’t hear what they say to me. At this point in time, I experience communication problems, feel rejected by ignorant people in society, and sometimes find it difficult to work with others.

I think it is important for hearing people to understand that people who cannot hear face great psychological distress because of their communication barriers. However, lip-reading and other techniques can and should be utilized in order to ease their communication with hearing individuals.

Nandin-Erdene Badamsuren



Mongolia - East Asia

A YOUNG WOMEN WITH HEARING DISABILITY

A story of a **hard-of-hearing** person from Mongolia

I am Nandin-Erdene Badamsuren, from Mongolia. I work as an assistance in a dental clinic.

I attended general education school from 2003-2014 and Mongolian State University of Education from 2014-2018. When I began studying at the university, classes were difficult. I could not understand what teachers taught, as they often spoke verbally rather than using sign language.

During study my friends helped me a lot. Sometimes teachers asked me about classes. It was difficult to do tasks given by teachers, but the support of my friends and teachers allowed me to overcome many obstacles. I also overcame barriers by self-studying. When I was in school, I felt that there was less accessibility and support for students with disabilities. I often wished there were sign language interpreters.

I was attending speech therapy when I studied in secondary school. However, now I can no longer access speech therapy.

I often communicate with family members verbally. However, sometimes I don't understand them. I use sign language with my friend while walking in public places. Sometimes I don't understand when I talk with people in public.

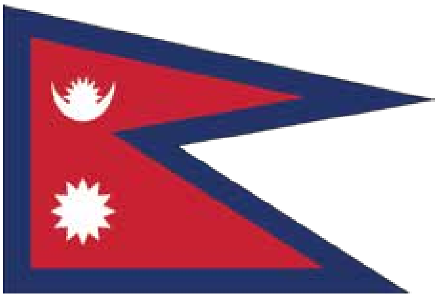
It is bit difficult for me at shops, I often used my mobile phone to learn about prices and communicate by typing.

There are no subtitles available when I watch TV. There should definitely be captioning for people with hearing disability on TV. When I visit a cinema, I often use my phone to type anything that I want to ask. I don't understand movies without subtitles.

I was blamed while using public transportation whenever I showed my disability card. I don't understand why peopled treated me in such a manner. I also wish drivers learned basic sign language in order to communicate with people who cannot hear.

It is difficult for me to visit a hospital. I use my mobile phone to communicate and sometimes doctors and nurses help by writing down messages. I use hearing aids, but I still don't understand during conversations with others. I often had to pay for the battery of my hearing aids, even if they didn't aid my communication very much.

Fupu Sherpa



Nepal - South Asia

ACCESS TO EDUCATION

A story of a **hard-of-hearing** person from Nepal

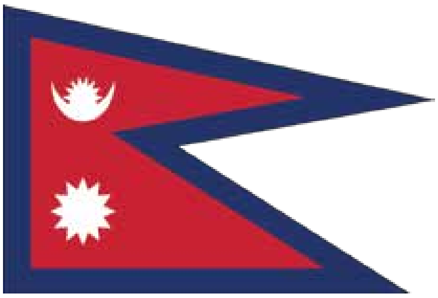
Namaste!

My name is Fupu Sherpa from Kathmandu, Nepal. I have sensorineural hearing loss in both ears. My parents took me to many hospitals for checkups and bought me a hearing aid 6 years ago. The hearing aid was not adjusted to my hearing needs, so I stopped wearing it after 2 months. It was really hard in my school days as I was discriminated against and bullied for not hearing properly by my fellow classmates. I couldn't understand anything the teacher was saying, and when trying to talk with friends, I would have to ask them to repeat themselves many times. Also at that time, I was not aware of what being “Hard of Hearing” meant, and teachers were not trained on how to assist students with hearing loss. I think it is very important for every school, college, and even kindergarten teacher to be knowledgeable about all types of disabilities and how they can ensure that their students with disabilities are both psychologically and educationally successful.

I completed a bachelor degree in Social Work, but I was often confronted with a lack of accessibility during my education. I had trouble understanding the assignments that were given to us, and when I asked other classmates for clarity, they would only give me some brief descriptions and offer no details. I even scored low in the practical sections of exams because I heard the question wrong. Even in my early school days in Viva, I would receive low test marks because of my lack of accommodations. In schools and colleges, there are no screening of study materials or captioning, which are important for hard of hearing students. While education plays such a vital role in shaping our futures, even now, we hard of hearing people face so many difficulties in our educational experiences, and the government is not even providing the most basic needs, such as captioning.

I was introduced to SHRUTI (National Association of Herd of Hearing and Deafened) and with the help of their consultancy I have been able to get the right hearing aid. After starting to wear hearing aids, I took IT training for 4 months in SHRUTI. It was during this period that I learned how regular students took classes. Since this training was for HOH (Hard of Hearing) people, our sir was really knowledgeable and assisted us in every possible way. He spoke slowly so that we could understand him. Due to Covid, we had to stop in-person classes in the middle, but we attended online classes with captions available. I wish for classes to be like this in every educational field so that people with hearing loss will not feel detached from their peers and also not fall behind in studies. Our organization has been fighting for HOH rights and has been conducting sensitization programs about hearing loss for teachers in order to show them how to better uplift hard of healing youths. I am also a board member of SHRUTI, and serve to help people who are HOH like me.

Agnishikha Acharya



Nepal - South Asia

ACCESS TO HEALTH SERVICES

A story of a
hard-of-hearing
person from Nepal

Namaste!

I am Agnishikha Acharya from Lalitpur, Nepal. I am hard of hearing. Initially my speech wasn't any good because in the "Deaf school" where I studied, speaking was not allowed and Sign language was the only language of instructions. I start using hearing aids from teenage. While my hearing capacity is still not much better, my speech has improved after using hearing aids. Hearing aids are big cause of speech improvement. While hearing devices can be used at every age, wearing hearing devices from childhood can help improve young people's hearing and speech capability.

I have a lot of problems while visiting hospitals and clinics. I go to hospitals and clinics 2-3 times per year. I don't feel comfortable visiting hospitals and clinics because I always need someone to help me communicate with doctors and health workers. I would very much prefer to go alone. I always misunderstand routines and medicine. I always check who will go into the doctor's room before me and also always check other people's token number papers because there isn't a screen sign board. Dental treatment, blood tests, and gynecology tests are the main services I go to the hospital for.

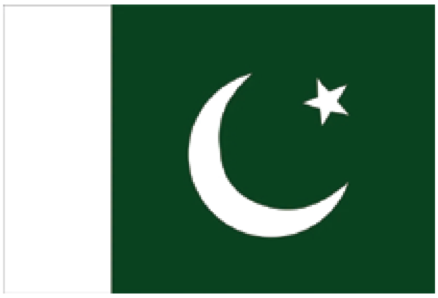
1. **Dental Treatment:** I always need to remove my hearing aids when I go to attend dental appointments. This keeps me from understanding well and communicating face-to-face. I never know what's going to happen next in an appointment or what treatment is going to include. The doctors always wear masks, and no live closed captioning is provided on screens. Therefore I have no way of understanding what they say. I always need someone to support me.

2. **Blood Test and Physical Exam:** Blood tests and physical exams are very important for human beings. They are how we get information about our bodies and their conditions. During blood tests and physical exams, it isn't easy to understand what doctors and health workers say. I would always wait for my physical exam report after a few minutes of it ending. Waiting for the results always made me feel stressed, especially as I wasn't able to understand the doctors' thoughts during the exam. Having my blood test before a physical exam often results in a bad report, as stress is never good for bloodwork.

3. **Gynecology Test:** I had both good and bad experiences. Only two doctors wrote down messages for me, as no one from outside was allowed to enter the room during gynecology tests. I once had a bad experience after a gynecology test because the doctor didn't tell me about the test report in detail. He wrote a short note about treatment and medicine. He didn't tell me the reason I needed them. I didn't feel good about the way he treated me.

Doctors and health workers should use face-to-face communication and also remove their masks. We can stay 2-3 feet away from them and also adjust the light in the room.

Hayyan Ahmed Zuberi



Pakistan - South Asia

NOW I CAN HEAR

A story of a **hard-of-hearing** person from Pakistan

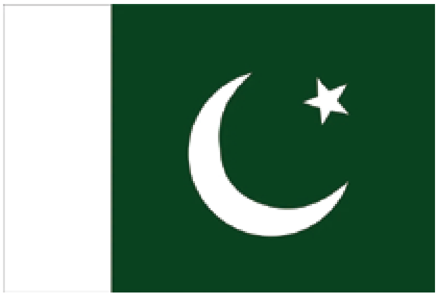
السلام علیکم

My name is Hayyan Ahmed Zuberi, and I am from Karachi, Pakistan. I have a hearing disability since birth. My parents did not know about the hearing issues until I was three years old. After they found out about the problems, I got treated and received a cochlear implant. My mom taught me sign language and how to recognize the sounds different things make. I went to speech therapy to improve my language. Doctors told my parents I would get back on track in 3 years, but I got lucky and was able to pull it off in a year. This was not always an easy task for my family and I.

Now with the help of hearing aids, I can hear and understand most things. Despite that, I still struggled with hearing at times. Sometimes I didn’t understand what the teachers said in lectures or what my friends were talking about, so I had to do lip reading, which was often quite frustrating. There were many people in my life who used to make fun of me due to this disability. O levels and A levels weren’t easy for me personally, and I had to confront serious difficulties, but I had friends and teachers who supported me and helped me get through this journey.

Now I am in university doing a bachelor’s in Computer Sciences. I am thinking of doing an internship to begin pursuing my career. Nothing in life is easy, and to achieve something, you need to put in a lot of effort. I always try to do this, even while having a cochlear implant. I can watch movies, football matches, and Tv-shows without subtitles, which is a huge relief for me. I can socialize with my friends and family. The most important thing is I can drive a car!

Zaren Taj



Pakistan - South Asia

SUCCESS WITH CHALLANGES

A story of a
DEAFENED
person from Pakistan

My real name is Zareen Taj, but I logged on Facebook with Shaheen Zaman since I was not allowed to use my real identity. Shaheen was my childhood friend and I liked it a lot so I decided to use it instead of my real name.

When I was 10 year old, I met a road accident due to which I lost hearing. This created hurdles in my education. I could not hear teacher's voice and could also not understand her teaching. I managed to learn reading and writing with the help of my friends and also by self-studying books. I completed 12 years of education (Inter / FA) but despite immense efforts I failed in English. Our English teacher was very strict and he had aggressive personality. Therefore, in fear of him, I couldn't gain confidence in learning English and fail in this subject. This put me in inferiority complex.

Later I thought to learn some skills, to keep myself busy. In 1995 I joined Naval Skills Center to learn a skill. TV show by the name " Boltey Haat" aired on PTV was also of great help in learning. In this program they used to teach different skills to people who are deaf, with Sign Language. This increased my interest in learning different skills, further. I learned a lot and made different art and crafts. My younger sister is Hard of speaking. She suffered this due to "typhoid" in childhood. Like me, she was also very interested in learning skills. She studied from ABSA school.
Seeing her interest in learning skills, I joined World Memon Foundation where I learned multiple skill courses and would teach the same to my younger sister. I was so interested in learning skills that I took six classes of skills learning in a day.

In 2005 I got married and months later to my marriage, my younger sister died. My marriage also ended in 2013. The two traumatic incidents left me in sheer depression. To keep myself busy I joined Facebook and there I met an incredible person who became a friend of mine and helped me move on with life. She taught me arts and craft and also how to market It on the platform.

I have learned 40 different skills, I am now a jewelry designer and Wedding crafter.
Allah had been very kind and with his will my work start gaining popularity. My friend on FB who was a fashion designer, introduced me on TV and Media, I was on air on Mr. Saher Lodhi show in 2019. I got good response and then PTV, ARY TV, Sama TV, TV One, Metro TV, GTV and other invited me in their programs. I got many awards for my work and also attended so many exhibition, Fashion Shows and other events. Now I design Jewelry for different TVs morning shows, Photoshoots. My face book name page is "Shaheen Zaman Wedding Jeweler Designer" and my YouTube channels is "Shaheen Zaman Official". Now Shaheen Zaman is now my brand name.

With the help of my friend I started a Volunteer Institute by the name "Entrepreneurs Launching Pad". The prime purpose of this institute is to help differently abled and transgender to attain education and earn on their own . We also have few more additional projects to launch. Apart I also want to do lot of work as Sadqa-e-Jaria for my parents.

Zaren Taj ... *continued*

I request you all to pray that I succeed in my mission. My message to you all is never to give up. Keep moving in life with dedication. Allah will make ways out for you all.

This story was submitted in Urdu language, this English translation is done by Ms. Mariyam Arshad voluntairly.

Jefferson Cortez

Philippines - Southeast Asia

A Deaf and Hearing Person in Between

A story of a
hard-of-hearing
person from Philippines

Jefferson Cortez is currently an Accessibility Engineer at a next-generation global technology company which helps enterprises reimagine their businesses for the digital age. As an accessibility engineer, he tests various software applications, ensuring they comply with the accessibility standards for all technology users. He is also a Digital Accessibility Lead and resident Sign Language Interpreter at a social enterprise which supports Persons with Disabilities and other excluded communities. Moreover, he is the co-founder of TERPCAP Incorporated – a digital accessibility services company which equips organizations to become more disability-inclusive and accessible in their processes and workspaces. The company name, TERPCAP, is derived from two of the major accessibility services it offers. The first part, "TERP", comes from Sign Language inTERPreting and the second part, "CAP", stands for Closed CAPtioning.

Jefferson cites impact-driven work and accessibility through technology as his primary reasons for establishing TERPCAP. As one of its co-founders, his vision of making the world more inclusive and accessible to everyone is what keeps him going. Among other things, Jefferson brings his leadership, teaching, and people management skills to the TERPCAP table. He believes that accessibility is empowerment, and with the aid of technology, barriers for Persons with Disabilities can be reduced. Being a CODA (Child of Deaf Adult/s) and a Hard-of-Hearing (HOH) person himself, Jeff experienced exclusion and discrimination first hand. He was also faced with a dilemma: he was in some ways hearing, in some ways deaf, and in others, neither. In search of a community with which he could identify, he came across the Hard of Hearing Group of the Philippines (HOHGP) and started helping out in its pioneering efforts to raise awareness of the HOH identity and the importance of closed captions in everyday communication. To be of support to his fellow HOH people, Jeff would volunteer to help with captioning during events like meetings and webinars.

He also pioneered a community group called CODA Philippines where he was able to meet and empower fellow CODAs to embrace their identities and advocate for belongingness amidst misconceptions that CODAs are supposed to be well-versed in sign language and interpreting.

He is also part of a local church which oversees the Deaf ministry and handles the church's social media account. He is currently earning his Masters in Theology.

Alongside his corporate career and impact work, Jefferson enjoys playing chess and online games in his spare time. He wears many hats in life, and being a husband to his wife Jael, is his favorite. If he could give any career advice, he would encourage others to pursue purpose-driven work which sparks joy in their hearts and impacts others.

Allaine Jay Sanico

Philippines - Southeast Asia

FACING BARRIER WITH A DETERMINED HEART

A story of a **hard-of-hearing** person from Philippines

My name is Allaine Jay Sanico a hard of hearing person from the Philippines. I am a regular employee of Henkel Asia Pacific Service Centre as a Senior Specialist in Source-to-Pay Department.

I studied Bachelor Science in Business Administration major in Business Management in De La Salle College of Saint Benilde and was qualified with a full scholarship, it is an inclusive school and was able to study along with hearing students. Since I am a hard of hearing, communication is the barrier I faced during my college education. I always tell my classmates and professors that I am a hard of hearing so my seat should be in the first row so that I can hear properly, and lip read well. But sometimes there are situations in my class that I am unable to clearly hear the discussions because the professor keeps walking within the classroom and the level of voice is sometimes low. I had to rely on the power point presentations, my classmates notes and lip reading even though I am not good at it, but it was helpful. However, when an unforeseen event like COVID that it became pandemic, our class set-up was changed into an online class. I thought at first it will be difficult for me, but with the use of online speech to text apps and built-in captions in google meet and zoom meeting, I found myself adjusting to the class set-up. However, the cons side is, it is not accurate especially in our country we speak “TagLish” a mixed of Tagalog and English language. Overcoming barrier is like making an effort to myself to be resourceful and share awareness to my fellow classmates. I was given an opportunity to share myself in class, that was really satisfying to share my life as a hard of hearing and for them to realize how to handle and communicate to a hard of hearing like myself.

In daily life, I communicate through lip reading to my friends and family. In public places there are times, I communicate with them through handwritten form especially now that were in pandemic that most people wear face mask, so it was really difficult for me to communicate through lip reading. There was a time I had to go to the clinic and when they know that I am a hard of hearing they have assisted me, and the doctor was aware of my disability, so we communicated through written form. On online shopping or ordering of foods through online the cons side is, we don’t get a person with disabilities discount on ordering foods or basic goods through online unlike if we order through onsite, we get a 20% discount. Getting a food discount was really a great help to persons with disability struggling in daily life especially this pandemic however ordering online without a discount on top of it is charged with a delivery fee was really a big difference in our daily life before pandemic and when on pandemic.

Unfortunately, we don’t have a TV at home but on free time I mostly spend binge watching via Netflix because it has subtitles which is very helpful for me in understanding the movie’s story. And in Cinema, our local government unit implements free movie watch for persons with disability and the cinema has subtitles whether it is in local language or foreign movie an English subtitle is available.

Allaine Jay Sanico ... *continued*

For online entertainment, there are programs that speak in our local language, so my phone doesn't have a caption built-in for "Tagalog" language so to be honest I rarely watch local entertainment online for the reason that, I hardly understand what the entertainment is all about since there's no captioning for local language and even so to our local entertainment programs on television.

On daily travels, there are times that I am new to this specific place, so I had to ask the bus or jeepney driver to drop me off and give me a hand signal to alight and I had to use a google map apps so that I won't be lost. While on air travels, sometimes the monitor displays in the airport are not working so I had to look for the schedule via on-line and the good side is there's a text message of my departure time and there's a priority lane for persons with disability upon boarding the plane and of course as a person with disability we are entitled with a discount for people with disabilities whether I book a ticket via onsite or online, so it was really helpful. But I hope that the airlines will provide a monitor with a captioning about the explanation of the safety measures in case of emergency inside the plane since the information is essential to traveler's safety, I hope airlines will become a bit more inclusive on explaining those things before departure. Although they are using gestures, but I hardly understand what the flight attendant is saying.

The cost of hearing aid in the Philippines is a bit expensive. However, there are other organizations like Starkey that provides free hearing aid, and unfortunately, government funding about hearing aid for persons with hearing loss is limited only to selected individuals. Only few were able to get financed or granted with full package hearing aid.

In the Philippines, it is known as a republic country, so I am able to express freely my political views. I hope that, in our country captioning services, to local events and in the entertainment will be legally implemented so that we hard of hearing persons can fully enjoy watching local shows, news and others.

(From left to right) Allaine Jay with HOHGP leaders: Laurence Alfrey, April Rose, Bowen (President of IFHOHYP), and Raphael.

Bui Thi Ngoc

Vietnam - Southeast Asia

A TEACHER WITH HEARING LOSS

A story of a **hard-of-hearing** person from Vietnam

My name is Bui Thi Ngoc, and I am from Vietnam.

Born and raised in a family in which teaching is tradition, I became a teacher without hesitation. I love my job; I teach at the school I studied since childhood, with friendly, loving and connected colleagues (some are my former teachers) and good, studious students.

One day, I felt that I had a problem with my hearing: I couldn't hear the bell signaling the start/end of class, and I couldn't hear everyone's words clearly even though I could still hear the sound of them speaking. Medical examinations and treatments did not improve the situation. The doctor concluded that I had sudden hearing loss (left ear 90 dB, right ear 115 dB) and recommended using hearing aids.

I applied for leave but it was not approved. People encouraged me to continue teaching. My life has turned a new chapter since then; living with hearing loss while working in a community of hearing people. I have changed the way I live and work to accommodate my hearing loss.
When preparing lesson plans, besides focusing on the knowledge points to be conveyed, I consider possible challenges that may arise, limit calling students to speak, and use mind maps on the board to give instructions.

In professional classes, I always sit at the front desk, underline the main ideas in the lesson, and borrow my colleague's notebook for revising. When performing sample lessons or doing thematic reports, I inform the participants to write down their questions and send them up after the lesson. Then, I read the comments in the minutes instead of listening to the suggestions directly in class.

After retiring, I continued to teach as a guest teacher for 3 more years and then moved to work at the Center for Research and Education of Deaf and Hard of Hearing (CED), founded and directed by Ms. Duong Phuong Hanh. I learned about experiences and methods of teaching children with hearing loss from the Board of Directors and my colleagues at CED. A specific tool the CED has designed to support communication, teaching, and learning is a transparent mask that helps me and my students in lip-reading. This makes my teaching much more effective.

My dream at the moment is that people with hearing loss are given opportunities, access to information, and equal treatment in schools and workplaces, so that the road to social inclusion is no longer difficult or hindered for them.

Importance of Early Identification and intervention

by Neeta Keshary Bhattarai

Early identification and intervention about hearing loss is most important for children's cognitive, speech, vocabulary and language development.

According to WHO fact sheet by 2050, 2.5 billion people might have some degree of hearing loss and many of them requires intervention and rehabilitation program.

Hearing and speech plays vital role for any person by birth. Hearing capacity will naturally develop speech and language when a child grows up. Unless development of speech and language a child cannot communicate well through spoken language with family, friends and society. Their vocabulary and language development depends on early identification of hearing loss and intervention programs which includes ear disease treatments. In most of the cases conductive (mild to moderate) hearing loss can be prevented with timely intervention. If the conductive hearing loss develops sensorineural hearing loss it will not be prevented and will have permanently hearing damage.

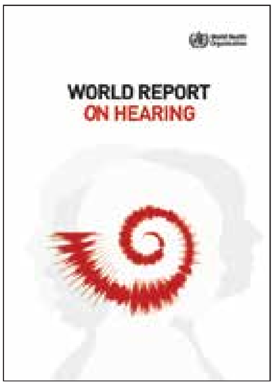
Despite of all of these hearing loss if any child had permanent hearing loss it mentions as disabling hearing loss. According to WHO if children have hearing loss from 30 dB it falls under the categories of disability. Which means without hearing aids or any hearing assistive devices children cannot communicate well through spoken language by understanding surrounding sounds.

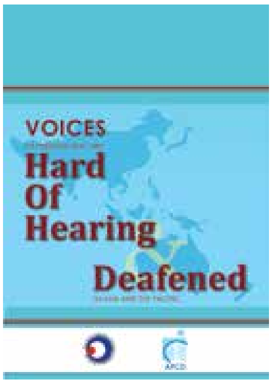
Hearing loss affects children's language and vocabulary development. When language skills are deficient and vocabulary is limited, reading and writing skills will automatically be poor which negatively impact to the children's academic progress. The effects of academic performances differ according to their hearing capacity. For example, children with mild hearing loss have moderate affect in their speech and language, and their academic quality and performances will be affected in the same level. Likewise, profound hearing loss in children will severely impede in their development of language and academic performances.

Children with hearing loss needs specific support in the classroom that require teacher support to ensure their academic development. The parents and school teachers need to know about the challenges involved in providing the support to the children with hearing loss for the improvement of learning, development of vocabulary and language in the home and school. The parents and teachers should know human auditory system, its functions, cause of its damaged, impact of damaged, possible solution, essential supports for student with hearing loss. As most of children with hearing loss require educational accommodation to achieve academic success, the teachers should know about the classroom adoption, visual aids, learning strategy, effective communication, and assistive devices and monitoring system for the development of children with hearing loss.

If a child has moderate conductive (external) hearing loss (conductive hearing loss), medication can be used to prevent hearing loss. Children often suffer from ear infections and temporary hearing loss. Outer ear infection can be treated with medicine. In addition, if there is a problem with the children's ear wax or if there is a minor ear bone problem, the hearing ability of the ear can be improved by treating it through surgery. There are different types of these surgeries. For example: if there is a problem of water accumulation inside the eardrum, a small tube is placed to drain the water from that tube, if there is a hole in the eardrum, an eardrum is made or replaced, if there is a tumor, it is removed, etc. Thus, sometime the temporary hearing loss ability improves after treatment or surgery.

USEFUL PUBLICATIONS





WHO World Report on Hearing
https://www.who.int/publications/i/item/9789240020481

WHO Basic Ear and Hearing Care Resources
https://www.who.int/publications/i/item/basic-ear-and-hearing-care-resource

APFHD Voice of Hard of Hearing and Deafened in Asia-Pacific
https://apfhd.net/

IFHOH Position Papers
https://www.ifhoh.org/position-papers

WHO's Priority Assistive Products List

Following Products listed in WHO's "Priority Assistive Products List" are useful for us, the people with hearing disability. Governments should made these available and affordable.

01. Alarm signallers with light / sound / vibration
07. Closed captioning displays (Captioning / Subtitle)
12. Deafblind communicators
14. Gesture to voice technology ... *
17. Hearing aids (digital) and batteries
18. hearing loops / FM systems
26. Personal Digital Assistant (PDA) .... *
27. Personal emergency arlarm systems ... *

Hearing aids with batteries and Captioning is very important for education, and access to information and communication.

DID YOU KNOW?

3 MARCH IS WORLD HEARING DAY

“World Hearing Day is held on 3 March each year to raise awareness on how to prevent deafness and hearing loss and promote ear and hearing care across the world. Each year, WHO decides the theme and develops evidence-based advocacy materials such as brochures, flyers, posters, banners, infographics and presentations, among others. These materials are shared with partners in government and civil society around the world as well as WHO regional and country offices. At its headquarters in Geneva, WHO organizes an annual World Hearing Day event. In recent years, an increasing number of Member States and other partner agencies have joined World Hearing Day by hosting a range of activities and events in their countries. WHO invites all stakeholders to join this global initiative”. For more information visit https://www.who.int/campaigns/world-hearing-day

APHD’s memebers are actively celebrating World Hearing Day since 2013

January 2020 issue

ASIA PACIFIC FEDERATION OF THE HARD OF HEARING AND DEAFENED

NEWSLETTER

Do you know that 466 million people worldwide have hearing loss?

The majority of these people live in the Asia -Pacific

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years

Volume 2 - October 2017

NEWS LETTER

Asia Pacific Federation of the Hard of Hearing and Deafened

Did you know 360 million people worldwide have hearing loss? The majority of these 360 million people live in the Asia-Pacific.

Volume 1 — October 2016

NEWS LETTER

Asia Pacific Federation of the Hard of Hearing and Deafened

Did you know? 360 Million people have hearing loss!

Nothing about us
Without us!

Asia Pacific Federation of the Hard of Hearing and Deafened (APFHD)

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