# VOICES OF PERSONS WHO ARE Hard Hearing Deafened IN ASIA AND THE PACIFIC







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

The Asia-Pacific Federation of the Hard of Hearing and Deafened (APFHD) was founded in March 2012 by the representatives from 10 Asia-Pacific countries, namely Bangladesh, Indonesia, Lao PDR, Mongolia, Myanmar, Nepal, Pakistan, the Philippines, Papua New Guinea and Vietnam. They gathered at the Asia-Pacific Regional Workshop on Hard of Hearing and Deafened from 29 February to 2 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. The Executive Committee members 2012-2014 are: Ms. Hanh Duong Phuong (President, Vietnam); Ms. Victoria Diresa Avei (Vice President, Papua New Guinea); Ms. Rachmita Maun Harahap (Vice President, Indonesia); Mr. Muhammad Akram (Secretary General, Pakistan); and Mr. Maheshwar Ghimire (Treasurer, Nepal).



# Asia-Pacific Development Center on Disability (APCD)

The Asia-Pacific Development Center on Disability (APCD) is a regional center on disability and development established in Bangkok, Thailand as a legacy of the Asia and Pacific Decade of Disabled Persons, 1993-2002, by the United Nations Economic and Social Commission for Asia and the Pacific (ESCAP).

APCD is managed by the Foundation of Asia-Pacific Development Center on Disability (APCD Foundation) under the Patronage of Her Royal Highness Princess Maha Chakri Sirindhorn. APCD has been endorsed by ESCAP as a regional cooperative base for an inclusive society in the Asian and Pacific Decade of Persons with Disabilities, 2013-2022, through the Incheon Strategy to "Make the Right Real" for Persons with Disabilities in Asia and the Pacific.

## Third Country Training Programme (TCTP): Knowledge Creation Forum on Community-based Inclusive Development 2014

The Third Country Training Program "Knowledge Creation Forum on Community-based Inclusive Development 2014" is conducted by the Government of Thailand in collaboration with the Government of Japan as part of their Technical Cooperation Scheme.

The course arrangements are set up by the Asia-Pacific Development Center on Disability (APCD) in corporation with the Ministry of Foreign Affairs of Thailand through the Thailand International Development Cooperation Agency (TICA) and the Japan International Cooperation Agency (JICA), with support from the Ministry of Social Development and Human Security of Thailand.

#### **Course Title**

Knowledge Creation Forum on Community-based Inclusive Development 2014

#### **General Objective**

Empowerment of young persons with intellectual disabilities, autism, and hard of hearing in Southeast Asian countries from the perspective of Community-based Inclusive Development

#### **Specific Objectives**

- 1) To develop the capacity of young leaders who are hard of hearing in Southeast Asia by providing opportunities to enhance understanding of the Community-based Inclusive Development (CBID) concept;
- 2) To provide a forum for young leaders who are hard of hearing by exchanging information and knowledge on not only hard of hearing but also other emerging disability groups such as persons with intellectual disability and/or autism;
- 3) To strengthen regional collaboration between the Asia-Pacific Federation of the Hard of Hearing and Deafened (APFHD) and APCD, with support from TICA and JICA in line with the principles of the Incheon Strategy to "Make the Right Real", 2013-2022.

#### **Anticipated Benefits**

- 1) Young leaders who are hard of hearing in Southeast Asia will gain information and knowledge on disability and development in the CBID context, including other emerging groups such as intellectual disability and autism, and will be prepared to utilize this new knowledge locally in their home countries;
- 2) New information and knowledge on hard of hearing will be created, exchanged and elaborated on by young leaders with disabilities and resource persons in Southeast Asian countries and Japan for future implementation.









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# **OUR VOICES**



Ms. Fahima Boshry Trisha

I am Fahima Boshry Trisha from Bangladesh. I started losing hearing at the age of two years. Now I am studying BFA (Hon's) first year.

I cannot communicate with my family well, nor can I communicate over the phone. I feel bad when I see my sister talking over the phone. I want to be able to communicate freely and equally.

There is no support for hearing aids. I got my hearing aids from HI-Care School & SAHIC.

I dream to be a Jainul Abedin Artist!!!

I am Md. Sharafat Ali from Bangladesh. I am working as an Assistant Coordinator (IEC material development and computer management). I am hard of hearing since childhood. I had access to a good accessible school with trained teachers, so I did not face much problem in school. My colleagues and management are very supportive, and have taken essential steps toward an inclusive work environment.

I use a hearing aid for my right ear. This hearing aid was provided by my office, Centre for Disability in Development (CDD). This hearing aid is very helpful for my life and job. It is my life line.

Yes, I like to watch TV, movies and listen to music. I especially like the movie 'TITANIC'. Captioning and subtitling are very important to improve our access to entertainment.



Mr. Md. Sharafat Ali



Mr. Muhammad Ishaque Mia

I am Muhammad Ishaque Mia, President of Bangladesh Hard of Hearing Association (BHoHA), which is a member of APFHD. I am hard of hearing and wear hearing aids.

Most of the time I feel excluded from society. Often, I feel discrimination in finding a job, everything goes fine but when it comes to the face to face interview, I am rejected because I cannot listen clearly, and I need to ask them to repeat what they said.

I enjoy theatre and cinema but these are painful. I cannot understand what they are speaking or fighting for. I wish there could be a captioning system to display the text of spoken word in my mobile phone. Without captioning it is difficult for us to have equal access to recreational activities. I am waiting to see the UN CRPD implementation in Bangladesh.

I am Rachmita M. Harahap, Chairperson and Founder of Sehjira Foundation. I am from Indonesia. I earned my Master of Interior Design and now I am a lecturer at a university.

I am hard of hearing since birth. My parents sent me to a speech therapist so I developed my speaking too. To develop speaking skills, speech therapy is very important to help children who have difficulty in listening.

I use hearing aids so I can listen to music. "Hellen Keller" and "Children of a Lesser God" are my favorite movies. I am lucky that, in Indonesia, foreign movies always have Indonesian or English captioning. But local movies do not have any captioning.

My mission is to stop discrimination - in schools, colleges and workplaces.



Ms. Rachmita M. Harahap

My nickname is Aly. I live in Vientiane, Laos PDR. I have had a hearing problem since childhood. I am hard of hearing but I don't use hearing aids because of inflammation. Every 3-5 months I visit a doctor to help me dry my ear. I studied in a mainstream school, and now I am studying Computer Information Technology. I think it is best for me to work as a technician because I won't need to hear much. And I'd like to learn English language. In my country there is no support for students who are hard of hearing and deafened. There is no school that can help with lip-reading, and teachers don't know how to help. Real-time captioning in education can help us to understand lectures. Most of the companies do not accept persons with disabilities. I was employed by a company that helps persons with disabilities and the poor.

As a person who is hard of hearing, I sometimes feel bored. And because I can't hear well, people do not pay attention to me, except my family. So I feel nobody is with me. But I am trying to accept and show my positive side. I like to watch movies on TV. Some movies have subtitles, and I try to read lips too. But I don't understand singing. I only listen to music to be cheerful. I watch movies in the cinema with subtitles, but there is noise and loud voices. So I don't feel comfortable and it causes ear inflammation. So I don't go anymore. I think it would be great if all entertainment had captioning or subtitles. I would like to tell society that I am hard of hearing and face difficulty in hearing, but I have heart. I feel, I love, I get disappointed, same as you do. We should care about the feeling of other people too.

I thank my parents who never hurt me. They taught me to be strong and struggle to stand on my feet. If you ask me about my wish, I wish to have captioning everywhere.



Ms. Soutalynorasing Sisane

I am Orgodol Baast. I live in Ulaanbaatar Mongolia. I have had a hearing problem since birth. When I was a child in school, I could not play with other children due to my hearing and speech disability. I got my hearing aids from hospital, with half of the price paid by the welfare office and half by myself.

Now I can hear and understand when I use hearing aids. But my oral language was very bad so teachers and classmates could not understand my speech. With efforts I did a bachelor degree in journalism and later worked as Director of "Tulga5" TV studio.

Now it is much better I can socialize among society. I enjoy movies too as I can listen with my hearing aids. But I think if there is captioning it will help more. I'd like to say that we are all the same people and have equal human rights, although we can not hear or speak well. If parents trust their hard of hearing children and do not think they are bad and cannot do anything. If the teachers teach students who are hard of hearing sincerely and if government provides equal opportunity to us for study and work. We can live an active and productive life, the same as other hearing people do. Now at age 46, I have almost fulfilled my dream and I want to help other people who are suffering like me.



Mr. Orgodol Baast



I am Tuya Mijiddorj from Ulaanbaatar, Mongolia. At the age of 8, I became hard of hearing due to brain damage. I used to wear hearing aids and struggled to listen, but due to my brain condition I am not using hearing aids anymore.

I graduated in social work, but I studied by myself as there is no system to support hard of hearing students in my country. I could not understand lectures and often missed important appointments. When I entered the vocational training school all my classmates were hearing children and the teacher complained why management had accepted a hard of hearing person in her class. At that time persons with disabilities were not accepted anywhere in the mainstream. For entertainment I like to watch foreign channels because they have subtitles.

I have attended IFHOHYP summer camp where they had loop and captioning. At local events I usually don't have much access to information. They should have captioning to include us fully. I wish to have captioning everywhere. If captioning is everywhere, it would be convenient for deaf or hard of hearing people. I dream to live equally in society.



Ms. Tuya Mijiddorj

Hi! Here is Neeta Keshary Bhattarai from Kathmandu, Nepal. I am a happily married lady with 2 growing kids and a wonderful husband. I am leading SHURTI (an organization of hard of hearing and deafened) as President. I am hard of hearing since birth but it does not hold me back to live as a full human, of course I have faced barriers and discrimination during my whole life and still feel excluded many times.

Despite that here in Nepal we don't have a concept of accommodation, no real-time captioning, or other support. I was able to graduate in Business Administration. Living in mainstream society of a poor developing country, is really challenging for women with a hearing difficulty. You know what, if I am laughing with other people in a group it does not mean I am really laughing, often it happens that people laugh at a joke or some conversation, and I have to follow them even though I could not understood what was said. I bet most of us hard of hearing and deafened people have to pretend like this one time or another. Singing in a group is done a lot in the culture of our country, especially at wedding parties. I want to join, and I do join, but I feel embarassed when I don't understand the music and am unable to sing the song with others.

Despite that I cannot hear well, I go to the cinema and theatre with friends and family, only to join them otherwise I would become isolated. It is best if the cinema hall and theatres provide captioning, then I too can join equally. There are so many people like me who will benefit from captioning. I am active, I join various workshops, and conferences, and the organizers try to help me by giving me a front seat, and by giving notes when asked. But I miss a lot during the event due to the lack of assistance, and cannot participate fully as other hearing participants. The CART system would be best for people like me, but we do not have such a system here. In this situation, if speakers try to understand, and speak slowly, it can be helpful. Providing a note taker, and giving time to read notes can help us in improving our participation.

I wish to join in every conversation with family, society, community and others. So, I can laugh and share the joy equally and at the same time with others. I want to have dignity in life by having a proper job and to be self-standing.



Ms. Neeta Keshary Bhattarai

Namastay - I am Rajeev Thapa from Butwal, Nepal. Since my 16th birthday my ear rings all the time and I hear abnormal sounds inside my head and brain. Even though I am used to it, sometimes it is very painful.

In Nepal we face discrimination everywhere and it is difficult to live in mainstream society. I faced discrimination in college, there were only a few who understood my communication problem, but the rest of the students took me as a "character or comedian". When I applied for a job, soon after they knew I was hard of hearing they would reject my application. I feel discriminated at home because my family think due to my hearing problem I am not able to do anything. At first they spend a lot of money to cure my deafness, but they found there is no cure and they start treating me differently. It hurt me, I wish they encouraged me, and they understand my situation, this is more important for me than any cure.

Since I became hard of hearing I don't go to the cinema, because I get so annoyed in crowded and noisy places. It increases my ear ringing double, so I stay away from such places. I would like to see captioning included in all entertainment and it should be in local language. Then I can turn off the sound and still understand the movie. I'd like to tell society that the most important thing is education. Society should make every effort to educate the hard of hearing and deafened children and adults. If we are educated we can do something positive for our society. Government, UN Agencies, INGOs too should make sure that people who are hard of hearing and deafened have access to education and equal opportunity for employment.

I know about the cochlear implant and the pair of hearing aids (tinnitus masker). I would surely wish to have them. After becoming deafened, I always dreamt to restore my hearing, but now after living many years with my deafness, I dream to do business and earn income for my family. When I have an opportunity I do something for my fellow hard of hearing and deafened, and try to change the conservative thought of mainstream society.



Mr. Rajeev Thapa

My name is Huda Zahid, I am from Lahore, Pakistan. In my childhood I was diagnosed with severe sensorineural hearing loss. Doctors recommended me to use a hearing device as there is no cure for this disability.

I received a Doctor of Pharmacy (Pharm-D), but despite my high education I could not get any job for years and years. At one time I was thinking to learn sign language and become teacher in a school, but in Oct. 2012 finally I got a job as a documentation officer in a pharmacy company. I get a low salary, so sometimes I feel inferior.

In school I used to be lonely. I always use to wish that the teacher would encourage me to participate in extracurricular activities. When it comes to entertainment I cannot go to the cinema and theatre as there is no captioning, but I do watch 3 foreign TV channels that have captioning.

Living in mainstream society is not an easy task, I am a very sensitive person, when people neglect and ignore me just because of my communication problem, I feel hurt and discrimination.

I wish to have captioning everywhere in every thing of our daily life, like caption telephone, local caption channels and captions on laptop and tablets in order to participate in meetings and seminars. Speech to text technology can make my wish come true.

I always dream to have something high. I wish to have a good job with a good salary and I want to go abroad. In addition, I want to do some creative work and raise my voice for the rights of people with disability.



Ms. Huda Zahid

I am Muhammad Akram, I live in Karachi the biggest city in Pakistan. I lost my hearing all of sudden when I was in school. My parents and family love me so much they tried every effort to restore my hearing but there was no cure for my deafness. I wonder why the doctor did not say this clearly to my parents? This could have save a lot of their money and time. Today I look back, how much medicine I have eaten, and how many needles the doctors put in my head and ear (Chinese acupuncture) and feel pity for all the money, pain and loss of time for nothing. Once I realized there was no cure for my deafness it was shocking that I have to live my entire life without hearing. During this time all school friends were gone, they have to carry on their study in college, I was feeling frustration and was not willing to meet people for more frustration due to communication breakdown. People expect me to read lips, I cannot read lips, I did not grow practicing speech-reading.

I was never able to go to college because my deafness is profound and no college provided any assistance, in Pakistan. All I could do is self-study and pass my bachelor of commerce from home study. I was not happy about that but I had no choice. If there was support with Real-time captioning in our education system I could carry on with my school friends.

I learnt sign language, and I thought this way I can go for higher study but what I found was shocking. Their study system is different, they pass their graduation with good grades, but they cannot write even a single sentence correct. There was nothing for me in their education system. I supported the Deaf community for 8 years voluntarily. They respect me for my support but Deaf people call me "half deaf" not Deaf because I speak. Later I got to know I am deafened.



Mr. Muhammad Akram

My name is Felix Sam. I am 31 years old. I work at the Red Cross Special Education Centre as an assistant teacher for sign language. I lost my hearing at 2 years of age due to an illness. Since then the hearing in my ear has been terrible. However, I am good with lip reading and if I did have a hearing aid, I would be able to hear what people are saying. Hence, I like to consider myself a Hard of Hearing individual.

Getting educated with hearing loss has been the biggest challenge I've ever had to face. My highest grade was grade 5 and since then, I have just spent my time at the Red Cross special education Centre being an assistant.

At my employment place, I earn a small salary which isn't adequate to cater for my livelihood. The government does little to assist people like me. I wish the government had a special coverage program for the disabled persons. We (the disabled) try our very best with our abilities but society is too strong. People like myself have to just bear the brunt of what society does.

I have a wife and she too is Hard of Hearing. We both are assistants at the same centre. One thing I dislike is people screaming at me to make me hear. It is a very poor attitude problem. How does it look if you tell a blind man to differentiate between colours red and white? It would be a silly thing to ask coz colours cannot be seen. In the same way, why can't they realise that screaming at us is similar in nature.

I enjoy watching TV however it isn't very accessible for me. Most television programs do not have subtitles and only the pictures help give me information on what might be going on. I have not been asked to attend any workshops. This is evidence of favouritism in disability accessibility programs. The Deaf and Hard of Hearing are usually overlooked because of the communication barrier. Most organisers do not have the drive and nerve to see to our special needs.



Mr. Felix Sam

My name is Joshua Yembo. I am 37 years old. I work at the Red Cross Special Education Centre as an assistant teacher for sign language. I lost my hearing in 1988. My highest level of education was grade 9. I attended the college of distance education. Since then, I have provided service for the Centre.

As a Hard of Hearing person, I face many barriers in life. Discrimination is also a big factor. Many times, people misinterpret my abilities and embarrass me. However, I am always positive. I have a wife and two children. My wife and I struggle to make ends meet each day and provide for our kids.

I am very fluent in sign language and have adopted it as a means of communication. However, if I did have a hearing aid, I would be able to hear what people say. I can speak clearly and often communicate via speech. I dislike people who gossip about me and being ignored. I am an open person and enjoy socializing. However, my disability limits me to only few events.

I have attended conferences after being invited. However, those are not so accessible for people like me as organisers do not go to extreme measures to accommodate our needs. A lot of Hard of Hearing people face this main barrier in life. Because of their communication problem, they get overlooked. People need to be more enthusiastic about Hard of Hearing individuals. We are fun to be around.

My dream in life is to see my RIGHTS. I would like the government to recognise my special needs and help me. Also, as a Person with Disability and a family man, I would like the government to make special provisions for us with children and help us educate them in the right way. My small salary I earn at the centre is never adequate and I worry about my children's education and welfare needs.

I enjoy watching television but it is not very accessible as I cannot hear anything and there aren't any subtitles.

All in all, I am positive. God has a plan for me and my little family. And I remain positive in life.



My name is Victoria Avei and I am from Central Province in Papua New Guinea. I work for the Government of Papua New Guinea under its National Department for Community Development. My area of speciality is Administration Officer for the National Advisory Committee on Disability Secretariat.

I have been working for this organisation since 2010. I enjoy my work and it pays me well. Through this job, I have enjoyed my life and the challenges and rewards that come with it. I lost my hearing due to the popular tropical illness called Malaria. I was in 6th grade back then (14 years old). Losing my hearing was a very difficult thing. One minute, I am enjoying free flow of conversation, next minute, I just couldn't seem to keep up. Medical practitioners advised me that I had lost my hearing and given our economy, there was little help available. Goods and services in the country were very expensive.

In the end, I grasped my situation and accepted myself as a hearing impaired person. I always knew God had a wonderful plan for me. I continue my education to the highest level possible (college) and straight after that, I found a job with an insurance company.

I have at times engaged the use of hearing aids but I find them a bit uncomfortable to use and they also cause pain in my eardrums. I have faced many barriers in life but having a very positive frame of mind, I have not allowed these barriers to prevent myself from enjoying my precious life.

I remain thankful to all my family members and friends for helping me come this far in life. For having confidence in me. I still have a long way ahead of me but I know God will help me as I go on. I also thank my beautiful mother for all that she has done to make my life the way it is today. I know in my heart that if she wasn't my mom, I would never have come this far. I am so indebted to my mother. Recently my life has been blessed with the birth of my daughter Caitlin. I hope my abilities will enable me to provide for my baby the best I can possibly give to her.

My dream in life, is to establish a Deaf and Hard of Hearing Society for Papua New Guinea. At this stage, my fellow HOH people face a lot of barriers and discrimination from society. I leave you all with the famous saying "if someone can do it, I can do it too".



Ms. Victoria Avei



Ms. Magbanua, Fannie Mary Laurie F

My name is Magbanua, Fannie Mary Laurie F. My friends call me Laurie. I live in Aborlan, Palawan, a province of Philippines. In our organization, APFHD, I think I am the only who has Neurofibromatosis type2, and wear a device called Auditory Brainstem Implant. My hearing loss occured at the age of 22. At that time I had completed my Bachelor of Science in Nutrition. I dreamed of being a medical doctor, but I think, losing my hearing is one way of God telling me..."I have other plans for you my child." Sometimes later, I did a Postgraduate Course through a modular type. Though I considered my situation, I still encountered some minor issues related to it. For example, once our instructor gave us video material as a reference for an assignment, but it was not captioned. So, I told him I am hard of hearing and then he gave me other material which was written. Though I trust that the two materials were the same with regards to purpose of the assignment, I still felt a little alienated. Now I am running a family-owned water refilling station. I tell our customers about my difficulty in hearing and tell them that I prefer communication through writing or through SMS. Since I am surrounded mostly by hearing folks, and the fact that I am late deafened, I am grateful for my implant. Still, I always remind new acquaintances to speak slowly so that I can grasp.

Being a hard-of-hearing in a hearing arena offers a variety of feelings for me. I admit, most of them are not as joyful as it could be. Like in gatherings, if no one is willing to be patient enough to repeat or explain to me what's going on or what's funny, I am left in the dark. I can't help feeling left out. Also I feel bad if I ask people to repeat what they're saying and they start laughing (especially those who don't know my case). It is not a funny thing, and it's rude.

For entertainment I watch movies but only those with subtitles. Sometime ago, I wrote to some TV/Cable operators regarding captions, I'm not sure if it's because of that writing but I am so happy that some movies in Star Movies Channel are captioned, I hope other networks will follow.

One thing I want people to know is the difference between Deaf and hard of hearing. If one cannot hear well, it doesn't mean he/she will start signing automatically. I feel somehow offended and irritated if I have a new acquaintance who would tell me "ahh you're deaf? Why don't you do sign language?".

I wish captioning would be as common as speaking. Having hearing aids and implants are a personal choice. I just hope everyone who wishes to have these aids/implants, be properly oriented. The pros and cons can be presented to them in a neutral manner so that they can decide without pressure.





Ms. Maria Filomena C. Gaya

This is Maria Filomena C. Gaya, from Antipolo City, Philippines. I developed a very high fever with measles, and as a result my hearing was affected and I become deaf. My parents took me for screening and bought me hearing aids. In school it was really painful for me because all of my classmates discriminated against me and they imitated my voice, and made fun of me. At that time I was not aware of the meaning of "Deaf" and "Hard of Hearing". I think it is important that children with disability should be empowered with knowledge but also the teachers should be trained about how to deal with hard of hearing and deafened children, how to educate other children in school to develop a better environment so students who have difficulty in listening, or are not able to speak well, will not be discriminated against by fellow students. I did a two-year vocation training course in Computer Operating. The education system was not very accessible for me.

For entertainment, I don't go to the cinema rather I watch DVDs because DVDs have subtitles. If I go to cinema I have to depend on lip-reading and ask my fellow what was said. I'd love to see captioning / subtitles in all TV channel programs and also in movie theatres, and music performance. I love to listen to music. I attend many events. The organizers provide only sign language interpreters for the deaf since we don't have a CART system for the hard of hearing and deafened. Honestly, I'd prefer captioning, I want to read from the white screen, SL would be my 2nd priority.

My dream is to make our organization strong. I also want my country to become completely accessible for the hard of hearing and deafened with CART/Captioning system, Hearing Induction Loop, Telephone with captioning and amplifier. So we can live independently and participate fully and equally in whichever activity we want. Also, I want to be successful so that I can support my mother and my brother who has down syndrome with blindness.

I am Raphael D. Torralba. You can call me "Raph" for short. I am from Quezon City, Philippines. At the age of two years old, I started to have a hearing problem due to an accident and now, I have severe-profound hearing loss. When I was young, I felt like my world came crashing down on me after learning of my hearing loss. I felt like a hopeless kid. People, some of them my classmates, shouted in front of my face and I was ridiculed and felt embarrassed in the class. And you won't believe that even some of my teachers also discriminated against me. I finished with a college degree of Bachelor of Science with Business Administration Major in Computer Based Information Systems in a regular school. Although I passed my bachelor degree, there was no accommodation for my hearing problem during my 5-year stay at school. I faced discrimination from my classmates, some school employees, and teachers, due to lack of awareness to deaf and hard of hearing.

Another discrimination is that after graduating from college, many companies are reluctant to hire me. They look more on my disability than my ability. It was painful for me when people discriminated against me. It took me years to finally accept my disability, believing that God might have a purpose for me in the later part of my life. Indeed, I believe that I finally realized the purpose of my life. I treated my disability as a challenge for me to work harder and to show to the world that I can be what I want to be, and reach my goals. Now, I'm successful in my life. Currently, I'm working as Marketing Communications Specialist and a freelance photojournalist for persons with disabilities. Prior to that, I worked as photojournalist, Resource Coordinator, and Project Manager. I usually tell my employer, clients and fellows that I can communicate via lip reading, SMS, chat, and email.

I'm a movie freak. I always love watching movies. Sadly, there is no captioning available and I really mostly on lip reading. Sometimes, I ask my companion about what the actors are saying. In order for the cinema to become accessible for people like me, movie producers and cinema operators should work hand-in-hand to put captioning in the movies.

During my course as a photojournalist and in my current work, I attended many events but sad to say, organizers only provide deaf interpreters. It only benefits the deaf, not the HOH persons who have no knowledge of sign language. So I rather do lip reading. I missed a lot of words so I would always ask the organizer to provide me a copy of the presentations of the speakers and the contact numbers of the speakers so that I can follow up what was discussed.



Mr. Raphael D. Torralba

My name is Duong Phuong Hanh. You can call me Hanh. I am from Hochiminh City, Vietnam. I have had a hearing problem since the age of 6. My hearing loss is too complex and profound so hearing aids are of no use for me. My parents found many good doctors to treat my hearing loss. But regardless of the money spent, my hearing did not get any better.

When I was studying I could not buy hearing aids at that time. The university environment was not accessible and my professors and classmates did not know what was deaf and how to communicate with a person with a hearing disability like me. I could not hear my professors' voice so I just self-studied.

I have had valuable experiences when living and working in "the hearing world" for a long time, and recognized that my will and belief are the solutions of treating my hearing disability. "Where there is a will, there will be a way".

As a leader and activist, I attend various seminars and workshops. Organizers include me by providing captioning and interpreter. I tried to take full advantage of participations to comprehend advanced knowledge and enrich my capacity; and recognized my value.

I think I am lucky I don't face any discrimination in society due to my hearing loss. I participate in many movements of hearing loss at international and national levels. I deeply understand what life is.

Now, I am the director of the Center for Research and Education of the Deaf and Hard of Hearing (CED) of which I am a founder, General Secretary of International Federation of Hard of Hearing People (IFHOH) and President of Asia Pacific Federation of the Hard of Hearing and Deafened (APFHD). I love the saying "Deaf people can do everything like hearing people can do, even hearing, but do by other ways" (I.King Jordan).



Ms. Duong Phuong Hanh

# REFERENCES

# UNITED NATIONS CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) is a unique international legal document, and also known as the first Human Rights document of the 21st century. It does not openly create any new rights but, rather it gives tools and legal obligation to those States who signed and ratified it to ensure that human rights are reached and enjoyed equally by all persons with disabilities.

CRPD is also known as a non-definitive document as it does not give clear definition of disability and neither any list of types of disability. It is not about getting privilege; it is mainly focusing on recognition of persons with disabilities as members in the society.

In the Article 1 of the CRPD, it states:

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

On the basis of the purpose and principles, CRPD has recognized in many articles about the specific provisions for effective communication tools and modes of communication. In the description of the document, we are legally equipped to claim appropriate modes/means of communication that persons who are hard of hearing/deafened can participate in society as equal as other members.

In the following articles of the CRPD, State Parties shall take all appropriate steps to ensure that reasonable accommodation is provided in order to promote equality and eliminate discrimination, including denial of accessible information and communication technologies and systems. The articles and the provisions give emphasis on the communication need of hard of hearing and deafened people. We must bear in mind that it is about equality, non-discrimination among all people with disabilities and non-disabled, and within cross-disability.

#### ARTICLES IN HOHD CONTEXT

#### Article

#### **Definitions**

"Communication" includes languages, display of text, Braille, tactile communication, large print, accessible multimedia as well as written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communication technology;

"Language" includes spoken and signed languages and other forms of non spoken languages; "Reasonable accommodation" means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms;

#### **Equality and Non-Discrimination**

3. In order to promote equality and eliminate discrimination, States Parties shall take all appropriate steps to ensure that reasonable accommodation is provided.

#### Women with Disabilities

1. States Parties recognize that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms.

#### Children with Disabilities

2. In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration.

3. States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right.

#### Awareness-raising

- 1. States Parties undertake to adopt immediate, effective and appropriate measures:
- a) To raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities;
- b) To combat stereotypes, prejudices and harmful practices relating to persons with disabilities, including those based on sex and age, in all areas of life;
- c) To promote awareness of the capabilities and contributions of persons with disabilities.

Article

**Accessibility** 

9

- 1. To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems,
- b) Information, communications and other services, including electronic services and emergency services.
- 2. States Parties shall also take appropriate measures:
- a) To develop, promulgate and monitor the implementation of minimum standards and guidelines for the accessibility of facilities and services open or provided to the public;
- c) To provide training for stakeholders on accessibility issues facing persons with disabilities;
- e) To provide forms of live assistance and intermediaries, including guides, readers and professional sign language interpreters, to facilitate accessibility to buildings and other facilities open to the public;

Article

Freedom of expression and opinion, and access to information

a) Providing information intended for the general public to persons with disabilities in accessible formats and technologies appropriate to different kinds of disabilities in a timely manner and without additional cost;

b) Accepting and facilitating the use of sign languages, Braille, augmentative and alternative communication, and all other accessible means, modes and formats of communication of their choice by persons with disabilities in official interactions;

- c) Urging private entities that provide services to the general public, including through the Internet, to provide information and services in accessible and usable formats for persons with disabilities;
- d) Encouraging the mass media, including providers of information through the Internet, to make their services accessible to persons with disabilities;
- e) Recognizing and promoting the use of sign languages.

Article

Education

**24** 

- c) Reasonable accommodation of the individual's requirements is provided;
- d) Persons with disabilities receive the support required, within the general education system, to facilitate their effective education;
- e) Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion.
- 3. States Parties shall enable persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education and as members of the community. To this end, States Parties shall take appropriate measures, including:
- a) Facilitating the learning of Braille, alternative script, augmentative and alternative modes, means and formats of communication and orientation and mobility skills, and facilitating peer support and mentoring;

Article 27

#### Work and employment

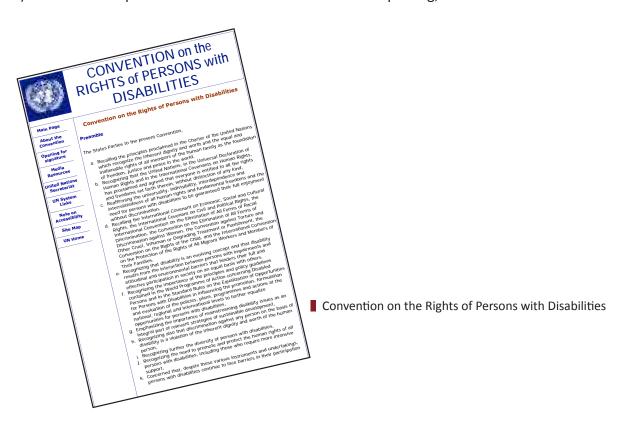
- a) Prohibit discrimination on the basis of disability with regard to all matters concerning all forms of employment, including conditions of recruitment, hiring and employment, continuance of employment, career advancement and safe and hevalthy working conditions;
- $i) \, Ensure \, that \, reasonable \, accommodation \, is \, provided \, to \, persons \, with \, disabilities \, in \,$

the workplace;



#### Participation in cultural life, recreation, leisure and sport

- 1. States Parties recognize the right of persons with disabilities to take part on an equal basis with others in cultural life, and shall take all appropriate measures to ensure that persons with disabilities:
- a) Enjoy access to cultural materials in accessible formats;
- b) Enjoy access to television programmes, films, theatre and other cultural activities, in accessible formats;
- c) Enjoy access to places for cultural performances or services, such as theatres, museums, cinemas, libraries and tourism services, and, as far as possible, enjoy access to monuments and sites of national cultural importance.
- 4. Persons with disabilities shall be entitled, on an equal basis with others, to recognition and support of their specific cultural and linguistic identity, including sign languages and deaf culture.
- c) To ensure that persons with disabilities have access to sporting, recreational and tourism venues;



# INCHEON STRATEGY TO "MAKE THE RIGHT REAL" FOR PERSONS WITH DISABILITIES IN ASIA AND THE PACIFIC, 2013-2022

The State Parties of the Asia-Pacific region developed a regional policy on disability and development based on the principles of the CRPD called The Incheon Strategy to "Make the Right Real" for persons with disabilities. The development of the Incheon Strategy benefited from the contributions of governments, organizations of and for persons with disabilities, and other key stakeholders.

The Incheon goals and targets are set at specific time periods, 2013 – 2022, that need to be achieved for accelerating implementation as well as facilitating the measurement of progress by countries and territories in the Asia-Pacific region. One of the Incheon goals aims to enhance the accessibility and usability of information and communication services that will facilitate hard of hearing/deafened people to participate equally in society.

An access to assistive devices and related support services is highly recommended for persons with disabilities to optimize their level of independence in daily life and live in dignity. In Asia-Pacific region, people who are hard of hearing and deafened experience discrimination every day because they have limited access to services such as education, health care, employment, disaster relief and recreation. They often feel excluded from social interaction due to lack of reasonable accommodations.

### **GOALS & TARGETS IN HOHD CONTEXT**

3

# Enhanceaccesstothephysicalenvironment, public transportation, knowledge, information and communication

Target B) Enchance the accessibility and usability of public transportation.

Target C) Enhance the accessibility and usability of information and communication services.

Target 3.D) Halve the proportion of persons with disabilities who need but do not have appropriate assistive devices or products.

# Goal

# Expand early intervention and education of children with disabilities

Target A) Enhance measures for early detection of, and intervention for, children with disabilities from birth to pre-school age.

Target B) Halve the gap between children with disabilities and children without disabilities in enrollment rates for primary and secondary education.

# Goal

#### Ensure gender equality and women's empowerment

Target A) Enable girls and women with disabilities to have equitable access to mainstream development opportunities.

Target C) Ensure that all girls and women with disabilities have access to sexual and reproductive health services on an equitable basis with girls and women without disabilities.

Target 6.D) Increase measures to protect girls and women with disabilities from all forms of violence and abuse.

# Goal

#### Ensure disability-inclusive disaster risk reduction and management

Target A) Strengthen disability-inclusive disaster risk reduction planning

Target B) Strengthen implementation of measures on providing timely and appropriate support to persons with disabilities in responding to disasters.

# Goal

#### Improve the reliability and comparability of disability data

Target A) Produce and disseminate reliable and internationally comparable disability statistics in formats that are accessible by persons with disabilities.

Target B) Establish reliable disability statistics by the midpoint of the Decade, 2017, as the source for tracking progress towards the achievement of the goals and targets in the

Incheon Strategy.



Incheon Strategy to "Make the Right Real" for Persons with Disabilities in Asia and the Pacific, 2013-2022

## **TECHNICAL TERMS**

Each person uses their experience of life with disabilities to shape her/himself and define their identity. Hard of hearing and deafened people faces different kind of challenges, cope with life transitions, and deal with cross-cultural issues and adjustments. Some people have hearing loss in one ear; some people are born with a hearing loss; and others lose their hearings later in their life.

#### HARD OF HEARING -

People with hard of hearing refer to those with some level of hearing difficulty, including those with mild to profound hearing losses to those late deafened. Hearing loss leads to difficulty in understanding conversational speech. They need reading or verbal communication by lip reading. Assistive hearing devices, hearing/induction loop and real-time captioning are useful for them.

#### **DEAF**

People with deaf have severe hearing loss. Deaf people represent themselves as a cultural minority with a unique language and culture. Some deaf persons use sign language as their first language. Sign language interpreters bridge a gap between hearing and deaf people. The lower case "deaf" is used to refer to inability to hear while, the upper case "Deaf" refers to cultural identity and linguistic aspects of the deaf community.

### **DEAFENED/POST-LINGUAL DEAFNESS —**

Deafened or post-lingual deafness refers to a person who lost hearing as an adult and faces different challenges. Deafened person has already learned a language so they usually can speak very well but they cannot understand speech clearly when losing hearing.

#### **DEAFBLIND**

Deafblind refers to a person who is both deaf and blind (e.g. usher syndrome and other visual impairments). Deafblind people have their own specific rules of behavior such as pro-tactile, braille, cane and other characteristics. They may prefer to put their hands on the top of other person during the conversation in sign language, or stand in distance while a person signs in same position.

\*\*\*NOTE: Tinnitus is a physical condiion where noises (e.g. ringing, buzzing or whistling) occur in one or two ears or the head, but there is no such external noise present. It is not related to any psychiatric condiion. Most people with hearing loss suer from innitus. Most people fid it disturbing and uncomfortable. A person who has experienced with innitus is highly recommended to see otolaryngologist (or "ENT" doctor who specialize in treaing ear, nose, and throat infecions). Audiologists only evaluate the level of hearing loss and provide expert advice on the selecion of hearing aids and other assisive devices. \*\*\*

## **MODE OF COMMUNICATION**

#### LIPREADING -

Attempt to understand what is being spoken in oral language by observing the speakers' lips movement. Observing the face and body language is also part of lipreading or speechreading. Speech therapy may be necessary to develop speech ability; the ability to understand by lipreading depends on many factors such as speaker's mouth style and "accent." Some people who are deaf or hard of hearing are very skilled lip-readers, but many are not. For example, only 30-40% of spoken English is visible on the lips because many speech sounds have identical mouth movements. Also, people have unique "accents" where their mouths show different movements. Some hard of hearing and deaf persons rely on lipreading for most social interaction and they maximize the number of words they will understand.

#### SIGN LANGUAGE •

Sign language is a visual system that involves simultaneously combining hand shapes, orientation and movement of the hands, arms or body, and facial expressions to express an individual's thoughts. Sign language is not universal or international language. All countries have developed their own native sign languages, but some sign languages are legal recognition by the governments (most sign languages cannot be found in dictionaries). The grammar of sign languages relies on visual and tactile features unlike spoken languages, which only one sound can be made or received at a time. Not all persons who are deaf, hard of hearing, and deafened can communicate in sign language; some have their own preferences such as writing on papers, lipreading, reading captions and other modes of communication.

#### **CUED SPEECH**

Cued speech is a phonemic-based system which makes traditionally spoken languages accessible by using a small number of handshapes (as cues representing consonants) in different locations near to the mouth (to represent vowels).

## **ACCESSIBILITIES**

#### CAPTIONING-

Captioning (or subtitle) normally refers to the display of voice into text in any media such as movies in DVD or at the cinema and programs on television. Captioning can be closed or open. Open Captioning is always on and visible to the viewer and cannot be turned off, while Closed Captioning (or abbreviated as CC) can be turned on and off by the viewer. CC symbol is often used to present whether Closed Captioning is available. When pressing the CC (or subtitle) button on a movie panel or television remote control, it can be turned on or off.

## 

Communication Access Real-time Translation (CART), Speech to Text Reporter (STTR), or Real-time Captioning are used to transcribe the voice into text in real-time. It is usually done by trained people who can type more than 200 words per minute with the help of software, a special keyboard and shorthand (stenography).



Real-time Captioning in meeting

### SPEECH TO TEXT/ SPEECH RECOGNITION =

Computer software can recognize spoken words or take dictation and convert it into text automatically. Training is required so that the software can understand the voice of the speaker correctly. There is still room to develop the software and to use it for real-time captioning.

## **ASSISTIVE TECHNOLOGY**

#### HEARING AID —

Hearing aid is the most basic assistive device that allows people who are hard of hearing/deafened or deaf to understand verbal communication. It is an electroacoustic device which amplifies and modulates sound for the user. Some individuals benefit considerably from hearing aids; others may only be able to detect the sounds of the surrounding environment such as a fire alarm, car horn, or drum. Some individuals may not benefit at all from hearing aids, depending on how high or low pitch each can detect. Only audiologists have access to adjust sounds in the hearing devices; individuals only can adjust the volume of the hearing aids.



Hearing Aid

#### COCHLEAR IMPLANT —

A cochlear implant (CI) is a surgically small complex implanted electronic device that can restore partial hearing. A CI may help to provide a sense of sound to individuals with severe to profound hearing loss who do not benefit from a conventional hearing aid. A CI provides direct electrical stimulation to the auditory nerve, which allows for the perception of sound sensation.

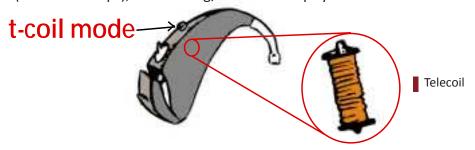
\*\*\*NOTE: Hearing devices such as hearing aids and cochlear implants may enable or improve an individual's hearing, but it may not make their hearing functionally equivalent to "normal" hearing. Increasing the volume on hearing assistive devices or cochlear implants doesn't increase the clarity of sound. Some individual cannot recognize their own voices. \*\*\*



Cochlear Implant

#### TELECOIL, T-COIL, T-SWITCH —

Telecoil, T-coil, or T-switch is a tiny cooper coil around a core to expand functionality of hearing aids or cochlear implants by filtering out background noise. Telecoil can be used with telephones, FM systems (with neck loops), and hearing/induction loop systems.



## **HEARING/INDUCTION LOOP**

Hearing/induction loop is a loop of cable around a designated area, which generates a magnetic field picked up by a hearing aid or cochlear implant. The benefit of hearing/induction loop is that it allows the sound source to be transmitted to the hearing aids or cochlear implant with a telecoil (or T-coil) clearly and free of other distracting noise in the environment.

Neck loop has the same function but it can be hooked around the neck of a listener. It does not need to be installed and is available in a small portable form. There are also portable loop systems available which are handy for small meeting/conference rooms. If you see a symbol of cross ear and a letter "T," it means the area has the hearing loop installed.



Hearing/Induction Loop

#### **EMERGENCY EQUIPMENT**

There are many types of alarms available for daily life and emergency for people who are deaf, hard of hearing, and deafened that cannot always detect the sound of a smoke alarm. Smoke alarms with strobe lights, vibration notification appliances are activated by the sound of a smoke alarm. Door lights let people who are hard of hearing/deafened and deaf know when someone rings the doorbell. Wake-up alarms under a pillow or mattress can either vibrate or flash lights.



Flash Alarm

### VIDEOPHONE/RELAY SERVICE •

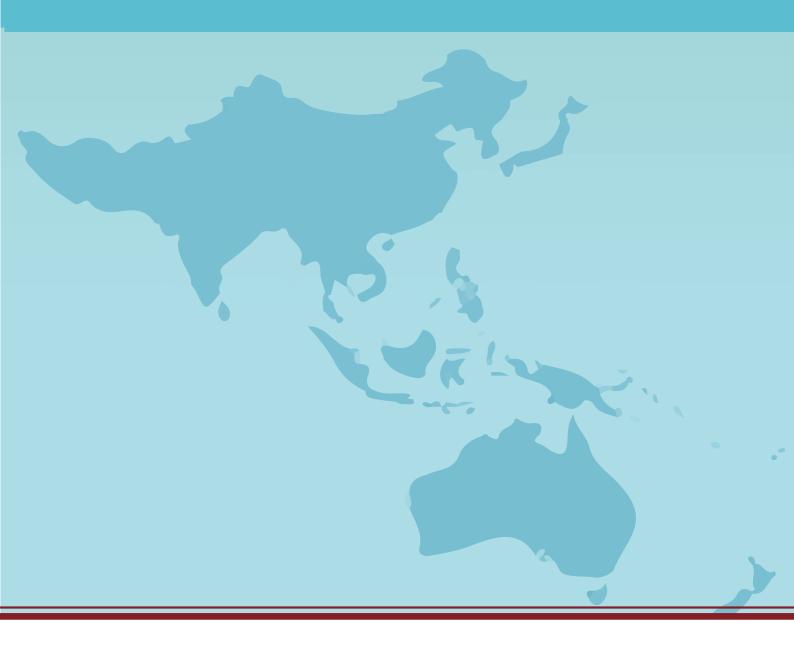
Videophone (VP) facilitates the conversation between two persons who are deaf, hard of hearing, or deafened in sign language. Videophone also functions as relay service where a hard of hearing, deafened, or deaf person can communicate with a hearing person through a voice telephone.

Relay service providers facilitate the conversation between individual and hearing person. Relay service contains professional sign language interpreters voice the sign language to a hearing person and sign the hearing person's words to a person who is deaf, hard of hearing, or deafened. The service also provide another option, voice carry over (VCO), which a person is deaf, hard of hearing, or deafened can speak directly to the other person on the call while watching sign language interpreters to interpret on the screen.





Accessible for Persons with disAbilities



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