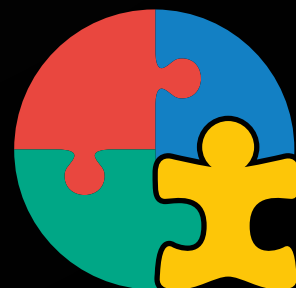




WE NEED TO UNDER- STAND

Workshop Series
Booklet of Real Stories



Avrupa
Birliđi **sivil
düşün**



Introduction

With the support of the European Union Sivil Düşün (Think Like a Civilian) Programme, we - as Dem Association, have carried out workshop series consisting of six meetings held between September 8, 2020, and September 24, 2020, intending to discover and identify the problems encountered by the deaf and hard of hearing (HoH) individuals living in Turkey.

For ease of coordination, at each workshop - addressing different target audiences and each lasting two hours, we respectively gathered the healthcare professionals, representatives from the non-governmental organizations working in the field, relatives of the HoH and deaf individuals; college students, educators and individuals, who have hearing loss at different levels.

This booklet consists of selected stories that were shared during meetings and has been gathered anonymously.

Wish you a thought-provoking read!

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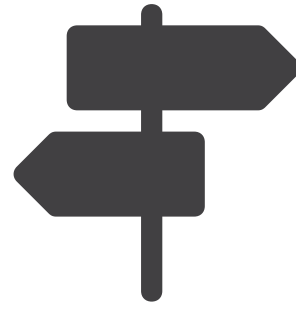




SYMBOLS AND MEANINGS



At home



On street



At work

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I have hearing loss. One morning, I went to the grocery store. I finished shopping and headed to the cash register. Naturally, both I and the cashier were wearing face masks due to the pandemic. At one point, I realized that the cashier was speaking, but I did not understand what s/he was saying. At any time, I could not understand what s/he was saying for numerous different reasons, however, these masks have made it even more difficult. I kindly told her/him that I could not understand and asked her/him to repeat it. **The cashier started yelling at me. Yet, I actually could not understand what s/he was saying.** Communication should not be this difficult.



I am a representative of a non-governmental organization working in the field. I can never forget that my phone rang on one of those days during the pandemic when there was a curfew. CODA was calling; one of our hearing children raised by deaf parents. After chatting for a while, I said I had to hang up the phone due to my busy schedule. When I was about to say goodbye, I heard a response I was not expecting at all. The child said, **“But, I need to talk to someone”**. Then, I asked, “What should we do?”. The child replied, “Maybe you can read me stories.” So, we started storytelling. CODA children could not socialize during the pandemic and, therefore, could not satisfy their needs to talk and tell. And, we tried to be there for them by telling stories.



I am a sign language interpreter and also a CODA. One day in April, my phone rang. A deaf citizen was calling. **S/he had a health problem, yet there were no interpreters around. S/he tried calling the 112 lines for people with disabilities (ESiM), but could not contact anyone for 3 days.** S/he got in touch with a familiar association, asking for help. This is how s/he contacted me. Anyway, I called the ambulance. And, I gave them my contact details in case they needed it. They informed me nine minutes later. The ambulance had taken the patient from home and was on the way to the hospital. Tests were done and the coronavirus test result was positive. S/he stayed at the hospital for one week. We had video calls throughout the treatment period. I can say that the treatment process was really difficult. Sometimes, I had difficulty contacting her/him. At the end of one week, s/he was discharged home. However, the entire communication process following the discharge was maintained by phone. Information could not be shared by text. So, the deaf individual always needed someone. Briefly, the healthcare teams did not know how to contact hard of hearing and deaf people. This is why I had to provide remote support from the beginning of the process to the end.



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IV



I am a sign language interpreter and also a CODA, which means my parents are deaf. One day, my mother fell sick on one of the curfew days. I checked and saw that her fever was 40 degrees Celsius. So, I immediately called 112. The ambulance arrived and took only my mother. I was not allowed to get on the ambulance due to the pandemic. I, therefore, handed her phone in that tight situation, as I did not know who and how she would speak at the hospital. Of course, I went to the hospital immediately after her. I was waiting outside and my mother was inside. My mother's medical history includes many health problems, which worries me. We contacted my mother through the phone I handed to her. Who knows what would happen if I had not thought of passing her the phone at that moment. My mother tells me how scared she is and when she needs to use the bathroom, but she cannot say anything to anybody at the hospital. The reason behind that is the absence of interpreters and staff members who can speak in sign language at the hospital. Besides, nobody is informed about the ESİM application at the hospital. **I guess nobody volunteers to communicate.** Unfortunately, when people do not know what to do and how to communicate, they choose not communicating at all.



V



I have a deaf-hearing family. I have seven individuals with hearing loss in my family. For instance, the son of a relative is seven years old; his parents are deaf and the child is hearing. He finished kindergarten last year. We were expecting him to start elementary school this year. However, they said that it was better for him to spend another year at kindergarten. When asked why the answer was as follows: Children need parental support particularly in the first year of elementary school. Nevertheless, since the family is deaf, they cannot provide the educational support that the child needs at home, by communicating with the school, particularly during the distance education process. **Anyway, we managed to convince the teachers after long talks and I sent my younger hearing sister from Van to Kocaeli province, so that she could assist in the communication with the family.** From now on, my sister will live there. Schools need to learn how and make an effort to communicate with deaf and hard of hearing parents. Unfortunately, institutions are not informed about the means of communication.



VI



A hearing-impaired person is working at the hospital. Hearing-impaired persons, like all individuals with disabilities, were allowed to take administrative leave. However, when the hospital became understaffed afterward, they called the hearing-impaired staff member back to work. After a while, this was left to the initiative of the hospital management and they decided on what to do. Of course, there is nothing to object to at this point. This employee was first assigned to the COVID service. They trusted him/her and assigned his/her duties. The problem was, that person could not understand the people around them or express himself/herself effectively while wearing all those protective clothes and masks. **The communication process, which was already challenging, became even more problematic. Every issue turned into a discussion.** Then, this was discussed with the hospital management, and s/he was assigned to another service.



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VII



I am a Ph.D. student, using a hearing aid. I communicate by listening and reading lips. A high number of presentations are delivered throughout the doctor's degree. Giving distant presentations on video calls, listening to the teachers, and participating in the Q&A sessions is challenging. For instance, I prepare my presentation, then meet a friend and explain it to him/her, and s/he makes the distant presentation, and it appears as if my friend prepared the presentation. I could show what I have done if we were face to face, yet I remain passive when it is distant. Another problem I encounter is that, if the internet connection is bad and insufficient, the image slows down, freezes, and is delayed as the teacher gives the lecture on the video call. But, I need to follow the teacher's lips, as I read lips to support my understanding. I have difficulty with that. When the teacher asks something by talking, I request him/her to ask it by writing. Then, s/he asks it from another friend, but I receive the question as a summary. They convey the question to me in the form of brief notes. Well, when the question is shortened or incomplete, I cannot understand and answer it. **This process has exhausted me. Now the Ph.D. qualifying exam is approaching, I do not have any idea how it will turn out.**



VIII



I am a hard of hearing undergraduate student. As is the case with all universities, my university started distance education due to the pandemic. During the distant education, teachers preferred sending voice records to sharing written lecture notes. But, I am using a hearing aid. Lip-reading, on the other hand, is indispensable to me in terms of communication. I can't understand the opposite person completely without supporting what I hear with lip-reading. In other words, **the voice records sent during the distant education process were not sufficient for me to continue my education, and the video was required.** I talked to my teachers, asking them to send videos. Yet, they continued sending voice records. Then, I talked to my advisor. S/he said they would find a solution for the next term. This term, the school started and teachers of several courses give lectures live online. By this means, I can understand what I hear better through lip-reading. It appears like voice records will keep coming for some more time only in a few courses.



IX



I am an undergraduate student, using a hearing-aid. I got exhausted, in general, by people's unawareness of a group of people with hearing loss. From their perspective, there are only deaf persons or hearing persons. They are acting like only the elderly could be hearing-impaired. There is a common perception that young people cannot have hearing loss. But, here I am. For instance, I could not listen to my courses effortlessly by plugging my earphones into the computer. **I had to match my hearing aid with my computer directly, instead of the earphones, and also had to replace my computer to understand my courses.** I can say that I felt relieved when I started hearing the voices directly through my hearing aid, thanks to my new computer. I am still having trouble with the people who are mumbling. I know that not everybody has to receive diction training, yet it is still too bad when they say 'This is how I am' in response to the moment I mention the problem. They have no intention of improving themselves. I guess people cannot approach this subject with empathy.



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X



I am a deaf university student, using sign language for communication. I am studying at the School of Physical Education and Sports. When the pandemic started, I could not understand what was happening exactly. I was just told, "You will be punished if you go to school." When that was the case, I stopped going to school. They told me to stay home, so I stayed home. One day, a teacher of mine texted me and asked me why I was not attending classes. I was puzzled. Were there still classes? I was not informed of it at all. **Apparently, my teacher had started distant education and one month had passed, however, nobody had told me about it.** I was shocked. My teacher was mad at my friends. But, I was already late for my classes. I could not get accustomed to the process afterward and had great difficulty. I asked for support from one of my former teachers. S/He helped, still, I was already late. I filed a complaint to the university. They said they would assist me in that, however, that I had to handle the situation for a while.



XI



I am a teacher and I have hearing-impaired students. I have a student who is 1 year old and using a hearing aid. S/He is both the first child of the family and the first person in the family to have a hearing loss. S/He could receive education only for once before the pandemic. Within the scope of that education, only the family was informed. However, it was obvious that the family did not accept the disability of the infant. When the pandemic broke out, the family went through the acceptance process while they continuously stayed inside the same house with the child. This is a very difficult situation. As you know, infants start discovering their surroundings, crawling, walking, and socializing at these ages. But, that infant was forced to stay at home and s/he has been commuting only between home and special education since the normalization process. There is no other socialization area. **On the other hand, the child needs to be walked around and taken to places like parks, gardens, grocery stores, and butchers, to develop recipient and expressive language skills.** On top of it, the child saw so many people wearing face masks after staying at home for a long time, which is difficult to get used to. The institutional psychologist stepped in and we worked on family and child communication. I can say that they are doing better now.



XII



I am a hearing-impaired person, using a cochlear implant. Upon observing some symptoms, I applied to the hospital, suspected of coronavirus. I had difficulty communicating with the doctors. Sometimes, I can listen and understand, but other times I do not understand anything. I say that I am a hearing-impaired individual, ask them to speak slowly, and ask again when I do not understand. Yet, this process is highly difficult. After I tested positive, doctors sent me home. They could not communicate with me in any way. Even if they managed to ask me anything, I could not understand and answer. My mother was by my side, so she helped. **I tested positive for the coronavirus, but I could not find out what to do by myself.**



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XIII



I am a hearing-impaired person, using a hearing-aid. I live with my family. As there are individuals who tested positive for the coronavirus and I had a persistent headache, I wanted to get tested, as well. So, I went to the hospital, alone. Of course, everybody was wearing masks there. I got a number, but could not hear or track the queue numbers. Anyway, I found the doctor's room by asking people and went in. Naturally, the doctor was also wearing a mask. By the way, I can speak, but cannot hear. And, I state that every time. So, I started again. **But, the doctor did not understand my inability to hear in no way, as he saw me talking.** He repeated what he said so that I could understand, yet I could not understand no matter how many times he repeated. Finally, I called a friend, so that s/he could hear and translate them for me. The doctor was wearing a mask and my friend could not hear him, either. So, s/he could not tell me what he said. At last, I suggested writing. We communicated through writing. I was tested positive. They said healthcare teams would visit me. I said it was alright. The team called when they were at the door, asking me if I was available. Still, they did not text. What would we do if there was no hearing person at home?



XIV



I am a user of a cochlear implant. I was working in the early days of the pandemic. When the summer came, I decided to exercise my right to retire and I retired. I want to talk about the online meetings held while I was working. I had problems regarding the voices coming from the computer. It was easier for me with my mobile phone, as it was connected to my implant via Bluetooth. However, the sounds caused a problem on the computer. Adapting to and focusing on the voices were extremely challenging, as well as directing and keeping my attention. Even a two-hour meeting would, therefore, become extremely exhausting to me. **Whereas someone with normal hearing did not get exhausted by it, I did.** When I told my coworkers about this situation, they replied, "Attend the meetings or not, it is your call." In other words, they granted me the right to not attend the meetings. In their opinion, they solved the problem by leaving me out of the meetings, yet the problem was not solved at all. Because, at the end of the day, I had to know and understand everything mentioned in those meetings and keep doing my work. There is a person who notes down the entire process in this workshop. I noticed that this is a solution and can be achieved if wanted.



XV



I am a sign language interpreter and also a CODA. A deaf citizen I know tested positive for coronavirus. And, I was supporting him in the process as an interpreter. As the person had no chronic diseases, it was deemed appropriate that her/his treatment continued at home. However, when her/his complaints grew more severe, I sent an ambulance to her/his house and the paramedics took her/him to a state hospital. Since there were no interpreters at the hospital, they contacted me again. I had to enable communication between the doctor and the deaf individual. Still, we could not achieve very healthy communication. Finally, I went to the patient. They said, according to the results, her/his treatment should continue at the hospital. **I could not leave her/him alone, because there was no interpreter available, and I stayed at the hospital for six days despite the transmission risk.** If there was an interpreter at the state hospital, the interpreter could go in and out together with the doctor. But, I could not do that, as it was not accepted. I could not even leave the hospital room, because I was not allowed. Apart from the suspension of my works, my health was in question. When I look back, I think about how I was compelled to do it.



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DEM ASSOCIATION

Writers: Ayse Damla Iseri Sunman - Diclehan Sonmezoglu

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