A Glimpse of our Covid World

Stories of resilience from young deafblind people during a global pandemic
Maiden’s
STORY

I am Maiden, a girl from Meghalaya, India. I lost my parents when I was 8 years old and from then my aunt took care of me and my 2 siblings. When I was 13, I suffered from high fever because of which I started losing my hearing and vision. I live in a small village and people here are not aware of deafblindness and they make fun of me. I cannot study here in regular school.

I got admission at Bethany Society, a school for deafblind supported by Sense India in Shilong. There I learnt sign language and English. There I was lucky enough to find a teacher who cared for me like a mother. She gave me strength and encouraged me to try new things and learn. I am now 21 and can communicate mostly through sign language. I was doing OK at Shilong except for the fact that I could not clear grade 10 despite trying twice because of my low vision as I could not read for long hours. Things suddenly changed after this pandemic broke out.

Once lockdown was announced nationwide, I had to move back to my village. There I do not have any friends but I work at my home all the time. I could no longer communicate in sign language. People here in my village don’t know how to sign so I could not communicate with them. Fortunately, I had managed to buy a smart phone for myself and explored to learn to use WhatsApp. Now at least I could message everyone and stay in touch. I also make video in sign language and share it with those who can communicate in sign language. One thing I am worried about is my brother’s education. He studies in Bangalore in grade 12. Last year I could pay his school fees from the scholarships I got in sports but this year I have nothing so I could not pay his education fees.

Being the eldest of my siblings it is my responsibility to be able to take care of them. The illness I suffered earlier has also left me weak and because of it I cannot work on our farm to provide for my family.

I have kept myself very busy during the lockdown period. I love to cook and make cakes so I try to cook different dishes. My sister always loves my dishes. I also use Google to search for and learn new things. I am now using the internet to learn more sign language and other things that will help me. No one in my village helps me so I try to learn new things on my own. There are four other children who are deaf in my village but unfortunately no one is here to teach them sign language. I used my time during lockdown period to teach them sign language.

Now I only hope the situation will be better soon and I will be back in Shilong and will be able to finish school to pursue my dream of studying outside Shilong and become a well-known baker. I want to be independent enough to be able to financially support my family so that we won’t need to be dependent on others.
My name is Jenny. I have CHARGE syndrome so it means that I have a visual and hearing impairment. I use oral communication but I also use sign language to make sure I understand what’s being spoken.

I am currently studying at university doing accounting and finance. I started in September 2020 in the middle of the pandemic so I only went to campus itself for the first week before moving on to online only studies, given it was just too risky for me to actually go into campus itself.

It has meant that I could not meet new people properly, as I could have if Covid hadn’t happened, so the only way I could meet them was through MS Teams and Zoom. It is not the same as seeing people physically where you could see them and not just a load of text on a screen.

The university has been very supportive – they even organised interpreters to communicate to me via Zoom while they sat in the lecture halls and allowed me to have extra time for exams and I have a mentor to help me with academic work, which is great.

The upside of online studies is that, when I am watching a lecture on MS Teams, it does live captions, so that means I can read what the lecturer is saying and also it has a chat box where I can type in a question so the lecturers can read it.

The pandemic has also meant, like for many others, being stuck indoors at home all the time and, seeing I’m at high risk from Covid, I was not able to go anywhere except for hospital visits. I live with my Mom so, since the lockdown started in March 2020, she has been the only person I can see physically while other people outside the household could only interact with me from a distance or online.

My social life has been reduced to online only – using Facebook and Zoom for all social interactions and it will be like that until it’s safe enough for me to go to meet people outside physically.

In the UK the lockdown keeps being eased and re-implemented. What’s changed is that people don’t go out to socialise as much as before Covid.
Scott’s STORY

The pandemic is changing the way we all do things. I’m Scott, I’m seventeen and I live in Vancouver, Canada and social distancing, masks and travel restrictions have been in place for a long time. I miss my family and friends. I miss exploring different places with my Mom. I get too much anxiety if I’m around people who don’t wear masks. I love exploring: my whole life Mom and I would just go somewhere, to a park, or city adventure, just anywhere we wanted. But now we just go to the places that we know are less crowded. My school is great but I still get anxiety if I’m around too many people. I need to be close to others to see and hear but you can’t do that now. I am OK with that and I understand it, I just miss being able to get close enough to people to connect with them face to face. I like school online. It is much more available to me. I can see the teacher close up on my iPad. I love that. I still can’t see her clearly but I see her so much better than when I sit in class. I also can chat on the same platform as my classmates. I love that too. They forget I’m deafblind, we are all the same in online chat.

I have to say for me there have been lots of positives to the pandemic too. School online has been good for me. The time I have had away from my family made me look for new ways to connect with them. I decided to write a story for my little cousin. He is awesome and I love being his big cousin. I really missed him. He liked my story. I decided to send it to another friend for her kids. They asked for pictures. I decided, ‘Yes, let’s do that.’ I asked a friend to draw them. She had time because we were social distancing and she agreed. Her pictures are great. I loved how the book turned out. I got the idea to see if I could publish it. The book is now being sold and it is in the community library. I’m not sure I would have become an author of a book if I didn’t miss my cousin because of the pandemic. I really want to have life back to normal but I have good achievements because of the time it gave me to do things I probably would not have done if it was life as usual.
I have Usher syndrome, which means I was born deaf, have severe balance issues and am losing my vision. Because I am deafblind, I have had to work extra hard my whole life to do what most people take for granted. I have faced barriers with confidence and found my own ways to be successful in a hearing, visual world. My parents made sure I knew that I was loved and accepted for everything I am. I know I don’t need to be fixed, I need accommodations so I can have the opportunity to access the world at a more equitable level compared to my seeing, hearing peers. I have a high level of motivation, have learned to be a strong advocate for myself, and I have always had a positive attitude… but it is getting harder to do this during COVID-19.

I was a senior in high school in Scotch Plains, New Jersey when the lockdown started. When we were first sent home in March of 2020, I was still hopeful that graduation would happen, but that didn’t last long. As one event after another was cancelled, I realised that I was not going to have the senior year experience that I had really been looking forward to. There was disappointment after disappointment and I couldn’t do anything about it. No prom, no senior weekend and none of the activities that mark your senior year. I was crushed. Mentally and physically. In early 2019 I had become part of a Paralympic sports club and started competing in Paralympic swim meets across the country. I qualified to compete in the National Paralympic swim championships at the end of the year. I broke an American record and made 3 emerging times, which meant I would be tracked by US Paralympics Swimming. I started 2020 with such excitement but it all came to an abrupt end and I have barely been in a pool since then. This led to me losing all motivation to keep myself in the best shape I have been in my entire life.

On top of all this, I learned that I received 3 scholarships from my high school and community in a virtual ceremony. I found out that I was awarded the Union County Interscholastic Athletic Conference Scholar Athlete award in an email. I also received scholarships from the NJ Commission for the Blind and Visually Impaired, the Center for Hearing and Communication and Cochlear Americas. In a pre-COVID world I would have attended awards ceremonies, dinners and travelled to conferences; instead there were virtual ceremonies or they were sent in the mail. In some ways it felt like they didn’t even happen.

I have spent my life not feeling sorry for myself and dealing with adversity, but I have really struggled not to feel sorry for myself in the current situation. It was the first time in my life there was something out of my control that I felt like I couldn’t deal with. And there have been so many things that I have had no control over, but I was able to deal with them. This was really the first time in my life that I couldn’t move forward. With all this being said, I have moved on from that time in my life and I can’t wait for COVID to do the same!
Hi, my name is Shisna Anand, 28 years old from Kerala, India, born with cataracts in both eyes and I was totally deaf. At the age of 3.4 months I underwent an operation for cataracts but it affected my right eye and I lost vision completely in that eye. I also had developmental delay and for that I had to undergo physiotherapy sessions from the age of 6 months to 3 years. It helped me a lot. I also had a heart problem - patent ductus arteriosus (PDA). I had to undergo an operation to correct it at the age of 2 years.

I joined the Sense India supported deafblind programme at the Helen Keller Institute for Deaf and Deafblind in Mumbai at the age of 4. I was doing well at studies but things became difficult when, at the age of 6, my left eye got affected with glaucoma. I had to undergo operations three times but it didn’t help. At 10, I lost the little vision I had in my left eye. Now I was completely deafblind. I started learning Braille and computer.

I communicate through tactile sign language mostly and I can use Braille display also.

It helped but in 2017 I stopped my school education due to the boring syllabus. I decided to learn basic skills and other things like dance that interested me. My father was my greatest support during all this time. He helped me to learn and whatever I am doing today is because of him. I was curious to learn about dance and so my father helped me to learn. I performed on TV channels and went on to win the Phoenix award for differently abled women.

During lockdown, I decided to do something more and again my father supported me a lot. Now I am making umbrellas, paper pens, paper bags, foot mats, paper flowers, etc. I enjoy whatever I do. I am now getting orders for my products. I have been fully occupied during lockdown time and my family is always by my side whenever I need them. I now wish to open a Vocational Training Unit for differently abled women and help them to become financially independent and market their products.

The only thing that I was not comfortable with was the fact that I could not go out to my workplace but I made good use of time. I strictly follow all the guidelines and precautions and ensure that my family also follow them. I do not touch them when they return from outside, I send them directly to bath and get fresh before spending time together again. I take care of the whole house and changed all the cloth curtains. I also made lots of paper flowers and decorated the whole house. I loved all the time I got to be with my family. I now also attend online events and meetings organised by Sense India with the help of my father. He has been a great support to me.
Hello, my name is Sam, I am sixteen years old. I live in the United Kingdom near to London in Hertfordshire with my Mum. My sister is away at university. In 2018, I had surgery for cataracts. As a result, I now wear glasses. I have had two cochlear implants since being young. I read and write using Braille. Sometimes I use a Braille Note Touch Plus for my work at school and at home. I am a long cane user. I do not use it in the school building or at home, but I use it in unfamiliar environments.

Instead of going to school, being with my friends and doing lessons, I have had to stay at home. Some lessons were via video calls. Mum has done an awful lot of home schooling. It was odd as Mum became my Teacher! She had to do a lot of work. I admit it was hard; it was tricky at times because it was kind of odd for both of us, but we got on with it!

Before Covid 19 I used to go to a local youth club each week. I enjoyed using their drum kit, mixing desk and other electronic equipment. Unfortunately, because of Covid 19 it had to stop. I miss it and feel upset about this. I hope it will open again in the future.

Before Covid 19 I had a long session with my Sense Intervenor, she used to come to my house every week. We used to do lots of fun activities together. This had to stop. We now have video chats for an hour twice a week.

In the past some of my friends from Sense have met up to do activities such as ice skating and bowling, and we had a fun sports day, but this has all had to stop. We now have a regular online youth peer chat together. I find these peer sessions interesting. We share news and jokes, play bingo, do quizzes and at Christmas time we all wore silly hats! I also like to show off my new robots and explain how they work.

We cannot be as close to each other as we used to be, both physically and emotionally. Physically I have found it very hard to hear at times due to people having “stupid” masks on, covering their mouths. I know and understand why masks must be worn but, as I do not do sign language, I rely on hearing people’s voices and seeing their full face to work out who is speaking.

Because of Covid I have been home schooled. I have been able to have some lie-ins as I do not have to get up so early for my journey to school! I have had time to listen to Harry Potter audio books and music.
It’s impossible to deny that the pandemic was and has been something very surprising and, of course, devastating for human beings, and for me the impacts were not so different.

I am Alex Garcia and I live in the extreme south of Brazil. I am a deafblind person who also has hydrocephalus and a rare disease - Osteogenesis Imperfecta - “brittle bones”.

In my case, I had to face something more than the pandemic.

On December 13th, 2019, before all issues related to the pandemic started, I fell over in my house and had fractures in my hip bones. I was in hospital for ten days.

In March 2020 - with the pandemic starting here in Brazil - I managed to leave the bed and start using a wheelchair and start physiotherapy. In June, I could begin walking again with the support of a walker aid. Then I started using a walking cane and, finally, in November, I started walking again only with the support of a long walking cane.

I believe you can understand me: besides the pandemic, I had to deal with strong pain and a rehabilitation process. In my case, the trials were extreme. But I managed to overcome them and, with my family’s support, I won this battle!

From December 2019 to December 2020 I was isolated at home for many months. I only had (and still have) contact with my mother, father, brother and physiotherapist. From December 2019 to February 2020 I suffered from strong pains and I couldn’t even sit in bed so I was off the internet and I couldn’t use my computer.

My life has become a ‘virtual’ life. Yes, I have always been a deafblind person who tries to have as much physical contact as I can but I had to adapt myself to this moment. I have already written about the biggest enemies of a deafblind person: impatience and distancing.

The pandemic demands social distancing and it is like an atomic bomb to the deafblind community from all over the world! Social distancing in a pandemic is needed, but for us, deafblind people, it is a catastrophe.

Everything online, yes! I get it! I understand it because of the pandemic, but I have always warned deafblind people about the dangers we have been through when we have to live “on a computer”. No, this cannot happen! We deafblind people must have much more physical contact than virtual contact.

Be careful! We deafblind people are human beings and must be careful about an excessive “online” life. In spite of my complexity, I want to fight a lot to keep being a human being. I will never accept to become a piece of hardware, a piece of software.

My receptive communication happens through “pal of hand writing”.
Hi, I am Arihant from India. I lost my vision and hearing completely when I was in school and had to learn tactile sign language. I used to stay at a hostel far from home to be able to learn and become independent. I have managed to do well in school and cleared the secondary school examination well. I had not been able to spend enough time with my family earlier. This pandemic has changed many things for me but in a good way. It has changed my daily life.

I miss my school activities a lot and wish to go back. I used to be very active at school. Now, because of lack of physical activities, I am gaining weight. Since I am at home all the time, I am able to strengthen the bond with my parents and sister which was not so well developed earlier due to the hectic schedule of everyone. I communicate with them a lot through sign language. I keep myself updated about Covid 19 news with the help of my mother who makes it a point to share all information with me all the time. Keeping in mind the seriousness of Covid 19, I am now focusing more on a healthy diet for good immunity and overall health. I now have a lot of time to develop communication skills with my parents.

I help my mother with kitchen work and, whatever other things I can help with, I try my best to do. I learn a lot of things. As a family, we keep entertaining each other and enjoy ourselves a lot. We hoped this phase would pass soon and we could start living like before. I and my mother spend a lot of time trying to do something creative like making the best out of waste. We sit together and spend 30 minutes each day to discuss news. I sit with my father when he does his office work and this has helped us strengthen our bond further. This pandemic has given us a lot of time to be together and we cherish all the moments we have spent together. I am very happy to be able to spend time with family and bond with them.

I tried to keep myself occupied all the time by doing something productive each day. We as family now have all our meals together and spend quality time together.
My name is Hellen Shakele, I am Zambian by nationality, the mother of a congenital deafblind daughter who is now becoming a youth. I am writing a story on her behalf to share how the pandemic has affected her own life and that of her family. She writes that the pandemic has changed her family life and her relationship with friends. The pandemic has, however, brought stress on families. It has brought changes in the use of family time, child care, leisure activities, income and expenditures. The pandemic has also affected a change in work time as well as a negative change in household economy and a negative change in household work. She writes that her friends can no longer play with her due to fear of contracting Covid. She says, “My mother is my best friend” in this difficult time as we remain in physical contact all the time, as this is our way of communicating and, in our culture, everything relies on touch.

In Africa we have faced economic challenges as the pandemic brings rising debt levels and other structural issues: this has led most households to go hungry and to be unable to afford three meals a day. Most of the borders are closed, hence the economy has really gone down. It has really become difficult for my mother and other families that have children living with deafblindness to access food and other material things.

The pandemic has caused an unprecedented crisis in all areas. It has led to the massive closure of face-to-face activities making it difficult for me to communicate as I depend on face-to-face interactions as a deafblind person. It has led to the closure of schools and institutions in many countries in order to prevent the spread of the virus and mitigate its impact. This has made me drop out of school and I miss the interactions I used to have with my deaf friends at school. The suspension of face-to-face classes at all levels has given rise to the deployment of distance learning modalities through a variety of platforms with or without the use of technology. It has affected me in such a way that I struggle with loneliness and isolation as a result of lockdowns. My friends from the community I live in also have stopped visiting me, I can no longer play the traditional games I used to play with them. My life is very boring.
Hi, I’m Max and I’m 15 years old. I live in the UK with my mum, dad and my best friend – my dog Mylo. I was born deaf and severely sight impaired which has deteriorated in recent years (I’m registered deafblind) so my journey has been challenging. It’s a daily struggle, but I am a positive person and I’ve learned to accept and embrace life. I certainly don’t let it stop me from doing the things I love!

The pandemic has affected me and my family in a lot of unexpected ways. I wasn’t able to see anybody and couldn’t go anywhere, (e.g., local restaurants and shopping centres). The restrictions meant that I couldn’t meet with my school friends and do things like going to the park or going to Subway for our end of term celebrations, which we loved doing as a group! For the first 6 months, our school was closed, so there were no classroom lessons to try and limit the spread of Covid to people.

My mum and dad both had to work at home as much as possible, but Dad often went into work at the beginning for some important lab work until recommendations were made that if anyone could work at home, they should. It was good to spend so much time with my immediate family at home – our dog (Mylo) loved having us all there together all the time and I enjoyed going out for walks every day to get some fresh air. I am really close with the rest of my family, but since the pandemic, we were divided as we couldn’t be together anymore like we used to (for birthday gatherings or fun meet ups).

Also, my grandparents have had to shield in their own homes as they are part of the vulnerable category – it was strange not being able to hug my grandparents. We had to find new ways to connect to each other, so we used FaceTime and Zoom meetings to socialise (we had to teach my nan how to use the technology, which was
very funny as she struggled to connect the video and audio).

In the beginning, we had food shortages and panic buying and lots of businesses were closed (non-essential retail). The NHS (National Health Service) was overrun with Covid patients and they were under immense amounts of ressure, which meant that those working in hospitals and clinics were becoming overworked and stressed. There was advice given to us - wear face masks, use hand sanitiser as much as possible, stay 2 metres apart, avoid having lots of contact with lots of people.

When the pandemic began, no-one was prepared for what was to come and how to approach education. The government recommended to us that all schools should close, so therefore our school had to close, and I couldn’t see my friends or my teachers. The teachers tried their best by giving us worksheets to do at home but it wasn’t really in-depth and interactive as learning from my teachers in face-to-face lessons.

The school had managed to organise and set up Zoom sessions, so we could have classroom sessions virtually in the last 2 months of my school year, which worked well. At the beginning of March (2021), students were allowed to go back to school, but we were told to do self-tests at home twice a week to make sure we were completely safe to attend school without the risk of spreading Covid.

Another measure implemented at school was that we have to wear masks everywhere inside school (even classrooms) and I really struggle with this. The teachers wear clear face shields to help me lip-read, but even these make the speech muffled and it can be difficult to understand. Also, the face mask I wear was making my glasses steam up, which made it even harder to see with my visual impairment. However, we bought an anti-fog spray for my glasses, which stops this from happening and I can see clearly.

So basically, I can’t hear or see very well, and I can’t wait until we no longer have to wear masks. I also spend a lot of time disinfecting my support equipment that is shared between teachers (like my Roger pen microphone). My teaching assistant also has to maintain social distances, so we use Google hangouts to communicate during lessons over the live text chat. All of our GCSEs were cancelled last year, and the government created an algorithm for grading the exams and this was a big fiasco (a lot of students were given a poor grade which was lower than they deserved).

On the plus side, I did achieve my GCSE Statistics. This year, I won’t be taking my Chemistry GCSE, but my teacher will give me a grade based on my progress throughout the year. I am going to be doing tests and exams soon which will count towards the final teacher assessed grade and I hope I’ll do well!
Hi, I am Guman Singh Khati from Sikkim, India. I am 22 years old. I have a minor hearing as well as a visual impairment due to my physical features. The right side of my body is smaller than the left side, because of which I have some sort of impairment in my right ear and my eyes. My speech is well developed and I do not face any problem while speaking. I can speak on the phone with some effort. I have recently graduated from Sikkim College and wish to study further.

After this pandemic broke out in our country and lockdown was announced, I could not go to the gym and all educational institutions were closed. I got depressed during this time because I felt I could not develop my skills any more now. I was just spending all my time ideally at home. My communication skills were not affected as I could still speak on the phone. I do use the internet and connect with everyone through WhatsApp. In my area, network connectivity is an issue. I still learnt to attend online meetings and classes and moved on. I started doing physical activities to make myself strong and healthy. I have faith in God and I pray for peace and well-being. I spend time with family and friends and all this helps me to stay positive.

With the help of my teacher at a special school, I explored options to study further as I wish to carry on post graduation. I have now bagged a scholarship I applied for to be able to study further. I am feeling much more relaxed now.
It was 1991. In the first days of the official beginning of summer, I was born to my dear Mom and best friend, Metka. I was given the name Nika. In childhood my family soon realized that I have a hearing impairment. At the age of five, I got my first hearing aids, which allowed me to hear the “whole world”. I lost my night vision at puberty and later my peripheral vision. At the age of 28 I found out why and that I am a person with deafblindness.

All of this has shaped my life. There is always a lot going on for me but I like peace and quiet as well. I love sports, music, dogs and books with educational content. The sea, the view of it and contact with it always calms me down. I also feel great in the meadows amongst the flowers and on hikes in the mountains. The time we found ourselves in honoured me with extra time to enjoy all the things that I love to do, while also teaching me about important life lessons and opening up new perspectives on the world.

When I first walked through the streets of Maribor, the town I live in, after a week of a lockdown, I could hardly believe that my lungs breathed freshness between the apartment buildings. On the streets I saw cats sitting on benches and roads, instead of walkers and masses of cars. The dogs on the walks wagged their tails so happily that they created a draught that immediately drove away the bad thoughts. The birds generously sang the most beautiful melodies they can. Maybe not everyone saw the same thing, but the time we found ourselves in the spring of 2020 presented to me a new picture of how our world can be even more beautiful.

Speed, ignorance and robotism have been our daily routine and that system has prevented many people from doing things for themselves. We got so far thinking that something like illness, transience and fear had to happen, that people started to be a little more grateful. Many people were finally able to do the things they had been putting off for years – either tidying up the closet, hugging their children, husband or wife or taking a breath and resting, calling their friends.

I am aware that for many people this time did not bring beauty and joy, which saddens me. For some people a lot has changed and they can’t recognize anything good in the situation. A different mind-set has led to divisions between people, more violence in families and suicides of young people. The elderly are isolated in old people’s homes, many have lost their loved ones, people lost their jobs and poverty and hunger have increased greatly. All of this forced me to become even more active in helping more vulnerable groups. Sometimes I get angry at all these closures and ridiculous measures and big ambiguities which lead the country and individuals to ruin, but at the same time I prefer to turn my heart to the good and give my co-workers a nice word, buy flowers for my mother and thank her for giving me life. I call my friends and take them for a walk in nature, I help my neighbours with housework.

Perhaps we are to blame for all of this or we simply do not know any different. I wish you all to find your peace. I have dedicated this time mainly to myself and now I am even more aware that I will not give my time to strangers ever again. I spread love and good will and thus successfully overcome the Covid time. Though I already used to give a lot of focus to relationships, myself, surroundings, nature and animals before, I appreciate this even more now.
Tanja's STORY

My name is Tanja and I come from Slovenia. I am a deafblind person. I have Usher syndrome, a genetic defect that affects vision and hearing. I was born completely deaf. At the age of three, I had a cochlear implant implanted. I can hear well with the implant, as long as it's not too noisy. My visual angle is narrow, even the rest of my vision is getting worse. I see about as if you look through a straw.

I like to spend my free time doing sports. So I cycle, go for walks, swim, ski. I also train sport paraclimbing in the B2 - blind and partially sighted category. Since 2013 I have been participating in international paraclimbing (sport climbing for athletes with disabilities) competitions. The success I am proudest of is winning 2nd place at the World Championship in Spain (Gijón) in 2014 and 3rd place at the World Championship in Austria (Innsbruck) in 2018. In the same year I also received the title of athlete of the year among people with disabilities in Slovenia.

Initially the situation with coronavirus was that we have all been pretty scared in early March 2020, because we did not know what to expect. In March in our country there was a complete closure of stores that do not sell food, schools, gyms, service activities, restaurants, religious ceremonies and many companies decided to work from home. Also going out of the municipality of residence was prohibited. Wearing masks has become mandatory in all closed public spaces, as well as keeping a safe distance and disinfecting hands. They also restricted socializing in public places.

I really like going to grocery stores and look for products at a discount. This way a lot of money is saved and that gives me joy. Unfortunately, due to the pandemic in March, I completely ruled out going shopping. It seemed dangerous to me, as I find it difficult to maintain the proper safety distance by myself.

We didn’t have any particular problems with the virus at the time, summer came, things calmed down, also measures were largely released. But in October the situation began to deteriorate. The measures have been tightened again. The night curfew also came into force.

I was the saddest because all paraclimbing competitions were cancelled in 2020 due to the pandemic. What bothered me the most is that for a few months we did not know if the matches were just postponed or they were definitively cancelled. By the International Federation of Sport Climbing there was almost no notifications about the matches, when they will be, if they will be at all. Of course regarding the situation, it is understandable, that the organization found itself in a situation that it was hard to predict the future for a few days ahead,
let alone for a few weeks. The most painfully was waiting for news and monitoring the situation around coronavirus. I did not know whether to prepare for match or not and how to adjust training. There was also less motivation to train. I realized that matches mean a lot to me. In the Spring and Autumn also the individual training sessions with the trainer at the climbing centre were cancelled due to the closure of the centre.

In 2020 I also had eye problems. I was upset by the fact, that in March a hospital check-up, which I had been waiting for months, was cancelled. Everything was delayed for two months.

In addition to the pandemic, year 2020 was important and different from the others, as the right to personal assistance was granted for me as I am a deafblind person. In March, just before the coronavirus epidemic, personal assistant Tanja started visiting me. Tanja is of a great help to me at everyday tasks. We go to the shops together, where she helps me to read the product declarations and she helps me at preparing food. She reads daily news and advertisement to me. She accompanies me to the doctor, to trainings, to gatherings of the deafblind in The Deafblind Association of Slovenia DLAN in Ljubljana. She rides a tandem bike with me. She also helps me with communication with other people. Sometimes we just chat and exchange our opinions. This is how she helps me to drive away the boredom. I am grateful to have personal assistance.

In short, it was necessary to get used to the situation and accept it as it is. The fact that for the most people athletes around the world was the same, was a consolation to me. For this year matches are already on the calendar and I am looking forward to them immensely. I hope Covid will not thwart our plans again.
Hi, I am Shrutilata Singh from India. I have progressive deafblindness. Earlier I used to hear well but slowly lost my hearing and now I cannot hear any words. I can still read using a digital magnifier. Before the pandemic broke out, I used to go out and interact with people either through sign language or palm writing. I used to go out for shopping with friends but now things are different.

I can read messages in Whatsapp using the magnification option and my only way of communication was through text but it causes lot of stress if I have to use the phone for long hours and I also tend to make too many typing errors while typing. So I started sending audio messages and received texts to read and reply. Communication wasn’t an issue but, since I had joined Sense International India just after lockdown, managing my work only through my phone, with just 5% vision, caused a lot of stress. I stayed connected with other people as well using my android phone only, which again caused stress on my optic nerves. In the beginning it was OK and I thought I would soon work from an office using a desktop computer. But unfortunately it didn’t happen and I started having severe headaches. It was enough to scare me as I was afraid that one day I might wake up and find my vision gone, so I had to take control of the situation.

It had been seven years since I last used the internet on a laptop and with even lower vision it wasn’t easy for me to work from home. I arranged to have a laptop and with guidance from my sister and colleagues, and that too through messages only, I was able to slowly adjust and learn. Initially it was very frustrating but with each small success I became more confident and enthusiastic. This experience helped me to focus on positivity. I was not suffering but learning to be more and more independent.

Amid the Covid 19 pandemic, social distancing is recommended to curb the spread of Coronavirus. While we acknowledge that the guidelines are for our safety, the question arises, “How would persons with deafblindness communicate their needs with others while observing social distancing?”

Deafblind people are having the toughest time of their life as they mostly rely on tactile communication which requires them to use touch. Social distancing in such situations becomes very difficult.

Given the stay-at-home order by the government, companies around the world have switched to remotely working from home using various platforms like Skype, Google meet etc. For those who have difficulty using technology on their own and have multiple disabilities, adapting an online platform has become difficult for them. Lack of interpreter guides due to the current situation prohibits deafblind people from accessing information shared across such platforms.

I was in Ahmedabad before lockdown but luckily went home to Himmatnagar just before the lockdown, advised by my friends for my safety. So I didn’t face any other problems as my parents were able to take care of everything for me. Since I could not go out shopping in malls or take a stroll in public gardens, I started
using my time for other things. I don’t like cooking but still tried doing it and also started helping Mom around the house. I love reading so ordered a few books to read during weekends. At times I felt restless so I started doing Yoga which helped me calm down and focus more on positivity.

I am in continuous touch with family and close friends, as we share jokes and we laugh, making fun of the most serious things and that’s how these months are going by. For me this pandemic brought a positive change which was very much needed. I was able to stay with my family for a long time after almost eight years. I learned to look for new ways to do my things. I learned to be calm and content with whatever I have. I have learnt to take care of my health. I learned to be thankful for whatever I got. It’s a story that I lived and it’s a story that I tell everyone and it’s this time that I cherish.

I just want people to be aware that a person who is deafblind has a much harder time in the world today, so let’s get through this together.

**Shruti’s STORY CONTINUED**
In March 2020, Covid 19 first started circulating around Australia and by mid-March, the nation was sent into lockdown.

We still had some movement but it was only for exercise, shopping, medical treatment or going to work (if you couldn’t work from home).

Our Deafblind community was hit hard, all social group gatherings were suspended and we had to stay home for a period of time. By mid-June, Australia came out of lockdown and all the states were left to do their own lockdown if needed.

Unfortunately, though, my state (Victoria) was quickly sent back into lockdown and we were given the harshest and strictest restrictions around the world. This lasted for some time and the Deafblind community here became a lot more isolated as a result, more services were suspended and Communication Guides could only work with one Deafblind member per day.

During this set of lockdown, we have been training our Deafblind members to use Zoom and had a few Zoom catch ups. Although most struggled due to accessibility issues and the greater need for tactile supports, it was fantastic to be able to learn to use other forms of technology to catch up with people.

Masks became an essential part of life during this lockdown. Amongst the Deafblind community, there was a lot of discussion and debate regarding masks, especially with those who require facial expression and lip reading for communication.

From a personal point of view, I was uncomfortable about the thought of wearing a mask. After trying it out with support from my Communication Guide, I felt more confident in wearing a mask, to the point where I’ve bought my own masks online.

A downside to the restrictions, in my personal opinion, is the fact you have to be socially distanced from everyone. As a Deafblind person, I have found this to be challenging at times. I still hold on to my Communication Guide’s arm but I’d be a couple of steps behind them in order to limit contact.

Post lockdown, we’re slowly getting back to “Covid normal” and have started getting Deafblind members back out in the community again.

If this pandemic has taught me anything, it has made me feel a lot more confident using Zoom, talking on the phone (when I’ve had supports and therapy sessions via phone) and also recharging my life and finding new hobbies and things to do, such as learning to use Uber Eats, listening to music and podcasts, chatting to friends on Social media and learning to be a lot more aware of Covid 19.

In closing, one of the positives I believe this lockdown will have is that Deafblind organisations’ staff and Communication Guides around Australia and even around the world will get a greater understanding of the word “Isolation” as this is common within the Deafblind community, so they will better understand our usual experience.

I believe that, post Covid, there will be a lot more awareness of the needs of the Deafblind community and that service providers will start to open up more services and opportunities for Deafblind members to prevent further isolation.

Second and final thoughts are that it would be a good idea to undertake research around the members of Deafblind International and put all ideas about social distancing and Covid restrictions together and do research about what worked and what didn’t work, so we can put a plan in place so that deafblind people are well prepared to handle future pandemics.

An idea would be providing workshops at DeafBlind conferences.
My name is Raed Alshalli. I am hard of hearing and visually impaired. My hobbies are football, drawing and movie making using 3D animation on the computer. I really like to draw with pencil on paper. I was born in Damascus (Syria). My family and I live together. They are not deaf except for me. I had no hearing aids or cochlear implant (CI). I was seeing well between 2000 to 2009.

When I was 7 years old, I did not go to a school for the deaf, because it was so far away. We did not have a car. That was unfortunate. I went to a normal school. I was not happy there, because I couldn’t listen to teachers or students and I cannot communicate with the hearing students. I didn’t have any friends in this school. I learned very little, like writing or maths. But I had a best friend. He is my cousin. He is hearing. He knows how to communicate with me.

When I was 9 years old, I had bought for me two hearing aids. It was a strange feeling. After that I started studying in school and I got better than before.

When I was 10 years old, I missed my right eye, because someone hit my eye for no reason. After he hit my eye, I saw the shape of the retina. For almost two months I went to the hospital. After the operation, my retina was removed. But it was still not good, because it is difficult to read. Several times I had an eye operation, but it didn’t work. My eyes got very weak and I couldn’t go on any longer.

After about a year and a half, the civil war began and I could not study in school, because it is dangerous there. Then we travelled to the Netherlands. It is safe there. After a long time we lived in the camp and then at home. For the first time I went to a Dutch hearing school. I tried to learn, but I feel uncomfortable. I cannot follow the teacher well. After this year I went to a school for the deaf, but I feel insecure. Because I never had experienced communicating with deaf people. When I learned the Dutch Sign language I felt happy, because I can follow the conversation. And I can communicate with my other students.

My family and I have lived in a village named Renkum (in the Netherlands) for 5 years now. When I was little I wanted to become a painter but I was rejected, because after the person hit me in my eye, it has been difficult for me to see well. But I search for my new future. It is making a Three dimensional (3D) animation on a pc. This suits my eyes. This computer can make the letters bigger, so I can read the text.

It doesn’t matter if you’re deaf or hearing to do what you want. Mindset and standing up for yourself are more important for reaching your goals.
Nikhil’s STORY

Nikhil is a talented young man who likes to engage in art and craft activities. He has won many awards and is an active participant of the online meetings of Sense India adult deafblind network, ‘Udaan’. He takes pride in sharing his paintings during these interactive sessions and has used his interest very well to keep himself busy during pandemic.

Hello friends, I am Nikhil from Assam, India. I am 18 and have progressive deafblindness. I caught Rubella when I was born and had a cataract in both eyes. When I was 2 months old, I underwent surgery for correcting cataracts. Now I have almost 50% vision and hearing loss. I face difficulty while crossing the road and hearing the teacher in the classroom. Now my classes are online and I can attend them. I am able to speak well.

I loved attending all my classes and learned to use the Zoom app for online. I also attend many events online and I am very happy to share that my progress was very good during this time. I love to draw and I have been drawing and sketching in all my free time. I made many birthday cards, a Mother’s Day poster and many other cards. I also took part in virtual art competitions. I made a painting on the theme “How Earth looks in 2050”. I won 3rd prize in this event and was honoured by the Government of India.

I also attend English access classes and I am improving my English through them. I use the internet to find out information about Covid 19 and all the latest updates. I share all this information with my family members and tell them about precautions. I also tried gardening during this pandemic and loved the experience. During Diwali I tried making ‘Rangoli’ art and it was very exciting for me. I also coloured about 100 earthen lamps and decorated them. I loved each and every moment of the pandemic as I spent all the time with family and was also learning and sharing with them. But there have been a few things that I really missed during this time.

I miss going to school and interacting with everyone physically. My physical activity has decreased as I am at home all the time. I could not go out and go for shopping because of the fear of getting the coronavirus. I couldn’t go to an ATM and learn how to withdraw money but still I learned many things and I am very happy.

I hope this time will pass and I will be able to do other things as well.
Divya’s STORY

In the year 2020, the pandemic screwed everyone up. The pandemic changed my life so much because I was frustrated with the lack of accessibility, lack of independence, and having to face many difficult challenges in many ways. I am living with my hearing parents to help take care of them. I do have a hard time communicating with my parents. They do know a little sign language but not much. My younger, hearing siblings live on their own. Our family uses WhatsApp for group communications.

Part of the problem causing a lack of independence is lack of transportation. I used to be able to use transportation such as the paratransit, Uber, Lyft, etc. to go to work, meetings, or social events but now, with the pandemic, I have some safety concerns. How can I trust the drivers? What if they have Covid? Are they cleaning in between passengers? What about social distancing within the car?

On the other hand, I now have to depend on my family members to drive me around if I need. I am hoping when the pandemic is gone I will be able to ride on those transportation systems independently again. It is also difficult to see my fiancé who just moved to Orlando. Transportation makes it hard.

My fiancé and I are hoping to find a place to live on our own as we explore the new challenges with being independent.

I am currently working from home for a local government office in Orlando. I am only working two days a week right now. It is a challenge that I do not have any kind of accessibility to do what I need for working from home. Part of my job is to assess if various websites are fully accessible to all disabilities. I used to be able to walk to my boss’s office or talk with someone easily if a change needed to be made. Now, I have to send things electronically to the team to change them. I feel like there is very limited communication since the pandemic. Also sometimes work goes so slow and sometimes work is so busy. The important thing is that the City Hall of Orlando team is still learning how we all are facing a lot of change in the new system compared to when we used to have work in person.

The lack of a social life is becoming a huge problem. Before the pandemic, I felt isolated and lonely. Now it is even worse. My entire social life is on an electronic device. Some people prefer using telecommunication, some people prefer video chats, some people prefer Zoom meetings. With each service, I have to make sure what I can do to accommodate and ensure accessibility so that communication is equal for everyone. For example, when I have Zoom meetings, it is pretty challenging to have the interpreters. I have to watch the interpreters translate everything for me rather than watch the other people in the meetings so I cannot see their faces or reactions. I feel as though I am a limited participant in Zoom meetings because I am constantly trying to watch the interpreter rather than participating and contributing my ideas. I feel like I have forgotten some people’s names and faces forever. I have not seen them or even been in touch with them. I have a social limitation: my family and my fiancé plus his family are the only ones I can spend time with.

During the pandemic, I became lonely. Staying home and feeling so bored, I decided to keep busy doing some fun projects, exercise, doing yoga, visiting my younger sister to spend time with her at her place, playing some games with my parents, and doing advocacy for the Deafblind communities at city, state and national levels. I do what I can to keep myself busy.
Pushpa’s STORY

Pushpa comes from Delhi in India. She is doing her graduation in Arts and is associated with the Sense India supported deafblind program. She likes to go to the gym to exercise and has won national and International medals in Paralympics in weight lifting. She loves interacting with people and has been participating in activities like the marathon with Sense India support. Things were going good but suddenly the pandemic changed it all as follows:

Hi, I am Pushpa from Delhi, India. I am 21 years old and pursuing graduation in Arts. I have progressive deafblindness so currently I depend on large print books for my reading and I use Sign Language to communicate, which I learned only recently. At first I could not understand what was going on. I was scared as I heard many people were dying and we all were locked in our homes with nothing to do. Within a month, I got very much irritated as I was not allowed to do what I wanted to do. I couldn’t even go to the gym and exercise and it resulted in my gaining weight. It irritated me further. I got bored sitting at home all the time and I had no equipment with which I could exercise at home. My mother and sister were very tense for me as I became very moody and wouldn’t talk to them much. I would yell at them if I was not in a good mood. I became depressed. For the first time in life my classes were online and I didn’t know how to use gadgets, I couldn’t even understand anything in class. I used to get a lot of headaches and eye pain due to long exposure to a smart phone and laptop. This would make me lose my temper and I used to yell at my mom and sister out of frustration. There were a lot of messages on the WhatsApp group of my college and most of my time went in reading those messages. I became fully dependent on my elder sister and younger brother for my classes as I could not operate the laptop on my own. Although I had my family with me, I was still feeling depressed because I was handling so many problems together. I hated that time and used to cry a lot.

I started doing other things to calm myself. I loved drawing and so I spent much time drawing different things. Success in these small things makes me calm down. I started communicating with other people by sending messages on WhatsApp and also through “Samsung good vibes”. Since now I was home all the time, I taught my sister and mother how to sign and I am very happy that now my communication skills with my family have improved to a great level. I also love reading comics and romantic novels. I would watch Korean drama and me and my family would laugh together at scenes. We were having a lot of fun.

My family tried everything to keep me happy. My mom and sister always say “All is well.” This is dialogue from the movie 3 Idiots. They would tell me to focus on my activities and things would be better soon. During Diwali I tried making a flower garland and ‘Rangoli’ art. Oh dear, it was so exciting! My favourite was learning new drawings using Google.

We all did struggle a lot but in the end we enjoyed being as a family and created the best memories together which is the most precious of all memories I have because I was with my family full time and we shared all our struggles and joys. We learned together and became strong together.

I also tried many new things during this pandemic as I now had a lot of time on my hands. I would try my hand at cooking and make different dishes of different cultures and my family had to eat it whether it was good or not. I also tried writing with my left hand just for fun and learned it. To be able to attend my classes independently, I also learned how to use a laptop and to type on it. I used to try different hairstyles on my sister’s hair.
Waqr’s STORY

Waqr is a positive young man who wants to start doing a job soon to support his family. He is trying to complete his education after he finished his training and academics at the Sense India supported deafblind program. Lockdown due to pandemic has brought uncertainty in his life but he is trying to overcome the challenge through his positive attitude in life.

I am Waqr Ahmed from Delhi, India. I have about 60% hearing loss but I am able to hear with the help of hearing aids. I also have about 90% vision loss. I can read using magnification. I am currently doing a diploma in a Special Educator’s course after which I had planned to opt for a mainstream teacher course. Everything was going on well before this coronavirus came into our country and nationwide lockdown was imposed. I had only finished first year and was stuck at home, clueless about how to proceed. I learned to use online medium to attend class. I learned it late and with some difficulty but now I am independently attending all my classes and learning.

My family was also going through a lot of issues and it was tough for each one of us but we were happy to be together. In my home only ladies used to do household work but in the pandemic I too did most of the work and was able to give them some break. My whole family were together in all our struggles and we helped each other and spent all possible time together. We enjoyed it a lot. We stayed strong although we had a lot of financial struggles. We were taking all precautions during lockdown and followed all guidelines shared by the health department. I also spent time with neighbouring children and taught them online during this lockdown as I was doing the Educator’s course so I felt it was my duty to help other kids with their education. It also gave me self-training on improving my teaching skills.

I am very grateful to my parents who were with me to face every barrier together. I love them a lot and want to help them. I wish to complete my studies soon and get a job so I can take off some of the financial burden from them and I would be able to give them some break. I am happy about the fact that people are able to cope with the situation just like I did. There was not a single day I got depressed as I always think the positive way, there’s always daylight after a dark night!
My name is Emma, I am 14 years old and I live in Hertfordshire with my mum, dad, younger sister and my buddy dog called Luna. 

A normal day for me would usually be going to school and then doing different after-school activities. On weekends, I would typically go out with my family into London, go bowling, eat out in a restaurant, meet with relatives and friends from outside of school.

Last year everything came to a standstill and we were told to stay home to avoid catching and spreading the virus. 

This meant I couldn’t go anywhere, my school and clubs closed. My dad had to work from home and my sister and I were being home-schooled by our parents. The internet was the only way to communicate with others and as it was being used so much, it put a strain on the connection. My mum continued working during this time and sadly, like others, caught Covid. She had to isolate and we couldn’t spend time with her. I was very sad because she was bed ridden. Restrictions continued across the country but things started to look up. My mum got better and in July 2020, I got a buddy dog called Luna. Welcoming Luna to our family brightened things up. As a family, we spent lots of time together during lockdown and had fun playing games, doing different virtual quizzes and cooking. I enjoy cooking and explored new foods and recipes. Across the country people did their best to help others and lift their spirits by organising food parcels and clapping for front line workers, and Captain Tom Moore raised lots of money for the NHS by walking laps in his garden.

We’ve had several total lockdowns and during these times I haven’t been able to see my grandparents and extended family, but we have been able to FaceTime. I’ve also been able to continue some of my activities over virtual platforms. Over Christmas, we went back into lockdown, which was disappointing but thankfully we were able to open our presents with our grandparents over FaceTime. After Christmas our schools didn’t open. I was sad because I’d spent so much time away from school last year. This time round though school organised for my lessons to take place on a virtual platform called Microsoft Teams. This meant my lessons were delivered by my teachers and the day was structured like a normal school day. Because the lessons were live I could understand the content being taught.

Many changes have been introduced to keep people safe since we were told of the virus. For instance, all non-essential businesses had to close, people worked from home, travel was banned and social distancing was introduced. When I returned to school in March, my school implemented a one-way system and made it compulsory for all to wear masks. Sanitising stations are everywhere and we are reminded to sanitise our hands, windows and doors are kept open to ventilate the classrooms and we are doing weekly lateral flow tests which determine whether you have covid or not. Doing the tests makes me and others feel safe and reassured that we can go to school and not contract and spread the virus.

Last year no one knew what was going to happen, but now we have a vaccine to fight the virus. This year in the UK 3 million people have received it and with this news I look forward to doing the things I was doing before.
Ravinder has been associated with the deafblind program of Sense India in Delhi. He is employed as probationary officer with a state bank and has to travel a long distance daily to attend his duty. He is aware of his right to reasonable accommodation and is actively pursuing his case with the authorities to seek required support in delivering his duties. The pandemic affected his daily life and his story is as follows:

Hello, I am Ravinder Jadhav, from Faridabad, India. I am 26 years old. I was born with some level of hearing impairment for which I had to use hearing aids. When I was in college, I started losing my vision due to Retina Pigmentosa and Macular Degeneration. I am able to hear with the help of hearing aids and speaker devices. Right now, I can read big fonts only. I am a banker by profession in a public sector undertaking. I carry out my daily routine and work independently.

Since the Covid 19 pandemic started and lockdown was announced in our country, my daily routine also changed and impacted on me very drastically. My communication with others was not an issue as I could hear using speakers and was allowed to work from home for some time. I stayed with my parents so didn’t faced many problems. I switched completely to online shopping whenever I needed anything to avoid physical contact and maintain social distancing. I have many hobbies so I engaged myself with my hobbies all the time. I spend all my free time reading online audio books, surfing on the internet, listening to music and dancing. Throughout the lockdown time I kept in touch with all my friends, family and relatives as I would call or message them. Talking to people always makes me feel much better. Because I am a banker, working from home is not an option. My office is 53 kilometres away from my home and that’s the main challenge during this pandemic (as there is no mode of transport available on the roads).

I used to take public transport to reach my office but now social distancing has to be practiced and there is unavailability of transport. People have stopped helping now because they are afraid of getting Covid infection. Even family, friends and neighbours don’t help. Because of low vision, I cannot drive a vehicle. Now I have to take a private cab for which I depend on online service. It is very much more expensive than before Covid but I do not have options.

I stayed positive all the time and kept hoping things would be better soon so I could start travelling without the constant fear of getting infected.
My name is Lury Moraes Eminergídio, I'm 26 years old and I was born in Brasília on March 6, 1994. My school life started when I was 5 months old, when they found out I was blind, because I was born with a cataract. My parents helped me with concern and supported me. At the same age, I couldn’t sit or walk and I had a lot of difficulties in getting around and developing. I started having a seizure at 7 months. I had audiology and they discovered deafness. I was 3 years old and, at 12, I had depression because I lost my left eye that I could see a little with, with retinal detachment. It was very difficult. My mother had Cytomegalovirus when she was pregnant.

I finished high school together with deaf people and listeners; it was very important for my story. I studied English and in 2016 I passed the LIBRAS / Portuguese entrance exam at L2 and I entered the undergraduate course in Brazilian, with Portuguese Sign Language as a second language. The first deafblind student at the Federal University of Brasilia, I want to do a master's and a doctorate to help the deafblind and the project can help new research. I can never give up.

I feel safe together with my family and I only leave home when I have an obligation. I use a mask to protect myself and to avoid the pandemic environment. I really have difficulty understanding it but I received the news from my mother and she explained to me that things were closed. I am deafblind and I use tactile Libras. Everything was happening, but my academic life had to change.

I started studying on the Internet platform. My mother helps and I want to do a project to present for the master's degree because I want to have my future profession; to be a teacher. The social environment and contact with communication in LIBRAS is my life project. I graduated on August 5, 2020 and, as it couldn’t be in the auditorium, I had to cancel. The main objective is to go deeper to have my own ideas and during the pandemic period I had to find out how to get into class, on the platform. At home I sit together with my mother and we study. I was doing Libras and my mother was interpreting for the teacher and also making tactile LIBRAS teaching material for the teacher.

But in social life there’s nothing like this pandemic. I’m here at home, travelling by plane is dangerous and sometimes we go out in a car, but everything has a right time and I never stopped washing my hands and wearing the mask so I wouldn’t be infected, using the alcohol gel too, and when you leave and arrive, you have to bathe and change your clothes. You have to be protected from the virus, the main way to care to avoid problems and harm to your health.
Deafblind International Youth Network activities in Switzerland, France, Australia and England
The Deafblind International Youth Network (DbIYN) is part of a group of specialist networks that are recognised as one of the core activities of Deafblind International.

The youth network provides a global platform from which young deafblind people can form peer group friendships through experiencing a range of network events including holidays, short breaks, exchange visits and participating in conferences.

‘A Glimpse of our Covid World’ is a collection of personal stories from network members about their experiences of living through a pandemic. For more information about the youth network please contact the coordinator Simon Allison simon.allison@sense.org.uk

Previous publications from DbI Youth Network ‘A Glimpse of our world’