



# The experience of persons with disabilities with COVID-19

**A short qualitative research study**  
carried out between 1 May to 5 June 2020

*The moment the pandemic hit, the principles of 'leave no one behind' and 'reach the furthest behind' evaporated into thin air. Persons with disabilities and older persons have been left to die, often not because they contracted the COVID-19 virus, but because of the situation the pandemic created around the world and subsequent effects. **It's time to build a better world!***

*“I find the most complaining are persons without disabilities, who experience barriers for the very first time, like not being allowed to go outside. But maybe this situation contributes [for them] to understanding inclusion better.”*

*“We carried out a survey a few weeks ago when the pandemic began and it was notable that families’ concerns above all were on the health of their children with disabilities and them not acquiring COVID-19, followed by the education of their children and finally the economic issue. We carried out the survey again a few days ago and priorities are now the opposite. The priorities today for families are economic income, then education, and ultimately the health of their children with disabilities.”*

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## EXECUTIVE SUMMARY

This report is a qualitative research study carried out by the Stakeholder Group of Persons with Disabilities in May and June of 2020 to gain information on additional and new pandemic-related barriers that persons with disabilities encounter. The study aimed to complement existing COVID-19 efforts by gathering data from (1) semi-structured interviews with open-ended queries with leaders from the disability movement, (2) empirical data collection from regional focus group webinars to collect testimonials, and (3) empirical data collection and analysis of organizations of persons with disabilities in three countries in Latin America. The data were gathered around thematic units related to the global pandemic. These seven themes included living situation, safety concerns, home life and housing conditions, health care, social protection, employment and COVID-19 disability data.

Qualitative data reduction techniques were applied to synthesize and organize raw data from interviews, focus groups and public documents using content analysis. Gender, age, disability type and geographical representation were well balanced among the participants. Twenty-eight people with disabilities were interviewed in six languages, including International Sign. In addition, 65 people with disabilities from 54 countries participated in the focus groups.

Findings indicate that myriad barriers exist for persons with disabilities as a result of the pandemic, including additional and new ones. The most common barriers that emerged include: (1) lack of access to COVID-19-related information for all persons with disabilities, (2) barriers in receiving social protection measures and employment (formal and informal, losing employment first, and accessibility barriers in the virtual working environment) and (3) lack of disability inclusion in COVID-19 response efforts at all governmental levels, creating significant disconnections between national and local actions.

The report finds that most persons with disabilities around the world have been adversely affected by the pandemic in one way or another with additional or new barriers, including new barriers in the re-opening phase. As countries continue the management of COVID-19 as a public health issue, while also transitioning to open up economies and societies, removal of existing barriers and building back better are critical for future implementation of the Sustainable Development Goals.

A summary of recommendations discussed include to:

- Collaborate with and build on the International Disability Alliance and the International Disability and Development Consortium campaign and advocacy efforts to include persons with disabilities in COVID-19 response efforts;
- Advocate for accessibility for all persons with disabilities in all COVID-19-related matters and increase disability awareness by widely disseminating testimonials of persons with disabilities; and
- Develop a disability inclusion guide based on lessons learned from the pandemic for governments and local authorities.

This research had limitations due to limited time, shortage of human capacity, the inability to have in-person interviews and lack of funding.

Results from this study can be used in advocacy efforts to influence governments and bilateral and multilateral agencies to urgently measure the situation of persons with disabilities worldwide in the context of the COVID-19 pandemic. This can support the realization of disability-inclusive policies and programs to build back better, safer, resilient, and more inclusive communities worldwide.

## INTRODUCTION

In the light of the COVID-19 pandemic and its disproportionate impact on persons with disabilities, the International Disability Alliance took urgent action, produced and shared [key recommendations toward a disability-inclusive COVID-19 response](#). In addition, the International Disability Alliance and International Disability Development Consortium set up a joint advocacy group and communications campaign to urgently address the barriers and the range of risks that persons with disabilities face in this emergency situation. To complement this ongoing and important work, the Stakeholder Group of Persons with Disabilities carried out a qualitative research study to gather additional and new information on the impact that the COVID-19 pandemic has on persons with disabilities around the world. This study frames the findings and will be used at the upcoming High-level Political Forum to put the relevant Sustainable Development Goals, targets and indicators into a new light to address the situation of persons with disabilities today and in the future, post-pandemic.

## METHODOLOGY

In order to add to COVID-19 recommendations, the Stakeholder Group of Persons with Disabilities aimed to gain a better understanding of new pandemic-related barriers that persons with disabilities encounter. The Stakeholder Group of Persons with Disabilities attempted to complement existing efforts on gathering data by:

- Conducting online interviews with leaders from the disability movement to collect information;
- Organizing a series of focus group webinars to collect testimonials from different groups within the disability movement; and
- Carrying out qualitative research with organizations of persons with disabilities in Bolivia, Colombia and Guatemala to assess the situation in more depth in one region (for details refer to Annex II).

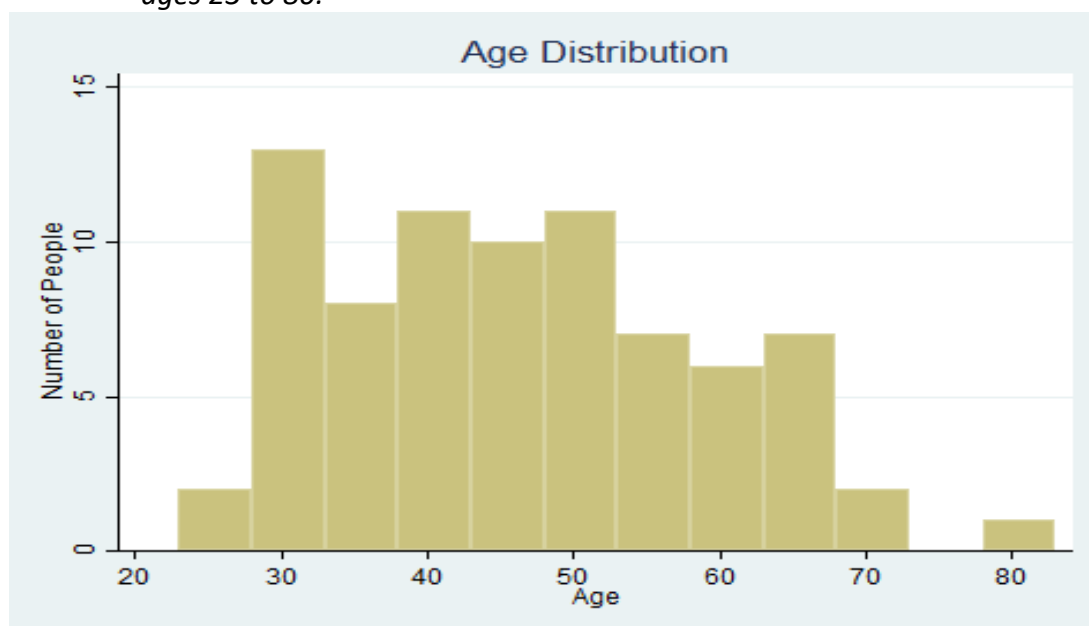
This project carried out qualitative research. The process of data collection occurred in May and the report was compiled the first week of June 2020 in different virtual formats, with empirical data collection using a semi-structured interview format with open-ended queries with persons with disabilities, empirical data collection from focus group discussions with persons with disabilities and document analysis.

All data were gathered around thematic units related to the pandemic. These seven themes included living situation, safety concerns, home life and housing conditions, health care, social protection, employment and COVID-19 disability data (for the interview questions, refer to Annex I).

All names, nationalities, and identifying characteristics of research participants were changed for their protection and confidentiality.

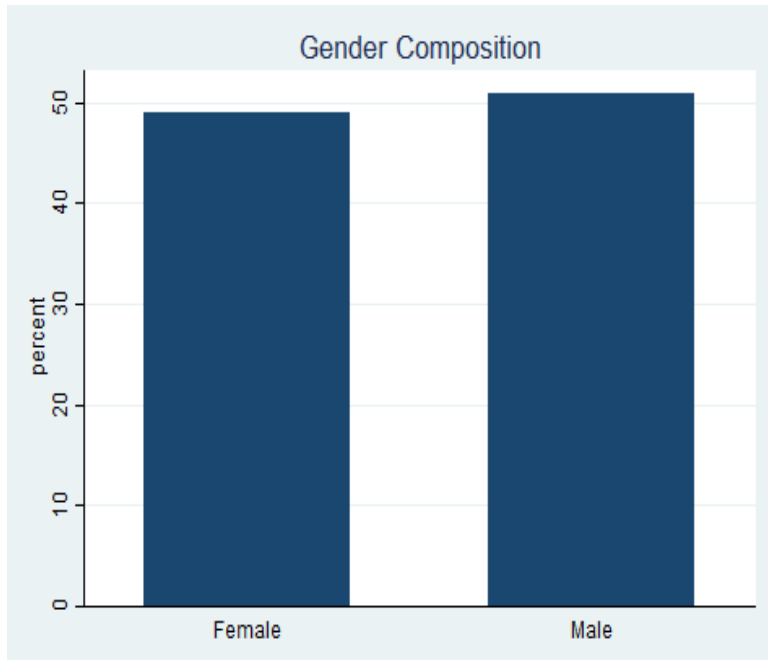
The data collected below is a combined analysis of all participants. The data has been collected and disaggregated. However, a limited number of participants did not provide details.

**Graph 1:** *The total number of participants was 106 people. All participants were between the ages 23 to 80.*



**Graph 2:** *54 men and 52 women participated in the interviews and focus groups. Age and gender were well represented and balanced among participants.*





It was a balanced participation between men and women in all regions.

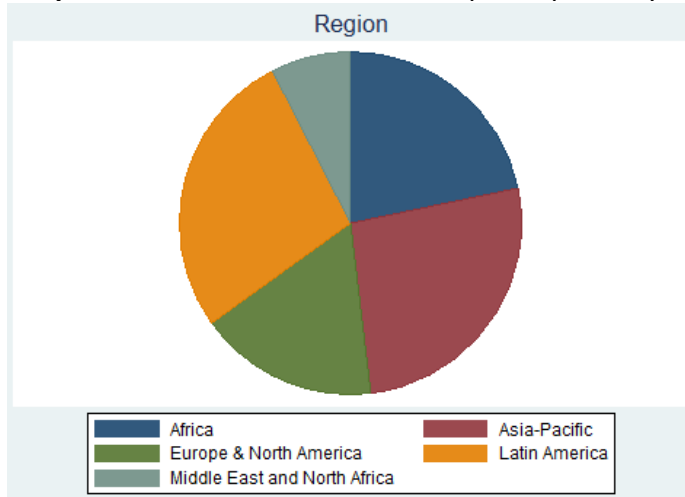
**Graph 3:** Gender balance of participants by region



Interviews were conducted with 28 people with disabilities in six languages, including Arabic, English, Hungarian, International Sign, Russian, and Spanish.

Four regional focus group discussions were carried out in English and Spanish via an online platform using real-time captioning and International Sign interpretation. Participants were from all regions from more than 54 countries and represented all types of disabilities. Specifically, 65 people with disabilities participated from 13 countries in Africa, 16 countries in Asia and the Pacific, nine countries in Europe and North America, 12 countries in Latin America and eight countries in the Middle East and North Africa.

**Graph 4:** Number of countries and participants by region



**Table 1:** Number of countries and participants by region

Region	Number of Countries Represented	Number of Participants	Percentage of All Participants
<b>Africa</b>	13	23	21.7
<b>Asia and Pacific</b>	16	28	26.4
<b>Europe and North America</b>	9	18	17.0
<b>Latin America</b>	12	29	27.3
<b>Middle East and North Africa</b>	8	8	7.5

Qualitative data reduction techniques were applied to synthesize and organize raw data from interviews, focus groups and public documents using content analysis.

Limitations existed in this research due to a limited time frame, lack of human capacity, the inability to have in-person interviews and lack of funding (no outside funding was used to carry this out).

The data gathered and related findings are important to identify new barriers for persons with disabilities in the global pandemic. Results from this study can be used in advocacy efforts to influence governments and bilateral and multilateral agencies to urgently measure the situation of persons with disabilities worldwide in the context of COVID-19. This can support the realization of disability-inclusive policies and programs to build back better, safer, resilient and more inclusive communities worldwide.

## MAIN FINDINGS

The moment the pandemic hit, the principles of “leave no one behind” and “reach the furthest behind” evaporated into thin air. Persons with disabilities and older persons have been left to die, often not because they contracted the COVID-19 virus, but because of the situation the pandemic created around the world and subsequent effects.

Since the adoption of the UN Convention on the Rights of Persons with Disabilities (CRPD), followed by the adoption of the 2030 Agenda for Sustainable Development and its Sustainable Development Goals (SDGs), we have witnessed a positive development and change in the lives of persons with disabilities. Slowly, societies began to move away from the traditional charity and medical model approaches to inclusion, towards a social and human rights approach, granting persons with disabilities more rights than ever before.

The findings indicated that most persons with disabilities have been adversely affected by the pandemic in one way or another, although some in more grave ways. In particular, persons with disabilities who also have underlying health conditions, persons with intellectual disabilities who have lost support services and daily routines, persons with psychosocial disabilities with increased anxiety and isolation from being at home, deaf and hard of hearing people who have significant communication barriers due to masks, and persons who use personal assistants who have lost this service, or it has been reduced.

In terms of the global situation, cities have access to information on a daily basis, and in some cases with sign language interpretation in news briefings, but in rural and remote areas there is a significant lack of access to information adversely affecting the populations that reside there.

Then the COVID-19 pandemic hit, and the world changed; perhaps it has forever in some ways. The focus shifted to survival. In many parts of the world, such as some countries in Africa and Latin America, the lockdown triggered unemployment, hunger and famine. These barriers became the new threat to life, not the virus. This was exacerbated by the lack of hygiene products, medication, medical equipment, medical services and access to clean water and food.

New rules, such as social distancing, which in reality is physical distancing, and wearing masks that have been put in place to protect humankind, have also created new barriers for persons with disabilities. Kindness is being replaced by discomfort. Blind people fear people will guide them less, wheelchair users may not get a needed push up a street, fewer people will give hugs that some people need for a more balanced life. Deafblind people need to touch to communicate, and both blind and deafblind people need to touch items to maneuver more easily, deaf people need to see facial expressions for communication and hard of hearing people need to see lips to lip read. Persons with multiple disabilities and those who need daily support may lose their personal assistants and consequently could affect eating, taking medication, getting in and out of bed, dressing, hygiene, and many other daily basic needs.

The only positive outcome that emerged from the findings was that the role and work of organizations of persons with disabilities (DPOs) significantly changed and increased. DPOs adapted and adjusted to the new reality and provided vital support to members. DPOs supported their members, and also supported refugees with disabilities, indigenous peoples with disabilities and women with disabilities. Communication with members shifted via the internet or via texts on cellular phones. DPOs carried out an important role for the community, often to address the lack of support and information from the government. DPOs checked on their members, disseminated information, shared prevention and awareness tips in accessible formats, such as easy-read or video messages for Deaf community members. DPOs also distributed food and secured social benefits for members. In some countries, international organizations also assisted in providing food, masks, and other kinds of support.

The disability movement is in survival mode, more than ever in recent times. What has been achieved since the adoption of the CRPD and the 2030 Agenda is at risk. Inclusion has been disrupted by the COVID-19 pandemic and we are at risk of going backward. The pandemic has taken away the curtain, historical inequalities are deepening, and discrimination is on the rise, but we must fight for inclusion more than ever. Nonetheless, participants from the disability movement showed incredible strength, resourcefulness, collaboration and the power of the movement. The disability movement once again will prevail, learn lessons from and build on the shortcomings of this crisis. International collaboration, and targeted and earmarked funding are key for the way forward.

We can build back better and create a new inclusive world if we take proper action. While most of the study reflects on barriers and challenges, it is also important to learn from the positive examples and replicate them to create a future in which all can participate fully and equally.

## **MAIN FINDINGS THROUGH DATA VISUALIZATION**



**Face masks create communication barriers for deaf and hard of hearing people**



**Lack of accessible information for persons with disabilities, especially in rural and remote settings**



**Lack of access to medication, medical equipment and medical facilities**



**No information on institutions**



**Lack of disability data**



**No support services, such as personal assistants**



**Persons with disabilities were the first let go from work**

## **THEMATIC DIALOGUES ON COVID-19**

The following section reflects on the seven thematic areas that have been the basis for all interviews and focus group discussions. The same questions were used for all participants. A condensed summary of participants' answers is included under each subsection. The original questionnaire can be found in Annex I.

### **1. CHANGES IN DAILY LIFE DUE TO COVID-19**

*“The lockdown brought greater opportunities to talk about family and cultural heritage. As time is passing and I am aging, my disability will change, life will become more difficult. These days give me a deeper understanding of my disability and allow me to reflect with my family and their future roles.”*

The first set of questions focuses on changes that took place for persons with disabilities in their daily activities and whether these changes affected their wellbeing. Specific questions were asked about access to water and food and the availability and use of personal protective equipment. A subsection on access to information was added since this emerged as a recurrent theme from participants. A summary of the findings is grouped by region.

## Africa

### Daily life

In many parts of Africa, people live in communities and interact closely but have to travel long distances between home and work. In general, getting around and the lack of accessible transportation were challenging prior to the pandemic, but since then this has become an even more significant barrier. In some African countries, a pass was required to get from one point to another to cover certain areas. When services (such as medical doctors or members of DPOs) were located outside an area, visiting became impossible due to the blockades.

“As a person with a spinal cord injury who requires daily medical supplies, the COVID-19 pandemic has imposed extreme difficulties. The government was going to give medication and palliatives, but many people couldn't send somebody to pick up these items. Because the movement between states has been locked down, those who relied on these supplies were unable to order and have it delivered to them from one state to another.”

For some, restrictions on movement were perceived as imprisonment, which significantly contributed to wellbeing.

### Wellbeing

COVID-19 has had a significant effect on the wellbeing of many persons with disabilities. The lockdown has increased anxiety, and in particular the restriction of movement has been difficult to endure. Many people indicated that they were afraid and concerned that their lives were at risk due to the virus. For deaf people, there was increased frustration and embarrassment at not being able to communicate and understand others because of the requirement to wear face masks. New fears were reported, such as kindness being replaced by discomfort from others.

In particular, the deaf and hard of hearing people have been impacted by the order to wear masks. For example, one participant indicated that “I have an example of going to the bank. I had a lot of difficulty communicating with the man who worked at the bank because of the mask he was wearing. I asked him if he could remove it so I could understand him and he refused. This is a real challenge. I had another situation in a grocery store. A man came up to me and spoke to me and I didn’t understand him and he got upset. I explained that I am deaf, but this was very uncomfortable because everyone was staring at me. Another example is when I went to buy a pack of cigarettes. I needed to ask for a specific brand that I smoke. It is not easy to communicate with the mask and so I went to show the man working in the store which brand I wanted and he got very angry at me and I was told I wasn’t allowed to touch anything. It made me feel really badly and I had to calm him down, as he got very agitated.”

People with psychosocial disabilities have been quite affected by the pandemic. They already were dealing with many barriers and situations, and the pandemic added increased anxiety from the fear of getting infected with COVID-19. As a result, there has been a lot of fear, anxiety and depression. Some governments carried out interventions targeting persons with various disabilities, including persons with psychosocial disabilities. It was difficult for some governments to identify people with psychosocial disabilities since they are often invisible. As a result, DPOs took action and identified members since they know best where members are located.

Some participants indicated that people with intellectual disabilities had heightened stress and depression. Some individuals did not understand what was happening and little to no information was available in easy-read or easy to understand formats. Also, for some families it was difficult to communicate and break down information for members with intellectual disabilities. Furthermore, normal routines were disrupted, such as access to therapy sessions and education. Many people with intellectual disabilities rely on occupational therapy, physiotherapy and speech therapy in their daily routine and thus due to the pandemic have regressed.

“There is an issue around access to anticonvulsant drugs. Some people with intellectual disabilities have epilepsy, and therefore access to essential drugs has been a challenge to some families. With clinics being closed to access some of the drugs and all the focus is on COVID-19, families cannot access essential drugs for their children.”



## Access to water

In some parts of Africa and even within a particular country, especially rural and urban settings, the water supply and access to sanitation and hygiene was not guaranteed. In some parts, water was supplied via orders from text messages and then delivered.

“We have to clean our assistive devices, like the wheelchair or the hand rings of the wheelchair, because these are things that also can be contaminated. This has been challenging since the water supply has been limited.”

Some governments designated water tanks to provide water, but due to stigma, some participants were not able to compete with the community to fetch the water. Fetching water was done collectively as a community, but people deemed mentally ill by the community, had to wait to get their water.

## Access to food

This has become significantly more difficult. In most urban settings the food supply remained undisturbed despite some limitations that were put in place. In many urban settings, supermarkets had lines with long waits. Also, in rural areas, there were restrictions in accessing the market, which is usually the vibrant center of most African communities. As a result, families had to buy larger quantities of food, which was burdensome for many persons with disabilities to carry and transport home. The majority of persons with disabilities in rural settings had no access to food and instead relied on the social security system.

Many participants and their family members work as day laborers. They depend on a daily income to put food on the table, and because of the daily lockdowns, this has been a challenge. Many countries offered food packages, but in some countries, there was discrimination of accessing this food for people with intellectual disabilities.

Coordination of food delivery emerged as a critical issue. In most cases, either charity organizations assisted, or the local government worked with DPOs on distribution. This is important since many persons with disabilities were unable to leave their homes or government officials explicitly skipped houses with persons with disabilities. While engagement with DPOs has been a good solution to address such shortcomings, the government problematically relied on DPOs to carry out the work without compensation.

In many African countries, a large percentage of persons with disabilities, particularly women with disabilities, earn money on a daily basis from selling small items. Due to restrictions being implemented, it was not possible to continue this daily work. Consequently, for many, COVID-19 is not a threat as a disease, but one of survival. One solution to address this would be to provide microfinance revolving funds to women with disabilities who have business skills.

## **Access to information**

The findings indicated that there are many barriers to accessing information. In some cases when the government gave briefings regarding lockdowns, financial support and food distribution, the information was not accessible for many persons with disabilities, especially for deaf people. Deaf participants indicated that they felt ignored by the government, and it would be helpful to have support from international organizations.

Participants highlighted that generally in African countries, reaching out directly to people is the main way to convey information. In rural settings, often television and radio are not available, and there are also some challenges in accessing cellular phones. This has created barriers to access information, and consequently people were unaware of COVID-19 and did not receive important information and updates.

In many cases, social media was used as a tool to communicate and disseminate messages. For example, in certain parts of Africa, women with disabilities created forums to discuss what people were going through.

A participant shared the following:

“As an organization of women with disabilities, we conducted an assessment to document the experiences of women with disabilities with COVID. We realize that most girls and women with disabilities have little information about the pandemic. They were aware of the pandemic and that people have to stay home, but when it comes to protection measures and symptoms of COVID-19, they had no information.”

## **Personal protective equipment**

Masks and hand sanitizers were promoted in many countries as a preventative method against contracting COVID-19. Persons with disabilities overall made homemade masks and hand sanitizers since these items were not widely available and/or unaffordable. Even some governments were not able to meet the demands of the front-line staff in various hospitals and facilities. Often it was DPOs that provided sanitizers to its members, but it was challenging to reach all members across widespread regions. In some cases, buckets and wash basins were provided to communities to encourage the washing of hands but were not accessible for some persons with disabilities. This is because they were installed at a level either too high or too low.

Many people with intellectual disabilities could not obtain PPE. In some cases, international organizations distributed PPEs to persons with intellectual disabilities and their families, especially since there was not much effort from governments targeting persons with intellectual disabilities and families with regard to COVID-19 response. Many people with intellectual disabilities have preexisting health conditions and were worried because many clinics were closed, and they could not access other health services. This meant that the quality of life was really deteriorating. For example, in one country a number of families reported that

they went to hospitals and were turned down without any alternatives to access other health services.

## Asia

### Daily life

For some persons with disabilities, life has significantly changed, and this will continue for some time. For example, some blind and partially sighted people at times were unaware of important information such as how the virus spreads. This was vital information since blind and partially sighted people tend to rely more on touching surfaces to maneuver, which can increase the risk of getting the virus. As a result, many people were anxious about this, not only for the current situation, but because this could continue and become a serious issue for the future in the new “normal” way of life.

“I'm autistic and I've had to work very hard to go out into the community and talk to people and I've succeeded in that. With COVID-19 because I'm on my own, I don't talk to anybody and I'm losing that ability to speak. And the impact is that I also have other health conditions and have trouble getting help when I need it. So I'm even more isolated and that's true for quite a few other people I know as well. In many of the Pacific Islands, actual cases of COVID led to a panic. The whole country panicked and even the health department, the government came out to the community and tried to encourage community members not to panic themselves and to get the right information.”

### Wellbeing

The wellbeing of people with disabilities was impacted in different ways. Some participants expressed anxiety on how to effectively protect themselves from contracting COVID-19. This was especially pertinent for people who live far from the capital city and urban areas since there are more barriers to access medicine, hospitals and medical facilities and get tested. In some cases, if there were tests, they were unreliable.

People with leprosy are suffering disproportionately due to a double lockdown: They are restricted to their leprosy communities and they are also restricted to their homes within those communities. They are starving and dying due to other diseases in the absence of food and medical care. People with leprosy are saying that the world has forgotten that they exist.

“There is a lot of stress and depression because life is now very different than before. The pandemic affects my mental health from the constant negative news. My wife worries and then, her worry also affects me.”

...

“I'm an autistic person and in some ways, this has been a bit of a reprieve for me because of the fact that what everyone calls the old normal to me was difficult in terms of functioning. The amount of socializing and just a lot of things in the way the general typical society was running are contrary to the way I work best. And so, I have actually thrived in terms of being able to telecommute and not having to feel the need to always be out and be with people. For me personally, social distancing is kind of the way I would prefer to live my life so it does help.”

### **Access to water**

It appeared that most countries from the study did not have issues with providing access to water. One participant even indicated an improvement. “Normally there are problems with accessing water, but since the lockdown there is now always water in the faucet. So it has improved.”

### **Access to food**

In some parts of the Asia-Pacific region, in order to purchase food in a supermarket, people needed accessible transportation. Some people with physical disabilities had difficulty carrying groceries and there also was a shortage for some items, but largely food remained available. The challenges included widespread panic buying (which eased over time), large crowds, long lines, waiting outside and price increases for fresh vegetables and fruit, for example ginger and lemons. The latter made keeping a healthy diet more challenging along with budget adjustments.

In the Pacific, small islands often rely on transportation, such as ferries, to access food. With the pandemic, ferries stopped running and shops had limited hours, which created challenges with supply chains.

In Eastern Asia, people living in villages suffered the most since villages did not receive regular food and product supplies. Moreover, there was a shortage in agricultural work, which resulted in less produce being collected.

Other barriers included lack of accessibility. For example, in one country, supermarkets had different safety protocols put in place. One required that all shoppers spray their hands with sanitizer prior to entering the store, which was not accessible for all persons with disabilities.

Also, in a number of countries, personal assistant services were suspended during the lockdown, which made grocery shopping much more difficult, particularly when assistants typically gathered items for the person with a disability.

### **Personal protective equipment**

Overall, participants indicated that masks and hand sanitizers were difficult to obtain and there were additional costs, although washable homemade masks were a good replacement, and some volunteers distributed a limited number of masks.

When wearing masks, some people felt uncomfortable or suffocated wearing the mask. For deaf and hard of hearing people, there were communication barriers from people wearing masks, especially in rural communities where deaf and hard of hearing people rely on lip reading and facial expressions to communicate with their families. There was also a problem with discarding used masks and that they needed to be recycled or burned to stop the spread of the infection.

Pacific Islands communities are often tight knit, and as a consequence, in one example, there were no shortage of items as the community took care of its own people. People donated food items and hygiene products and then disseminated to community members. Community members also were provided with simple graphics and basic hand washing tips on how to protect themselves against contracting and spreading COVID-19. The community connected with each other and cared for each so community members would be less afraid about COVID-19.

## **Europe and North America**

### **Daily life**

Participants overall were not concerned about COVID-19 in terms of being a threat to their lives as a person with a disability, unless they also had underlying health conditions or were older in age.

### **Wellbeing**

Participants expressed both positive and negative aspects stemming from the pandemic. For some, life was calmer as it had slowed down and they could spend more time with their families and did not have to adhere to social obligations. Some people enjoyed the increased entertainment offered online, which helped to get through the period.

Others expressed fears, such as being exposed by personal assistants. So in some cases, those who could manage on their own decided not to have personal assistants. Others were fatigued since things that were typically easy became obstacles and consumed more energy. There was also a general fatigue and restlessness about going back to “normal.” People also often shared that at the beginning, they were anxiously and obsessively checking all of the updates going on

with the pandemic, keeping track of all the new numbers that affected wellbeing. For deaf and hard of hearing people, wearing masks has had an effect on mental health because wearing masks created a big barrier in terms of communicating.

“I have chosen to stay at home and do not go into the day-time institution. I am following rules that are shared every day on the news. But my emotional world has changed. I feel more clouded with negative feelings, I feel there is no end to this situation and the insecurity makes me desolate.”

....

“During social distancing, I am keeping up with more people than before the pandemic. We must distinguish between social distancing and physical distancing. Social distancing, you stay alone!”

....

“I have gotten stressed particularly because of the overwhelming media messages. After a week, I started to enjoy the situation due to the wealth of free online offerings, but going out is missed very much. It is sad, not depressing, I miss the travel lifestyle since I used to travel a lot.”

### **Access to water and food**

Overall participants did not have issues accessing water. Accessing food was easy for some and more difficult for others. In general, there was a shortage of food on some items that were high in demand, but only for a day or two. In some countries, food prices went up significantly, probably due to demand.

In some cases, charity organizations provided food to persons with disabilities and older people in collaboration with the local government. In other instances, people got support from family and friends. Some people had groceries delivered and set up deliveries in advance to avoid running out. But there was usually a much higher price for the service companies that delivered groceries. Other people were nervous about shopping and did not use delivery because of not knowing who was cooking and what measures were taken in preparing the food. In addition, there were issues with using the internet for delivery. In some countries, there was a priority list for persons with disabilities to receive online delivery. But, in order to get on the list, the individual had to call to register, which created a barrier for deaf and hard of hearing people who in turn could not register and did not get food delivered.

## **Access to information**

Access to information was an issue, particularly for deaf and hard of hearing persons. Participants indicated that lack of access to information impacted their lives and how to prevent getting the virus. There are many deaf people who were not informed on how to prevent COVID-19, did not know how to get in touch with sign language interpreters, and did not know how to wear PPE. This barrier was eloquently expressed by a participant:

“If you have a deaf person who is really ill and is requiring medication, they don't know how to do so. Who do they communicate with? Writing is not an option. Then there's the issue of if they do have PPE, how will they communicate? Then there's the expectation that you call on a telephone for an interpreter. There are 27 European countries, only seven provide a remote interpreting service and 20 do not make that provision. So how can a deaf person call to get their basic information?”

A positive outcome was that governments provided national sign language interpreters on TV and in different press conferences, which was a direct result of lobbying from national Deaf associations. Looking at the government acknowledgement of sign language, it is also importantly about the equality of information. In one excellent example of this, in Lithuania, the president of Lithuania stood up, looked around and saw no sign language interpreter. They actually waited until the interpreter arrived, and then started their proceedings.

It is important to add that while it is positive that interpreters were included in the media, there also must be a focus on individual deaf people having that right to basic information.

## **Personal protective equipment**

For many countries, especially in the beginning, it was difficult to obtain masks and hand sanitizers, there were limited supplies, and these items were very expensive. In some cases, people started to wear improvised masks, and in some countries, if a person was registered as a person with a disability, the government sent surgical masks, particularly to personal assistants.

Some people had difficulty wearing masks since it created communication barriers. Also, for some, wearing a mask for a short period of time was uncomfortable in terms of warmth, moisture and the pulling against one's ears. Deaf people who acquired COVID-19 and went to hospitals encountered significant communication barriers due to PPE. In some cases, they were not able to communicate with their families and friends, which caused fear and isolation. In one country, a deaf person was hospitalized because of COVID-19 and asked to use remote sign language interpretation (Video Relay Service) to communicate with his family, but the hospital declined to assist since it was not included in their budget. This significantly impacted the deaf person's mental health since he did not have the support from his family and friends.

“Persons with disabilities are treated equally or worse than older people. Some older people in recovery were sent back to institutions and moving far from protection.”

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“Vulnerability is the product of society. I am considered special. In an emergency I need more support than others because society produces more vulnerability to the disability condition. I became disabled because society treated me as a second-class citizen.”

## **Middle East and North Africa**

### **Daily life**

In many countries, people with disabilities expressed fear toward the pandemic and felt that their life and the lives of their family were in danger. They felt in danger because of the lack of health awareness and lack of commitment of citizens to quarantine, the weak health services, and living conditions, which increased the chance of spreading COVID-19. This was especially prevalent with people vulnerable to chest infections and other health conditions.

### **Wellbeing**

A number of people expressed that their religious belief helped their mental wellbeing. “There is no effect because of the faith of the chair of God and its ability to take reasons and prevention.” But also, busy daily schedules help maintain a good and balanced wellbeing.

### **Access to water and food**

Due to the diversity of the region, there were very different answers. In most countries, there was no issue with regards to access to food and clean water. However, some countries, due to some particular situation – being poor or being under siege/occupation – reported challenges in this regard. For example, in some countries in a region where water consumption is regulated. During the COVID pandemic, particularly during the lockdown period, the consumption of clean water, whether for drinking or washing, had become less available than before, and as such they had to rely on the use of medical disinfectants more than ever. Some people could not get the cleaning materials, gaskets, and protective materials purchased personally from the market.

### **Personal protective equipment**

Masks and protective equipment were often overpriced or not available. At the beginning of the spread of the pandemic, these supplies were exploited by some, and their prices doubled, but people had to buy them to prevent spreading the virus.



## Latin America

### Daily life

Overall many participants indicated that there was a lack of or delayed response from governments regarding services and support for persons with disabilities. This included an absence of plans for personal assistants if the person with a disability acquired COVID-19. Moreover, the emotional health of families was not being addressed. In many cases, organizations were taking action to address the gaps in government response.

### Access to information

The lack of access to the internet was an issue in accessing services and information, especially for indigenous people with disabilities in remote settings. In some countries there were issues accessing information in indigenous languages that significantly impacted indigenous communities, including indigenous people with disabilities in these communities.

Overall there was a lack of access to information due to lack of sign language interpreters in mass media and due to the lack of information in plain language and pictograms. In many countries there were interpreters on some public TV briefings, but not on private television channels.

### Personal protective equipment

Masks created barriers for deaf and hard of hearing people. For example, going to the supermarket or pharmacy there were additional communication barriers because the masks covered people's mouths and it was forbidden to remove them. Not being able to see all of a person's facial expressions - which is part of the grammar of sign languages - generated a lot of confusion and led to frustration. Often deaf people were asked to write, and this was not always possible or a good solution. Also, PPE was not often distributed to people with personal assistants who were unable to socially distance for basic needs.

## 2. LIVING CONDITIONS DURING COVID-19

*"The old normal was difficult in terms of functioning. The amount of socializing and just a lot of things in the way the general typical society was running are contrary to the way I work best. And so, since the lockdown I have actually thrived in terms of being able to telecommute and not having to feel the need to always be out and be with people."*

In this section, a set of five questions were asked to understand how persons with disabilities are managing households, if roles and responsibilities have shifted, and whether they can visit extended family. In addition, there were questions about the impact on services or lack thereof and the situation in institutions. A summary of the findings is grouped by region.

## Africa

In Africa, mothers and older children become teachers to the younger ones. Also, multiple generations share a household. However, we also heard that parents keep deaf children home and do not provide education as they do not know how to use sign language. Deaf children are asked to do household duties. Some countries do provide online education during lockdown. However, this is only available in the households where there is internet and where the family has the proper technology to participate. Most do not have computers, smartphones or even TVs, or they do not have access to the internet or learning materials. Some families reach out to the teachers directly seeking advice. But others, those who do not have any or limited technology, those families miss out on education, because many families would not be able to provide learning to their children. The break from school is very abrupt, imposing stress on children as well as parents. Often, communities step in to support working parents, who have children with disabilities.

“Parents with autistic children were scared because the child had to stay home and was not allowed to go outside. The parents didn’t know how to explain the situation to the child, and as a result the child became aggressive, then annoyed and wanted to do things that she couldn’t do. The violence and aggression became challenging for the parents and they didn’t know what to do to resolve it.”

## Extended family

Often communities keep together and maintain (if at all) only a light social distancing. While some participants reported that due to the restricted movement extended families and friends do not visit, others remarked that these visits still happen.

## Services

For the Deaf community, working with interpreters is the key. Often these interpreters are hired by the DPOs. Because of the lockdown, these services were suspended, making communication more difficult. Persons with disabilities often require support with household duties/cleaning, but during the lockdown all these have been suspended. These duties fall on the shoulders of household members. Households where persons with disabilities live by themselves have difficulties to adjust and to receive information about how services are provided for or how to protect themselves from the spread of the virus.

Deaf people are not provided with any services, particularly in health facilities and hospitals.

“Deaf people are not fully aware of what COVID-19 is and means, but also governments lack an understanding what kind of services are critically important to be in place during the pandemic, particularly for deaf people. In one particular country in Africa, a participant shared that a lot of deaf people are dying from Coronavirus because they don't get access to information. They don't know what's actually happening. There are no interpreters. And that excludes people from participating and from becoming aware of the situation and how to behave under the current circumstances. When we go to the hospitals, we can't really understand the treatment we are receiving or if we are healthy or not. What is the prescription for? For example, a lot of deaf women and girls, who are also pregnant, go to health facilities because they have a breathing problem. As they cannot explain, plus there is no interpretation, thus without communication no differentiated diagnoses can be made, they are simply told to go home and that everything is fine. But actually, they are at risk being infected by COVID-19 and they are in pain. The problem is they are unable to communicate with the hospital staff due to the lack of sign language interpretation. “

## **Institutions**

There are schools for the deaf and schools for children with disabilities. These have been shut down, and no alternative education has been offered or put in place. Institutions for children with disabilities closed before the lockdown, and each family had to take their children home. Families are put into difficult positions as they do not have proper equipment and knowledge to take care of their children.

Institutions for persons with psychosocial disabilities and for persons with intellectual disabilities closed down during the lockdown and, with the exception of personal assistants, no visitors are allowed. The only access is by phone, and these people are the most vulnerable. This is very stressful, as some people living in institutions are allowed to come and go, but since the lockdown, they are only permitted to communicate via phone. Their anxiety level has increased significantly. One of the participants reported knowing that there had been an outbreak in one of the institutions, but without any detailed information or action steps by news outlets.

## **Asia**

### **Household duties**

Generally, the Asia and Pacific region relatively easily transitioned to online work and online education. However, several participants indicated that internet costs increased since the lockdown. It was again emphasized that parents have additional duties to support online learning. Blind children are now falling farther behind since they have difficulties participating in online educational opportunities.

A participant in East Asia shared that online education with Zoom classes using the internet have failed. Cities have internet access but outside regions lack this service. Homework assignments are received and sent via WhatsApp between the teacher and caregivers. Parents have become their children's teachers, and as a consequence, the quality of education has decreased.

Some participants reported a slight increase in household chores and family members taking on more duties. Several respondents highlighted that younger generations often help older ones, particularly with shopping.

"Three generations live together. It is the usual way for so many of us to live together. The lockdown has given greater opportunities to talk with the family and about our cultural heritage. We talk about expectations going about busy days. There is generally more time to talk about person's disabilities, what are family members' roles, how to support and how that affects the person with a disability living in the household. We talk about disability with the family. Over a period of time things will change as I age, and life will become more difficult. I have had time to reflect and have a deeper understanding of my disability and discuss it with my family."

### **Extended families**

All participants reported that while cultural visits from extended families are usual, most are following and understanding the rules of social distancing.

### **Personal assistants**

Overall in the Asia Pacific region, most reported a decrease or cancellation of personal assistant services. Many countries do not consider personal assistant services as essential. For example, in East Asia the daily service has been reduced from eight to four hours. Adding to the difficulty, accessible transportation services have been temporarily halted in many cities.

### **Institutions**

Participants shared that many workers, staff, nurses and doctors in many mental health facilities have been infected by COVID-19. However, beyond this fact there were not any other details about the situation in institutions. In one country, detailed reports on infected prisons were available, but not details regarding mental health facilities. One possibility for this is that most people who reside in mental health facilities have been abandoned by their families and thus the government is not as concerned about reporting detailed information.

In another country, institutions have simply been closed because of the sudden lack of funding. As a result, "some are on the verge of collapse. People do not know how to manage the staff or

the homes. So, some have closed, and some could manage to get home, and some are just abandoned.”

We have also received similar information on institutions in East Asia, with the caveat that the staff live inside the institution, so any news on the condition of inhabitants is even more of an issue. In some countries in the Pacific, nursing facilities have been closed and families were asked to take home their family members.

The following was shared from one country in South Asia: “People in institutions here have increased risk. Two things happened. Support workers started coming to work and they're a bit sick, but I haven't checked to see whether they're infected with COVID-19 or not. So, then it is passed on to residents. The other thing is not all employers provide support workers or residents with protective clothing and masks. So that means that they're more at risk as well. And the number of workers in institutions has diminished because many can't come in if they have to self-isolate for family members. So that's really a big hazard.”

### **Living independently**

Living independently has become more difficult and those who do not have any support rely on what family they have. Although, particularly in the Pacific Islands, if someone has no support due to a lack of personal assistant during the lockdown, and if they cannot live independently, relocation to the mainland was offered as an option where more services are provided. Independent living of persons with psychosocial disabilities during the lockdown and subsequent restrictive movement has raised an issue, as often people rely on regular human interactions and human contact, such as hugs. In addition, persons with psychosocial disabilities often rely on regular visits with therapists. Because of the lockdown, these sessions have been limited and virtual or via the phone, which do not provide for the same support. This isolation has put a lot of people at risk, such as “people who need communication through touch.”

One particular case regarding services was reported from Eastern Asia:

“We have issues with financial inclusiveness. Banks are not ready for people to get money via card—debit or credit. To obtain the help from the government, we need to get money to a special bank account. The banks refuse to transfer the money from the special account to our debit card and require us to come physically to the bank, which puts us at risk. This was an issue before the pandemic, and it was not resolved during the lockdown. We have applications, which are not accessible.”

Also in Eastern Asian countries, the military has been heavily mobilized to deal with the pandemic. For example, they have been employed to draw borders along cities, restricting the movements. They are also used to provide support for older people and persons with

disabilities. If someone in your home has COVID-19, the military set up an iron door on the block or apartment, so the person could not leave. The door only had a small hole to receive groceries.

## **Europe and North America**

### **Additional work from household members**

Families are spending more time together. There is more focus on food preparations/cooking since fewer opportunities are available for going out to eat (eating out can ease some households with members with disabilities). As many persons with disabilities in Europe have less assistance, cooking has focused on simple, less nutritious meals. Other household duties, due to the lack of assistance, take longer and more energy. Those who used to have personal assistants and due to the pandemic needed to manage themselves, reported difficulties with shopping in supermarkets, carrying food back home, and as much as possible relied on help from family members. Due to these changes, it was also emphasized that a healthy balance and time for self-care was highly important.

A good example was reported from one of the European countries: “The cleaning company suspended its activities due to the lockdown. However, the company reached out to households where persons with disabilities reside, and they offered continued services if needed, and at the same time putting all necessary precautions in place.”

### **Extended family**

The participants indicated that there were no outside visits.

In terms of personal assistants, several European countries in which personal assistant services are funded through the government, reported different practices. In most cases, the individuals (persons with disabilities) were the ones making the decision whether they wished to continue the service or request a suspension to limit the infection and risk exposure. Often countries allow persons with disabilities to hire their own personal assistants and they reimburse retrospectively. Some countries even offered to cover additional costs that incurred due to COVID-19.

### **Institutions**

In some European countries the government provides a budget so the individual has the choice to spend funds on either being in an institution or hiring a personal assistant, and they can change as they wish. During the COVID-19 pandemic, everyone had to make a decision and adhere to it, either to stay home or stay inside the institution, but splitting time in between was

not allowed. Consequently, in some cases, additional budgeting was needed to organize their own help while staying home.

In general, social services at the national level were closed without alternative solutions, and in most European countries, institutions were closed to visitors. Caretakers within the institutions were dressed like robots, for protection. This has made many of the inhabitants uncomfortable and even frightened as some expressed that they felt like they were being surrounded by aliens.

“One participant spent the majority of his days in institutions and only returned to his home in the evening. The interviewee chose to stay at home. These rules were imposed to prevent the spread of the pandemic. Rules were particularly important for him and that they are all followed as ordered. But he had difficulties adjusting to being home and not having routine activities that gave structure to his life in the institution. Despite choosing to stay at home, he experienced the lockdown period as a catastrophic disruption to his life and expressed grave concern about feeling constantly insecure. He expressed concern for his friends who remained in the institution, although positively he was able to communicate via video chats.”<sup>1</sup>

Other European countries do not have institutions, but instead rehabilitation centers. These centers were temporarily closed and are now beginning to open with activities resuming on a scaling basis. A challenge is that the centers are not prepared to resume work with new safety measures in place. For example, in order to maintain social distancing, the staff and center members are now required to wear masks, which can be challenging for some autistic people and people with intellectual disabilities. These facilities are not equipped to ensure that social distancing is carried out due to the physical structures of the buildings.

### **Family member roles**

Family roles and duties significantly increased with family members who had to stay home during the pandemic, instead of spending their daily activities in certain facilities. For some families with family members with disabilities, this situation created additional stress and even aggressive behavior.

The pandemic created a crisis for the inclusion of persons with disabilities.

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<sup>1</sup> While this person’s experience was negative, we do not want to imply under any circumstances that segregating persons with disabilities in institutions is good. We are summarizing the challenges during the pandemic and pointing out the lack of support, as in this case, in which the person had a choice, but no additional support was offered to manage his emotions or to structure his daily life. This case is from a different country than the one where individuals with disabilities received a budget and decided where to spend their days.

An insight on stigma: “The pandemic put inclusion at risk. Physical distancing, isolation and segregation will result in stigma. Persons with disabilities have been asking to be part of society for decades. But what happens when we enter society? During the normal times stigma remains under the surface. But during the pandemic stigma immediately returns. People think life has changed but when we see triage policies being put in place, where older people and persons with disabilities are at the bottom of priority, it clearly signals less value, exclusion and acting on stigma. During and after the pandemic, violations of human rights are constant, we must combat stigma on a different level.”

Those participants who require personal assistants expressed that more duties had been put on their assistants’ shoulders. There was also a fear that if assistants got sick, there would not be a possibility for a replacement. One interviewee shared that her personal assistant requested to not work because she did not want to adjust to the home and workplace travel and lifestyle for fear of contracting COVID-19.

In some European countries there is a significant barrier in accessing personal assistance services, and when the personal assistant got sick, the person with a disability was forced to go into an institution.

“When deaf children stay at home during the pandemic, many are now in a hearing family setting in which the family cannot sign and do not communicate at a proficient level, so the child is isolated in their own home, and communication and access to information is gone. There are some low-income families that have no access to computers, so the deaf children are truly cut off from everything.”

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“There is online education, but it is not accessible for deaf children when it is carried out through spoken language with no provision of interpreters. So, parents become more responsible in trying to source an interpreter, get them online, and with things that they are not familiar with, such as the facility called Zoom. As a result, parents are struggling. In addition, the recording of lessons are not accessible since they would need to be given to the interpreter first to translate. So, the family has to be more responsible, and are under more duress trying to facilitate all of that.”

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“The education system closed and there were some lessons online, but the communication system was not always accessible and usable for all. As a consequence, students with disabilities were excluded, particularly persons with intellectual disabilities.”



....

“Some systems work, and others don't. They are falling back on education, falling back on communication, and it's creating a higher risk for mental health issues.”

It is important to discuss the situation for DeafBlind people. The government has stated that people cannot be touched, so how does a DeafBlind person communicate with that restriction? Somebody has to be with them. They need their arms held to be able to walk to places. They need people in the home supporting them. All of the support systems that were in place have been taken away during the pandemic. It could be happening right now in their homes. There is so much to be said, but getting that information has not been easy. How do we create the support and awareness around this issue?

Parents are becoming caregivers, teachers, responsible for upholding the household and also often having to balance all of these responsibilities with work. Households with multiple persons with disabilities suffer the most. Social interaction and positive behavioral reinforcement are missing and contribute to the deterioration of disability. In North America some disability services have been completely disrupted due to the COVID-19 situation. Service delivery organizations have tried to resolve the new challenges but are struggling to manage this. Parents are stepping in but can neither offer qualified services like professional organizations nor are able to continue indefinitely.

## **Latin America**

Children, especially those with the greatest need for support, are the ones who are being left behind the most in the homes. This was particularly highlighted with the following information a participant shared:

“We carried out a survey a few weeks ago when the pandemic began, and it was notable that families’ concerns above all were on the health of their children with disabilities and them not acquiring COVID-19, followed by the education of their children and finally the economic issue. We carried out the survey again a few days ago and priorities are now the opposite. The priorities today for families are economic income, then education, and ultimately the health of their children with disabilities.”

Other barriers include the lack of accessibility of the physical spaces inside homes where children with disabilities are residing, and also education for deaf children via the virtual classrooms with no communication access. Also, when the offices are closed, there are digital accessibility barriers and that generates delays in receiving the income that the government provides.

From the beginning, some governments permitted personal assistants to use transit. But this is an issue since using public transportation increases the risk of the personal assistants contracting COVID-19 and then infecting persons with disabilities with whom they work. To add to the risk, in some locations, personal assistants and persons with disabilities who use personal assistants did not have access to PPE.

In some cases, people with intellectual disabilities are being minimized and treated like children. Overall, the government does not consider the needs or provide access to information and services for people with intellectual disabilities.

One self-advocate expressed this challenge: “I have learned about it because my family has explained COVID-19 to me. Because in the news I don't really see what is happening and there is a lack of access to information from the government, so I have not really understood what has been happening.”

## **Middle East and North Africa**

### **Family member roles**

For some participants, family roles have not changed much during the quarantine. There have been some shifts in responsibilities, such as sons and husbands buying food and husbands helping their wives prepare food and teach their children at home. Some participants indicated that there were increased feelings of anxiety, tension and friction at home, such as in the cases where extended families are living together, and due to power outages for long periods of time that affected communication. In addition, overall, visits with extended family decreased due to social distancing.

### **Living independently**

Overall the pandemic made it difficult for some persons with disabilities to live independently because of the loss of support systems, such as personal assistants. Organizations have assisted with households that do have assistants by raising awareness on safety equipment such as masks, gloves and sanitizers.

### 3. ACCESS TO HEALTHCARE DURING COVID-19

*“During social distancing I am keeping up with more people than before the pandemic. We must distinguish between social distancing and physical distancing. Social distancing, you stay alone!”*

In this section, a set of seven questions were to assess how persons with disabilities were able to access COVID-related and regular healthcare and treatment services. The questions were aimed at learning what policies have been implemented, what the treatment toward and barriers for persons with disabilities are, and the accessibility of medication and equipment. A summary of the findings is grouped by region.

#### **Africa**

One country shared a good practice in which collaboration took place between the ministry focusing on persons with disabilities and DPOs. When the pandemic started, this ministry took action, became responsive and now a solid partnership has formed between the two entities. A key positive outcome of the collaboration is DPO representatives are part of the presidential working group on COVID.

#### **Access to healthcare facilities and hospitals**

Overall participants indicated there are barriers regarding access to healthcare facilities. Generally, health personnel are not trained in disability awareness, which can cause issues. For example, deaf people are encountering communication barriers in hospitals and with doctors. From one country, a participant explained “I have a deaf friend who is pregnant and she wanted to be close to the doctor to be able to communicate and understand him and she was required to be very far apart and both were wearing a mask, so she was not able to communicate in this situation.” In addition, sign language interpreters overall are not provided or available in healthcare settings, and deaf people are not able to call emergency numbers.

#### **Access to information**

There was a wide range of answers in terms of access to information. In some countries, governments provided sign language interpretation for the main news briefings. In most cases, this was implemented as a result of DPO-led advocacy and in some cases with support from international organizations. The findings show that, in Africa particularly, DPOs play a significant role in addressing the gaps in government services. For example, many participants shared that they had become sources of information, were raising awareness with their members and were providing accessible materials in different formats, including easy-read.

Many governments did not provide sign language interpreters for all COVID-related briefings. For example, in one country, when the COVID-19 pandemic started to spread, the government provided interpreters in some briefings. But as time went on, gradually there were fewer

interpreters, and now they have stopped providing any. Additionally, there are no interpreters available at hospitals, banks, and for other public services that are very important.

“As deaf people we are receiving very little information about the COVID pandemic. When the government shares emergency information, there have rarely been interpreters. For example, there was an emergency announcement from the government on TV with no interpreter and I had to ask my family for the information. Fortunately, I was able to get the information from my family, but there are many deaf people who don’t have this access, don’t have hearing people who they can ask, and as a consequence are missing vital information. Many deaf people contacted me to get this information since they didn’t know what was happening. I was able to share information with community members, and this is how I know that many deaf people were missing this vital information.”

### **Access to medicine**

Access to medicine differed among countries. For some people with disabilities who regularly use medicine, they ran out. Psychotropic medicines ran out due to low production because of the pandemic. For others, accessing medicine was fairly easy even during the lockdown. In some countries, pharmacies and chemists were open 24 hours. The bigger barrier was moving around, accessing transportation and having the money to buy medicine, especially since internet banking was an issue.

“When the pandemic started, a lot of people were discharged, and for persons with disabilities who have difficulties breathing, we have been campaigning for the training of health professionals, the physical therapists, even doctors themselves. So, they are able to train and then teach patients also how to take care of themselves. And one of the particular things that they are supposed to be doing is teaching patients on how to practice their breathing, because some of us, especially those with broken necks, that’s the tetraplegia, find it very difficult. The lungs collapse and the muscles are not there, and they are not able to have a long infection, so COVID is something they are trying to avoid. They don’t have ventilators. Usually with a spinal cord injury, there are ventilators for patients with tetraplegia who have difficulties breathing. Now they didn’t, they just discharged them back home which obviously will cause more complications at home than in the hospital. But almost everyone has gone in the ward that has around 200 patients, but at the end of it all very few were left. So that’s one thing I have noticed as well.”

## Asia

### Access to medical services

In general, the biggest barriers were lack of access and staff with several interviewees expressing concern about not receiving disability-related assistance in health facilities. One issue was lack of accessible transportation to and from health facilities, as well as having personal assistants accompanying them to healthcare facilities. Moreover, in the beginning of the pandemic, in general practitioners did not wear masks, and lacked protective equipment.

Some Pacific Islands reported a positive trend, such as access to free testing and minimal cases of COVID-19.

### Access to information

All participants reported that governments provide daily briefings on COVID-19. Some countries provide captioning during news briefings and some have sign language interpretation.

“In one of the Pacific Islands there is a lack of sign language interpreters. They either work for the government or at schools. Currently, the interpreters are working increased hours without additional compensation. They are government employees and thus cannot stay home in order to interpret news briefings. At the same time, they are also interpreting in hospitals for deaf patients.”

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“There is no access to sign language in medical centers and hospitals. Deaf people use WhatsApp to call their relatives and ask them to speak with the doctor and interpret. This can be complicated, for example, for women with disabilities who need to use gynecologists.”

### Access to medicine

Hours of operation were reduced or were closed and as a result picking up medicine was more difficult. Health centers had a limited stock of medications. Also, there was general fear of medicine running low, for example for medications for diabetes.

Several participants from Asia raised serious concerns about additional healthcare costs associated with COVID-19. In some countries the costs have risen astronomically, thus often the poor choose not to be treated.

“One participant shared a tragic situation about a young child with a disability and multiple health conditions. One of the health conditions was a complication from pneumonia that happened before the pandemic. The parents brought their child to the hospital because of a complication from the health condition and the child had to be admitted. Because of the pandemic, they had to follow the COVID-19 protocol that any patient had to be isolated and not be accompanied, even by family members. As a result, the parents were not allowed to be with their child, even though the mother knew best how to care for the child, and the child passed away.”

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“A person with a disability with health conditions was told, ‘If the pressure at the hospital is high, I would not be resuscitated because I have an autoimmune condition, autism and am 70 years old.’ So that's quite hard to hear.”

.....

“You are not even treated as human beings at some of the isolation centers. Sometimes people who have COVID-19 and people who don't are kept in the same place and have to share the same toilet. It is impossible for 20 people to maintain hygiene and socially distance. Actually, this environment will kill healthcare providers. That's the situation. I would rather hide myself than report my case to the healthcare workers if I get infected.”

## **Europe and North America**

Several participants from different European countries said they feel that their life is less valuable than those without disabilities. In one country, a DPO directly asked the Minister of Health during an interview about the triage policy and in response the minister said no such policy exists.

### **Access to medicine**

Some participants reported a shortage of medicine, particularly medicine to treat COVID-19 complications. The COVID-19 triage system often excluded the appropriate treatment for persons with disabilities. The exclusion and denial of treatment were not on the basis of a medical condition, but because of discrimination.

## Access to information

In European countries, sign language interpretation was provided due to successful advocacy from Deaf communities. This is a significant achievement at the European level. Additionally, the importance of sign language interpretation has been taken so seriously that the President of Lithuania refused to start a press briefing until the sign language interpreter was in place.

Many European countries had to act urgently when the pandemic hit without much time to prepare. Consequently, alternative formats such as Braille were not widely available, although some blind people were able to access information through the radio and TV. To address this, national DPOs focusing on blind and partially sighted people provided information in alternative formats. This was a critical role as they became the service providers instead of the government. However, one country took quick action and provided all COVID-related information in easy-read format on the government portal. This particular government also provided captioning as well as sign language interpretation during daily news briefings.

One participant discussed the situation of refugees with disabilities. Refugees with disabilities are being left behind, are not receiving sufficient information and do not fully understand the crisis. Again, DPOs took action and became service providers instead of governments.

## Access to health facilities

Restrictions were put in place in accessing health facilities. A lot of medical consultations took place by video conference. In some countries, if signs of COVID-19 infections emerged, complicated protocols were put in place (where to go and whom to call). In many European countries, regular healthcare services were suspended, as well as rehabilitation and daily centers. For example, dentists only accepted urgent cases. Yet, essential treatments, such as for cancer, continued. It is important to point out that regular healthcare services, including dentists, are often inaccessible for persons with disabilities.

The ability to have a family member or support person accompany a person with a disability was extremely limited in some countries due to safety measures put in place. In other countries it was completely prohibited to have anyone accompany the person with a disability into a hospital.

“One particular government reached out to the national DPO to request a manual for healthcare workers on how to communicate with persons with intellectual disabilities and persons with psychosocial disabilities.”

In some countries, personal assistant services are reimbursed through the municipal budget. Consequently, this can trigger disputes between national and local authorities on the necessity of personal assistants. The COVID-19 crisis has provided municipalities an opportunity to try to change the regulations on personal assistance.

## **Latin America**

The information shared regarding access to medical settings and healthcare services in the Latin American region was particularly grave.

One participant shared that in one country all medical centers in relation to external medicine were closed, which implied that anyone who had additional problems had to resolve them at home and if not, they had no choice but to die. In another country, people 50 years old and above were not cared for in hospitals and were ordered to take care of themselves at home. To get an idea of the consequences of this, “In my city, approximately 10,000 people died in one month due to COVID-19 and other health conditions from lack of care.”

Another participant shared that in their country that “the government has a nation of dead people with disabilities as a result of the virus.” Less than one hundred people is the official number, but according to the disability movement the real number is likely triple that when taking into consideration what happened at the global level.

Another participant described a very serious situation of assistants unable to accompany persons with disabilities into hospitals and health centers:

“For people who use augmentative alternative forms of communication is very serious. Above all, when we need an assistant for our communication in hospitals and health centers, the guards do not allow the assistant to accompany us, not only now, but always. So, it is terrible to be in the hands of people who do not know us and to not be able to ask for something, and to not have anyone tell us what is happening to us. This is even threatening to make us prisoners. We were left alone without understanding and without being able to say anything, terrified and in pain and nobody realizes it. That has to change, and we are very afraid because at this stage, there is the added issue of infection and contagion. We need a communication assistant throughout the hospitalization and consultations.”

## **Access to medicine**

Generally, a lack of access to medicine was indicated for persons with disabilities who are either unable to go out or cannot get medicine sent to their homes. To compound this, in one country, unscrupulous people used the epidemic to make money and began to sell only selective medicine for COVID-19, with incredibly high costs, which was inaccessible for people with disabilities.

One participant indicated that the government had not carried out a contingency plan, which is in violation of Article 11 of the convention.



## Middle East and North Africa

In terms of regular healthcare treatment, many countries provided health services through telemedicine and medication was delivered to the patient. In-person treatment was reserved for critical and emergency operations.

Sign language interpretation was provided in most countries in the region, not only for press briefings, but also to facilitate communication in the hospitals. Also, in some countries, the Ministry of Health provided free COVID-19 testing for households with persons with disabilities. In addition, personal assistants were permitted to accompany persons with disabilities and sign language interpreters could accompany deaf people in healthcare settings.

## 4. CHANGES IN SOCIAL PROTECTION DURING COVID-19

*“The city might be more interesting without tourists and I am so much looking forward to enjoying it after the lockdown ends. “*

In this section, questions covered what social measures have been put in place by governments and municipalities to protect and support the most vulnerable during the COVID-19 crisis. Specific questions asked if regular services were upheld or broadened, whether cash benefits were provided or if commodities were delivered. A summary of the findings is grouped by region.

### Africa

In some countries, cash benefits have been provided, while in other countries, there was discrimination against persons with disabilities. As a positive example, in one country, people who regularly receive social protection cash benefits had an increase in their allowance for three months. Discrimination took place in various forms. One such case was not providing the same amount of money, as described below.

“Yesterday, the government announced a new law to provide benefits for people since they have to stay at home due to the pandemic. Hearing people get a certain amount and deaf people get half of the amount that hearing people get. Positively, there is a new law that deaf and disabled people won’t be taxed if they earn below a certain salary.”

In other countries, lack of access created barriers. Forms were distributed to receive cash transfers for COVID-19 relief. However, the form required a bank account number, but many people with disabilities, particularly those living in rural areas, do not have access to banks or have bank accounts. In another case, the government unilaterally decided how many people with disabilities should receive cash transfers. DPOs were not consulted and it was not clear

how the number was determined. As a result, the government came up with an incredibly low number, adversely affecting many persons with disabilities.

In many African countries, protective measures have been put in place by imposing curfews on citizens. In addition, governments ordered the use of masks and schools have been closed to prevent the spread of the disease. In one country, the government supported people with disabilities by providing food to them at home.

DPOs took action in many African countries and even took on the role of the government. Yet in other countries, due to the lockdown and curfews, there has been little coordination among DPOs since most are temporarily closed.

“One good example was provided. When DPOs worked with local governments to ensure that 3000 palliative food stocks reached households where persons with disabilities lived, the government provided the food stock and truck to transport it all. The DPO representatives identified the households and distributed the goods and were accompanied by government officials. There was one disagreement since the DPO representatives had to pay to travel to reach the truck. This travel cost is currently being disputed and a request has been put forward to reimburse the DPOs.”

Also, in a number of countries international organizations provided food to persons with disabilities and others.

## **Asia**

Many countries have distributed free essential kits and hygiene products to persons with disabilities. In one country, the Salvation Army and Catholic charities in collaboration with the Mayor’s office distributed free food. The shortcoming was in order to receive the free food, one had to go and get it, which imposed significant barriers. Also, there was no differentiation between the general public and persons with disabilities.

“In the Pacific Islands, one specific issue was that persons with disabilities needed medical equipment such as catheters and mobility devices. They often rely on family members to bring such items from overseas or from the mainland. Due to the lockdown, and since there were no flights, people were cut off from the usual supply chains. Moreover, there was not enough stock on the island. Despite growing calls, the health facilities were not sharing their resources.”

In terms of safety measures, some countries set up checkpoints on the roads in which people who were stopped would be asked if they had felt ill or currently felt ill. That was happening but has now stopped. Some stores recently opened and take your temperatures there. In other countries, stricter movement restrictions were imposed on persons with disabilities.

In many cases, personal assistant services have been suspended. In addition, transportation for persons with disabilities has been limited to fewer hours.

In some countries, COVID-19 cash benefits were distributed, or tax benefits were provided. In one case, the monthly pension could be paid in advance instead of being paid in three months installments. Another example, the government decided to give money to employees who worked in the last 12 months and to pensioners. This regulation again had a huge gap, in which persons with disabilities did not receive the benefits, because they often do not work 12 months in a row and are consequently not eligible.

“In one country, local authorities decided to carry out an in-person survey from house to house. The survey aimed to assess whose livelihood was threatened by COVID-19. The interviewer was unprepared and there were limited guidelines provided to them. They skipped households where persons with disabilities lived and they disqualified households where persons with disabilities lived alone or where a woman only lived, as they were not considered a household. The local government made the final decision on which households would receive benefits. Many relatives, friends and political supporters were granted benefits.”

“In one of the Pacific Islands, there is a company where they employ approximately 15% persons with disabilities, and they did not lose their job. They were able to keep their job and decide if they wanted to take COVID-19 annual leave or personal leave. Some took leave and others continued to work. This is an example of inclusive protection for people with disabilities.”

## **Europe and North America**

In Europe, mostly positive examples were shared. Unemployment benefits were provided, including for independent contractors. Also, employers could receive benefits if they kept employees in the company. Taking leave was easier, like parental leave for children 12 years and younger. If you had a child with a disability, new regulation dictated that parental leave can be taken until the child reaches 21 years of age. Regulations were eased on staying home with a person with a disability in order to provide care. Applying for disability allowance required a lengthy process including a number of medical tests, but during the pandemic these were reduced to teleconferencing, and disability allowance applications were expedited.

Local governments and municipalities often supported older persons and persons with disabilities with grocery shopping and the delivery of medication. And, day institutions closed but efforts were undertaken to maintain an engagement online. Guidance on daily activities was provided online, and self-help manuals were shared. Other areas of support reported included an increase in the number of paid vacation days for employed people with a family member with a disability to be able to assist at home, and a government contribution for babysitters.

A lot of services and entertainment were available for free online. A lot of these will remain after the pandemic. No cuts and checks remain available to be received. These will contribute to enrich the lives of persons with disabilities. Also, in one country the personal assistant services were increased by providing more hours per day.

In terms of a sign language interpreting provision, many deaf people needed sign language interpreters, and the interpreters could not work in the place of the assignment. As a result, interpreters worked remotely, but not all of the interpreters had strong enough internet connection. There was not strong support from the government to address this kind of situation, and again it goes back to the issue of access to information.

In North America, stimulus checks were provided to all families, and the distinction was only made on the basis of income. Some other benefits have loosened, for example, since the school closure children have not received free meals. Some schools tried to remedy this in one or another way, but serious reports on children going hungry surviving on fewer meals have been compiled. Food banks were established, and some additional items also have been provided.

While there were many positive examples, there were also extremely concerning examples. Some municipalities threatened to take away personal assistants and/or other different access to services for persons with disabilities. If helping the most vulnerable meant too much additional responsibility for the municipality, they preferred to take away all services, including personal assistants and suggest that the person move into an institution.

### **Middle East and North Africa**

In some MENA countries the government provided small grants to families with persons with disabilities as a social protection measure. A registration system was used to identify more impoverished families. Families then received a SMS code, which allowed them to access cash that was transferred into banks.

In terms of safety measures, rules on social distancing were put in place.

### **Latin America**

The support that the government gives today is not enough in many cases to cover the cost of those who require medicine. To add to this, in some cities, 70 percent of people with disabilities are engaged in informal activities so do not qualify.

In one Latin American country, the government implemented bonuses for people in general, and this benefited people with disabilities too. They also received a quarterly subsidy, although it is a minimum subsidy. The subsidies are not enough, so there are programs that allow people with disabilities to get food and medicine. But the main issue is that many times, the subsidies help at the moment, but people with disabilities and especially women will not have a solid economic base after the pandemic.

In other cases, NGOs are working to support women with disabilities in rural areas who need access to diapers and other items. So, aid is provided, but sometimes aid does not come at the right time, at the moment that it is needed. For example, women with disabilities have no way to buy or access even contraceptives. So sexual and reproductive health is being neglected.

A participant shared that in their country the federal government had set up a scholarship for people with disabilities, but there were barriers since applications had to be submitted through the internet, disadvantaging those who cannot access the platform.

Another participant pushed for their government to create a contingency plan. In Argentina, for example, the government has set up via WhatsApp a direct contact with the state and persons with disabilities. The person with a disability communicates with the state contact who can directly take action and try to solve the problem.

One government included persons with disabilities within vulnerable populations in a COVID-19-related emergency plan. This allowed the government to guarantee that persons with disabilities received the appropriate information, accessed medical attention in case of contagion and received social assistance.

## **5. THE EFFECTS OF COVID-19 ON THE EMPLOYMENT OF PERSONS WITH DISABILITIES**

In this section, questions focused on how the pandemic affected persons with disabilities and employment. Questions were also included on remote working opportunities and related issues around accessibility. A summary of the findings is grouped by region.

### **Africa**

In some countries, during the lockdown many people in large cities were able to continue working from home. They used the internet to provide guidance and to try to understand the future of employment. However, people indicated that they missed the social interaction with colleagues and talking with people.

Many issues arose concerning employment. Social distancing contributed to a sharp rise in unemployment, and in Africa that means an increase of extreme poverty, loss of food and no

money to sustain life. For many African countries, if the internet is available, usually it is poor quality with a slow connection, which affects people and the ability to work at home. In other situations, people with disabilities run microbusinesses, and as a consequence of the lockdown, they lost all of their income. Most people working in the service industry, such as washing clothes and preparing food, lost their jobs.

In some African countries, the government employs persons with disabilities. Even before the pandemic, these were not real jobs; people were just kept on the payroll and asked to come in to collect their salary, and this stayed the same.

Some deaf people from different countries in Africa shared their experiences regarding employment:

“I just discussed this with other deaf people. We are required to stay at home, so we can't work. We are provided a little payment to compensate, but it is very low. We are also not getting full access to information since interpreters are not provided for all government briefings. We miss information on COVID, and also the political situation as there is an ongoing change in government. We have internet access, but the connection is slower. It is not as easy to use, so we have been sharing information via texts.”

## **Asia**

Internet bandwidth was a problem due to an increased use of the internet in households that required stronger and more expensive connections. In the Asia Pacific region, many people with disabilities were not able to fully work via the internet, for example carrying out capacity building trainings.

In some Asian countries, blind and deaf people work in the massage industry, but due to social distancing measures, they stopped working. They expressed concerns about not working until there is a vaccine.

Many persons with disabilities work in the informal sector, such as selling goods. Their livelihoods are threatened by not working and also do not qualify for unemployment benefits.

Lack of accessibility has been a barrier. Some employers use working from home as an excuse to not provide reasonable accommodations or accessibility requirements. In particular, online platforms often are not fully accessible. There is not a fully accessible platform for all disabilities; all platforms have both advantages and disadvantages. In one country, a new app will be mandatory to monitor the health status of people. The app will use green and red colors, which will be inaccessible for blind people.

From lack of good internet connection, inaccessible online platforms, and being less efficient working at home, many people indicated that they are not working as effectively and consequently fear being terminated from their employment. Moreover, many people,

especially disability activists and advocates, have been reevaluating their work, since before the pandemic they traveled for work and now this has shifted to the internet.

## Europe and North America

Many barriers to employment emerged from the findings. Many people were able to work at home, but there were cases in which employers pushed their employees with disabilities to return to the office. Some people who were not able to work at home had to take sick leave. The isolation from remote working has been challenging for some persons with psychosocial disabilities. Also, for persons with intellectual disabilities who were used to getting feedback, support, and human interaction to carry out work, struggled working at home. Lack of accessibility was also an issue. For blind people, most of the online platforms, document sharing systems, and presentations are inaccessible. Although there were many barriers, some people with disabilities enjoyed working from home and hoped that this flexibility will be maintained in the future.

“The economy is on a decline and consequently many companies are letting go of their employees, including people with disabilities and deaf people. We know, as a fact, that people with disabilities and deaf people are the first let go. So, we need to consider all the people with disabilities who are unemployed, living in poverty, and all of the other conditions, the social isolation being missed through the gaps. **There is the immediate impact, but we need to consider the long-term impact of the coronavirus. What are we going to do about this?** It is mind boggling. We thought that we had recovered from the housing recession in 2006 by making our way back with people with disabilities employed. But now we have another decline and a lot of work needs to be considered for the long-term impact regarding these issues.”

## Middle East and North Africa

In this region participants also shared barriers due to lack of accessibility. For example, working from the office provided more freedom because there is more accessibility and also it is easier to resolve problems on site. It is more difficult to work remotely as work becomes restricted.

## Latin America

Many people with disabilities were able to work remotely while others were not able to adapt to this new modality. Others gradually worked fewer hours. For some, telecommuting did work as it did not reach the entire population. The isolation and lack of accessibility of working at home was also a factor. One participant indicated that:

“Here in the locked houses, we do not have accessibility so that we can be social that we had in employment. So, personally, I feel like I'm going backwards in progress that I've already had. So, I feel that what we need is that they support us a little more because,

for example, that we need a tutor to do certain procedures, we could not do the procedures because they do not let the person in, which we need to be, so that is also a bit frustrating. because we don't have access to what we really need.”

Many participants highlighted that many workers with disabilities had been laid off. Companies cut budgets and often persons with disabilities were the first to be let go. Similar to other regions, there is concern there will be high unemployment of persons with disabilities due to the pandemic.

Persons with disabilities not only have been laid off, but also in some cases are not able to access information or programs. For example, this participant explained:

“We have a registry for labor purposes, which is by law, an exclusive requirement for people with disabilities who want to enter the public service as a bid for an activity. Now with the new law they also took into account this requirement for private companies. Many private companies were going to carry this out, but when the Coronavirus arrived, everything was accelerated, not everyone was prepared and some people with certain disabilities were left out of this system.”

## **6. CHANGES IN CRIME AND VIOLENCE DURING COVID-19**

For this section, two questions were used: first, about an increase in crime and lack of security and, second, about an increase of domestic violence due to the lockdown or shelter in place policies. A summary of the findings is grouped by region.

### **Africa**

Many persons with disabilities in Africa did not receive full access to information on the situation and the restrictions imposed on the population. For example, in one case, a blind man tried to distribute palliatives (food stocks, rice, and tomatoes) to his blind friends. He got beaten by security because he violated the curfew (as he was unaware of the particular time, as being blind he did not realize it was dark).

There has been an increase of incidents, such as domestic incidents, for example a husband beat up his wife and, in the process, destroyed her wheelchair. This increase of incidents often made it impossible for police to arrive on time or come to the scene of the crime. Also, some rural areas were difficult to access.

Police and security were not always sensitive toward persons with disabilities and did not always recognize their rights. One participant stated that:



“People are definitely feeling a huge risk of crime, of police brutality, of brutality on the streets because of curfew. If you are taken by the police it is very dangerous for you. You may end up with people, not many judges are presiding over cases as we are at a standstill with access to justice.”

In some situations, police were not able to protect people. Participants indicated that in some countries, governments had been killing people, and people were very concerned because of the violence, so tried to avoid social settings. In some cases, people who owned land encountered people invading their land and called the police, but the police were unable to intervene.

One participant shared that:

“Persons with disabilities try to as much as possible to stay away from dangerous situations. When the State government provided some relief materials to people close to us, they did not go from house to house to distribute them. They instead gave them to youth leaders in the area to distribute. But these youths are cultists. They only shared the palliative among themselves and their members. People who recognize that those boys can be deadly, didn’t even care to go to where the distribution was taking place. They knew it could lead to extreme violence to argue with those boys or challenge their actions. No person with a disability dares to risk their life getting involved in such unorganized distribution.”

In Africa, women with disabilities are generally at a much higher risk of abuse. Due to the pandemic and lockdown, selling basic foods has ceased, and as a result many women with disabilities end up being sexually abused just to receive one dollar.

In some cases, fraud has been committed by people who were supposed to be doing contact tracing on behalf of the government. Exploitation by such people was reported particularly against persons with psychosocial disabilities. These people went to the communities and to people's homes appearing as health service providers, but in reality, were criminals.

In some countries, participants indicated that on the streets people were very angry. Many people were not staying at home the way they are supposed to, and people were kicked out of their homes. People indicated that they were not safe out on the streets, and the lack of medicine may have caused people to react more, which can cause misconceptions. The lack of food has increased crime as well.

In terms of deaf people, deaf people have had problems for years. But in terms of safety, deaf people have a history of meeting together for a chat to socialize, to give each other social support, and to support each other within the Deaf community. And when the government recently announced the food program, some bad people took all the food from the government and distributed it to their friends and thus there was an increase in violence. In extreme cases,

deaf participants reported that police sometimes shoot deaf people because they are not aware that they are deaf.

Despite the increase in crime in many places, in other parts of Africa, the police presence significantly increased and complemented the support of the military to monitor the restricted movement of people. As a result, crime levels dropped.

“During the start of the COVID-19 lockdown, the government prohibited gathering of more than five people at a time. However, once, some friends came to my home to view the broadcasting of a program, which I was streaming live on Zoom. Seeing people coming to my home one after the other, my landlord became suspicious and called the police (in normal circumstances, my flat can accommodate up to twenty people). A police officer who knows my number called and I gave my wife the phone to answer. He warned that I should disperse my visitors because there was an order prohibiting gathering of more than five people. In compliance with the order, I dispersed my friends. The point here is that many persons with disabilities are too poor to own a TV, buy phones and have internet access to follow programs that provide beneficial information in this pandemic.”

## Asia

Leaders of organizations of persons with disabilities and disability activists reported an increase of violence against persons with disabilities with alarming trends in regard to police brutality in Asia. In one country, “those who are in authority are more likely to be the one who will be perpetuating violence against people.” In one case, village officials explicitly skipped households with persons with psychosocial disability during food distribution. Following complaints, physical violence was carried out against the person by authorities. But in other parts of Asia, people received an official warning from the police itself to be extra cautious due to the increase in crime.

In Asia, crime rates are higher in cities, and overall, crimes have increased even in daylight. Persons with disabilities were easy targets and vulnerable, and criminals did not see them as real threats. Persons with disabilities were not only victims of physical violence, but also scams and fraud. Financial extortion was reported as common, especially from individuals who received public benefits. Often even “friends” take advantage of this. These so-called friends promised to provide help or services to persons with disabilities, and then stole all of their money. As a result, some individuals have become homeless. From East Asia, there are reports that people take advantage of weaker people (women, older persons, people with disabilities) and take away groceries forcefully. This is not per se about disability, rather about physically being weaker and older. If you do not take precautionary measures, then you are more vulnerable to such crime as stealing of food.

Blind people expressed a greater level of fear; cell phones have become even more precious as the main tool to communicate. Carrying cell phones and other belongings have become more dangerous. This is imposing an increased stress, that some are unable to deal with, so they stay at home and rely on their friends and families. This once again increased domestic fighting. People start fighting with each other, which ends up in physical violence especially towards people with a disability. Also, it is often experienced that persons with disabilities are the ones to whom all are complaining to, and this leads to burn out.

In a number of Asian countries, a curfew was introduced with retaliatory measures as grave as imprisonment. One participant indicated that, "We couldn't help some of our members with disabilities in terms of sending them messages about the lockdown and curfew hours. As a result, they end up in jail as they break the lockdown or curfew."

While it is not entirely related to violence, some parts of the Asia-Pacific region face two crises at once: the extreme weather conditions and their aftermath, which make it difficult to maintain safe streets and order.

## **Europe and North America**

In Europe, people with physical disabilities in particular reported an unease being on the empty streets as this means isolation and creates a loss of social control. If you walk on the street when it is dark to your car, you are isolated. When you see someone in the city at night, it is a risk, there is no social control.

Many mentioned that European media reports about an increase of domestic violence, violence between partners and child abuse. There has been an increase in calls from children to help centers. Due to all kinds of tension (no personal experience was reported).

One of the participants indicated that due to the lockdown, there are small fights and more disagreements in the household due to the pandemic, but there is also much more bonding.

Looking at crime and violence, it is the same for Deaf women. They are at higher risk of domestic violence. How do they call for help for instance, how do they escape home during a lockdown? There have been incidents in some countries where they are developing awareness and they are promoting awareness for safe spaces, for people who are experiencing domestic violence, but it goes back to information. Who do they call for help? And, again, looking at who it will affect, one major concern for all of us is the lockdown. There is no way out. The law says that you must stay at home. So those kinds of situations have possibly seen explosions in the home.

Scam, fraud, financial exploitation in the promise of services or disinfecting surfaces are common. People engage in fraud by requesting private data, pin codes and emails to gain access to bank accounts.

There is a fear that violence increased in institutions. However, there is little information about what has happened during the lockdown. A national monitoring body in one country indicated that there was potential increased risk of violence and abuse of people with disabilities in institutions and prisons, especially since visitors were not permitted during the pandemic. One particular case was reported when a person with psychosocial disabilities was unable to obtain regular medication and as a result abused and beat his own caregiver, who was his father. The father, as a result of the beatings, passed away.

An experience in North America from a group home:

“In group homes, it's very difficult to control your safety, whether or not you are going to be exposed to the coronavirus, because there are staff coming in and out, and you don't really have control over what other people in the household or the facility are doing. So that is a risk.

“There have been instances of people being refused service, from certain ethnic groups. So, you know, our quote/unquote President Trump has made a lot of very despicable comments, about certain ethnic groups, and there were a lot of Asian Americans being treated poorly, including both Asian Americans with and without disabilities. Other communities of color, again, there are a lot of disparities in healthcare already. So the circumstantial determinants that we look at, of people of color and people with disabilities, are more likely to have economic challenges, are less likely to have some of their resources that other more privileged groups have, and as a result are already at higher risk for various different illnesses. The situation with COVID-19 just really, really exacerbated that.”

## **Middle East and North Africa**

Due to the diversity of the countries in the MENA region, the majority of the participants in the research reported no knowledge of increase in crime or new forms of violence. However, from the poorer countries of the MENA region we have received reports that due to the increase of poverty situation, assaults on people's property has increased. Violence due to the change in the activities of daily life, the stay of all family members, the interruption of all work and the lack of money.

## **Latin America**

This was answered more in terms of lack of access to information and how that can create a security risk.

Some governments do not provide closed captioning or sign language interpreters on television for COVID briefings. Deaf people need information because many have families who do not know sign language, so cannot get the information. There is a concern about the issue of deaf

children as deaf children are worse off because they have no communication with their families.

“People are not trained to assist us (blind people), especially for those of us who are independent and who have no one to support us closely. As blind people who have to be touching everything and then, of course, that puts us even more at risk.”

People in poverty are at risk. They do not have connectivity, they are poor, they do not have easy access to televisions and information, especially indigenous people with disabilities who live in remote towns.

## **7. COVID-19 DISAGGREGATED DATA BY DISABILITY**

Participants were asked to share any resources on national-level data and COVID-19, related to persons with disabilities and/or general information. All participants knew how to find general data on COVID-19, such as number of deaths, infected, and recovered. But none had any information on disaggregating COVID-19 data by disability, which is a significant gap and subsequently risks leaving persons with disabilities out of COVID-related policies going forward.

Research indicated that some available resources have been shared or will be soon. The UK has a document on output on coronavirus and the social impacts of persons with disabilities in Great Britain. Click [here to read](#) more. The Ghana Statistics Office in Africa would like to engage with others on gathering data on vulnerable groups, including persons with disabilities, and they are using the Washington Group tool. More information [can be found here](#). UN Women indicated that although disability was not included in their first set of COVID-related surveys in Asia and Pacific, they have included disability-related questions in all other surveys, so they should have data very soon on that.

There are many surveys being carried out by DPOs and other organizations around the world to collect information from persons with disabilities. One example that we learned about is a survey conducted in the Philippines that will be shared with government agencies by the end of June that had 235 responses. There are also surveys from the Disability Rights Monitor, Women Enabled International, World Blind Union, and many others.

In the Dominican Republic, different organizations have carried out surveys to generate data on the situation, on the needs and experiences of people with disabilities as a result of the pandemic. UNDP conducted the online survey "COVID-19 Situation and People with Disabilities" to which 421 people with disabilities responded. The National Council on Disability carried out information gathering for the "Registry of persons with disabilities for response to COVID-19" with the purpose of channeling the demand for help from the population with disabilities to the different response entities.

## Summary of data findings

For most participants, updates on COVID-19 data were shared daily on government websites and in daily conferences. Information was also shared in text blasting from the government to update citizens on their cell phones. Usually the government data included the number of deaths in hospitals and in residential facilities, number of infected and number of recoveries. Disaggregation was available by age (older persons and children) and gender, in some cases location, but no participant had access to disaggregation by disability. In one country, there was research carried out on the number of deaths in institutions with a focus on older persons, and now another research study is underway related to persons with disabilities.

In some cases, participants did not trust the COVID-19 data shared by the government, or have inquired about disability data and the government is not sharing the information. Another issue is that in some cases, corruption takes place in which government officials take money for themselves instead of for services to people.

In terms of methods of collecting COVID-19 data in regard to persons with disabilities, participants shared information and other findings were included as well. Some ways of collecting data include door to door mobile that takes the temperature of individuals in the households, or the use of telephone surveys.

In terms of quantitative data, the questions developed by the [Washington Group on Disability Statistics](#) were built on the principle of “leave no one behind” and designed for disaggregation. The Washington Group Short Set on Functioning is well suited for monitoring inclusion, outcomes and concerns for people with disabilities during this pandemic. In response to the current pandemic-related needs of National Statistical Offices, DPOs and NGOs, the Washington Group has developed guidance and will be sharing this information soon.

The Washington Group recently published a blog on [Using the Washington Group Short Set in a Telephone Survey](#), as delivering a survey over the phone rather than in person is particularly attractive in the current pandemic.

The blog covers four key considerations when using this method to collect data:

1. Sample bias: consider the rates of phone ownership among the population of persons with disabilities.
2. General considerations: simple and straightforward questions work well over the phone.
3. Deaf and hard of hearing people and people with communication disabilities: consider methods by which to reach deaf, hard of hearing and people with communication disabilities (e.g. through sign language interpreters, Video Relay Service, and more).
4. Stigma: In some cultural contexts, significant stigma exists around disability, so it is important to refrain from using the word “disability.” It is also helpful to gently prompt the respondent to make sure everyone in the household is being included.

In terms of qualitative data, we recommend continuing to gather citizen-generated data to complement the traditional data sources such as the data I mentioned in my presentation. This can complement the qualitative data nicely and highlight information that cannot be captured in other ways.

## CONCLUSION AND NEXT STEPS

As the Stakeholder Group of Persons with Disabilities, we have been privileged to learn about many people's stories. We gathered so much detailed information, and the personal experiences, struggles and stories were often quite powerful. The following section summarizes the key takeaways with recommendations.

Throughout the world, often persons with disabilities are the most left behind and can become an afterthought. Some people idealize the world before the pandemic, yet in reality it was far from perfect for persons with disabilities as well as many other marginalized groups. Even with the CRPD and SDGs, persons with disabilities were still fighting for inclusion and equality.

During the pandemic, many persons with disabilities were left to die and remained entirely invisible in statistics and data. At the time of this report (June 2020), some parts of the world are beginning to reopen. We are learning about the new reality for many persons with disabilities. In fact, life has become even more difficult for some.

Life today is full of insecurity, increased discrimination and inequality, widespread unemployment and fewer services. In many cases, there is less kindness and comfort replaced with fear, aggression and physical distancing. It is not clear yet if the new world will continue as is until there is a widespread and affordable vaccine for all or if it is only temporary. Regardless, one key message needs attention: inclusion.

It is absolutely critical that persons with disabilities are key and active leaders and participants in all decision-making processes at all levels. Whatever the future holds, persons with disabilities must be key agents of change, because policies going forward are truly about whether people with disabilities live, die or are forgotten.

### Next steps

The International Disability Alliance and the International Disability and Development Consortium have been collaborating and leading a campaign and advocacy efforts on COVID-19 and persons with disabilities. This broad coalition has been gathering messages from the disability movement to remind governments and the UN system that persons with disabilities are being left behind and need to be included in all phases of COVID-19 planning and response. Building on these excellent efforts, we recommend the following key actions.

- Periodically visit the IDA website and follow the [key disability inclusive COVID-19 recommendations](#).

- Refer to key [resources and tools for action](#) to include persons with disabilities.
- Ensure all virtual meetings, events and activities are inclusive for all persons with disabilities and refer to [these periodically updated accessibility guides](#).
- Increase awareness by sharing [stories about people with disabilities during the COVID-19 outbreak](#).
- Publish and disseminate [information about persons with disabilities](#) in mainstream journals and periodicals to gain widespread attention about disability inclusion.
- Develop a disability inclusion guide based on lessons learned from the pandemic for governments and local authorities. This can save lives and ensure persons with disabilities receive the vaccine first.
- Launch a campaign on kindness as an integral part of non-discrimination and equality in order to remind people about the importance and value of kindness in society.

## ANNEX I

### Interview questions

#### Life

- Is your life threatened by the pandemic, or has it created an increased risk to your health and disability? If yes, please explain.
- How has your mental wellbeing been affected by the pandemic?
- Due to the pandemic, did you have difficulty accessing food or clean water? Or has the pandemic increased this difficulty?
- If you do not have access to clean water, how do you wash your hand and as such prevent getting COVID-19?
- Do you (or did you) have difficulty obtaining personal protective equipment (PPE), such as a mask, gloves, or gown? And, did you have difficulty wearing or putting the PPE on? If yes, please explain.

#### Safety

- Are you feeling more vulnerable or at risk to crime? If yes, explain why?
- Are you experiencing any new kinds of violence due to the change in daily-life activities? If yes, where? (e.g., at home, on the street).

#### Living conditions

- How have family member roles in your household changed due to the pandemic? Are there new or additional responsibilities, e.g., parents being teachers to their children.
- How has a shared living space with extended family members affected you and your household?
- Has the pandemic made it more difficult to live independently? If so, how
- Has the pandemic impacted on vital services such as personal assistants?
- Are you aware of what is happening to persons with disabilities who are in institutions?



**Healthcare**

- Are you concerned that if you contract COVID-19 that you will not receive life-saving procedures, or not receive equally to others?
- Are you aware of any policies where you live that would affect you in receiving treatment equally to others?
- In healthcare settings, are you able to fully access information, e.g. via language interpreters? If not, please describe what the situation is.
- Can a personal assistant or sign language interpreter accompany you in healthcare settings? If not, please describe what the situation is.
- Are you able to access hospitals to receive non-elective surgeries or treatment or even life-saving procedures during the Covid-19?
- If you require regular healthcare services, are you still able to access these? Please explain.
- If you require medication, how do you get this during shelter-in-place situations?

**Social protection**

- Have social protection measures changed in your country, such as regressive measures taking place?
- Are social protection benefits being provided? How?
- Have you received any cash benefits related to COVID-19?
- Have any new measures been put in place to ensure your safety?
- Is your local government providing you with any support during the pandemic (e.g., delivering groceries or medication)?

**Employment**

- How has the pandemic affected your employment?
- If you are working remotely, have you encountered accessibility barriers? If yes, please explain.

**Data**

- Please share any resources on national-level data and COVID19, related to persons with disabilities and/or general information.

**Closing**

Thank you for your time. Please let me know if you have any questions. If you would like, we can share the answers after we've written them so you can add and/or correct anything that we've written. In addition, if you have any information that you'd like to add, please contact me.

## **ANNEX II**

A qualitative research study on COVID-19 and organizations of persons with disabilities in Bolivia, Colombia and Guatemala.

### **Introduction**

The Stakeholder Group of Persons with Disabilities and CBM Global Disability Inclusion conducted an online survey in May and June of 2020 to gather new and additional information about the impact of the COVID-19 pandemic and how it has affected persons with disabilities. The sample includes people with disabilities from three countries, various ages and disabilities from urban and rural areas. The information gathered has been framed within the Sustainable Development Goals through relevant objectives and indicators. This brief was carried out by a consultant, Ramiro Nochez-McNutt, with support from CBM Global Disability Inclusion.

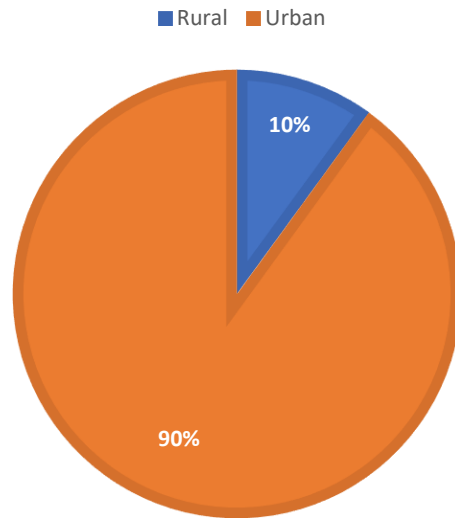
### **Methodology**

To carry out the study, a questionnaire was designed with 46 questions covering the following topics: personal data, life, security, living conditions, health, social protection, employment, emergency plans and information. The tool was transferred to a web form and distributed through representative organizations of persons with disabilities. The responses were obtained from three countries. People with disabilities directly answered the questionnaire, expressed their thoughts, perceptions and experiences regarding how they think and feel the COVID-19 pandemic is affecting them. The data was cleaned, sorted and tabulated. A quantitative and qualitative analysis of the results was carried out, and graphs were then produced.

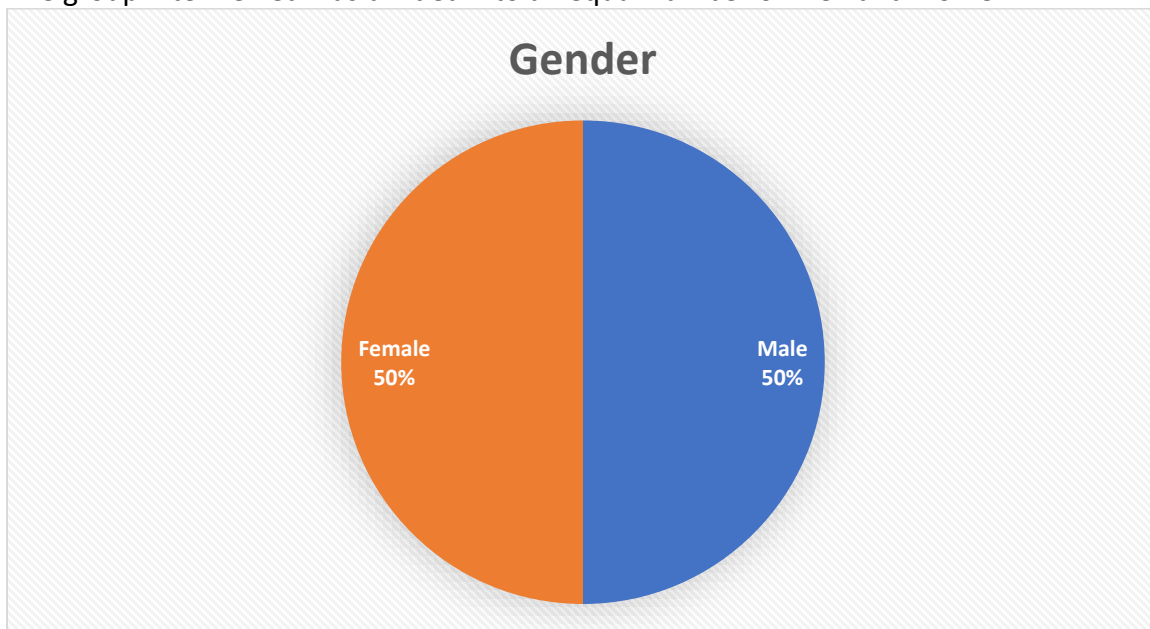
### **General Information**

The reporting group included representatives from three countries: Bolivia, Colombia and Guatemala. 90% percent live in urban areas and 10% in rural areas. The ages of the interviewees varied from 19 to 47 years, with an average of 36 years old. Ninety percent of the interviewees stated that they live in an urban area and the remaining 10% in a rural area.

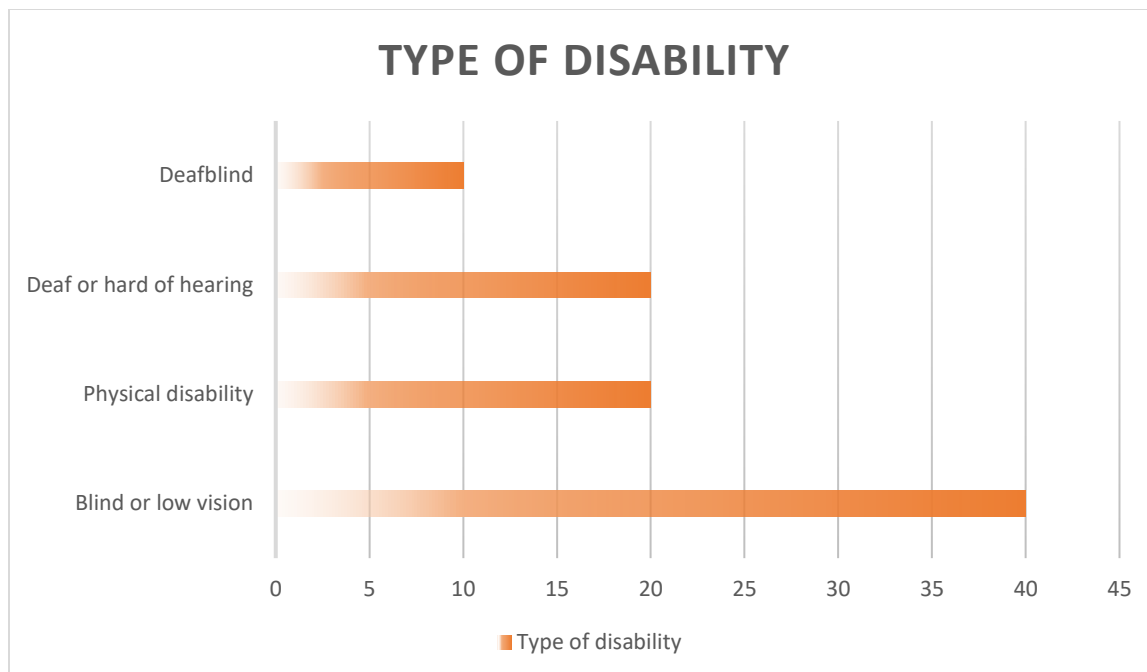
## AREA OF RESIDENCE



The group interviewed was divided into an equal number of men and women.

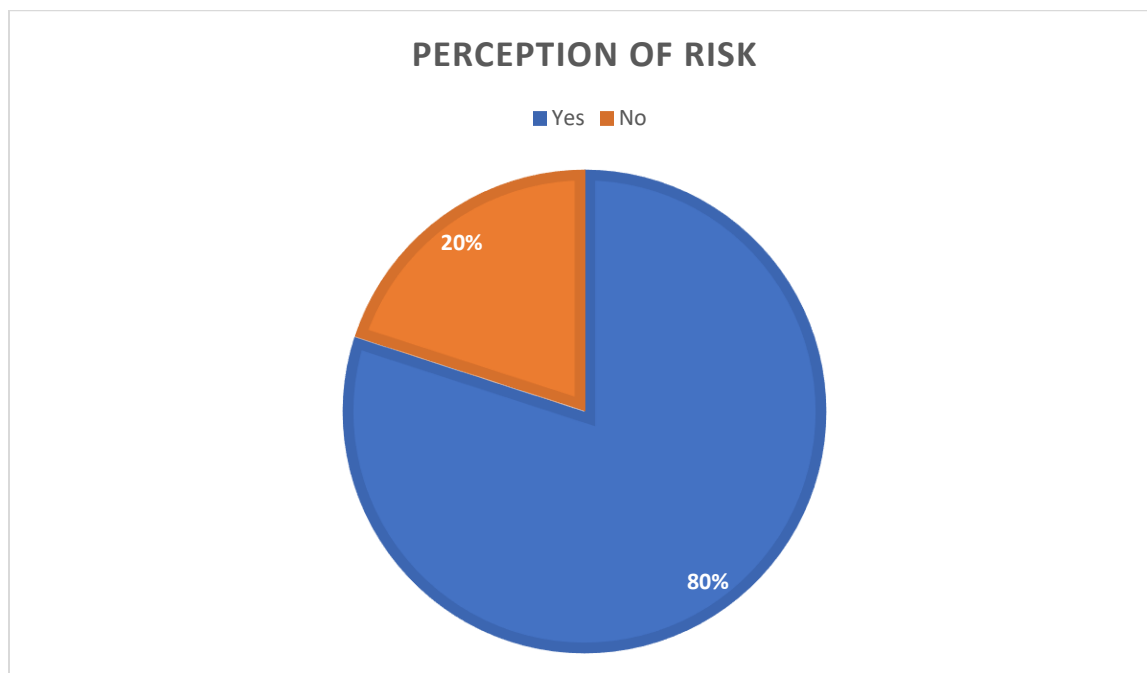


Forty percent indicated that they were blind or had low vision, followed by 20% with physically disabilities, 20% deaf or hard of hearing, 10% deafblind and 10% had no disability, because, in some cases, a person with a disability had difficulty responding to the questionnaire and had a family member respond for them. Seventy percent of respondents belong to or run an organization of persons with disabilities.



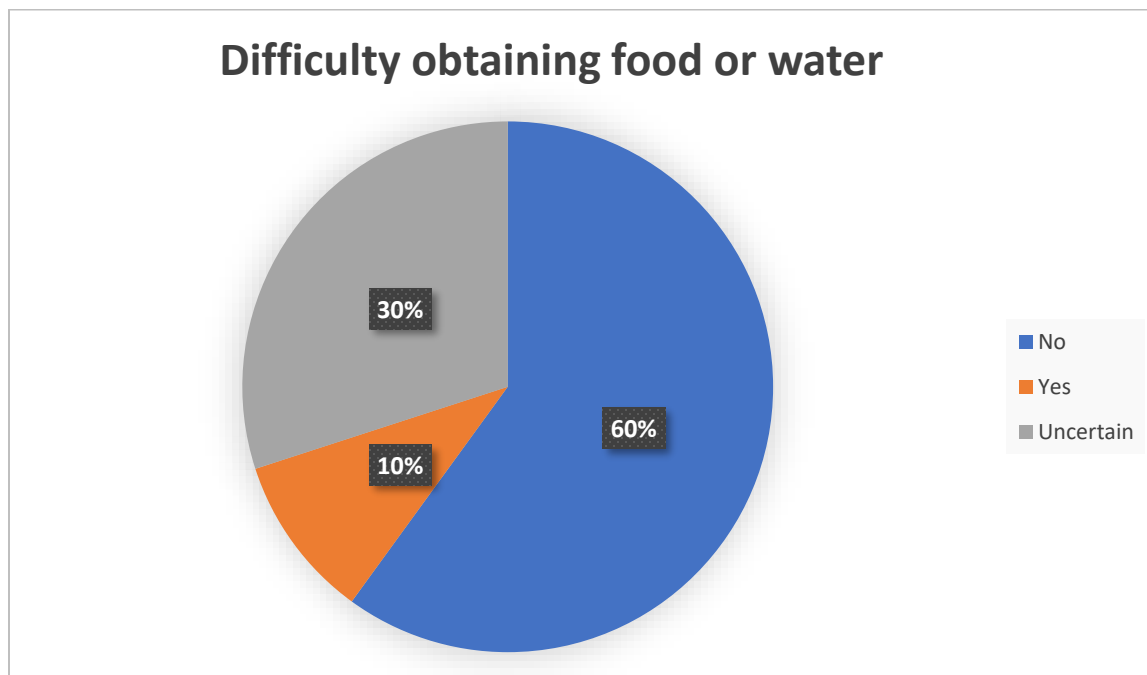
## Life

The majority of respondents (80%) reported that they felt their life was threatened or felt a perception of increased risk to their health due to the COVID-19 pandemic. When asked to explain why, their responses ranged from preexisting health conditions to risk of infection, but also because they felt helpless, and a lack of response from the State.



Interviewees were asked how the pandemic affected their mental wellbeing and they responded that they had feelings of stress, aggressive behavior, fear, uncertainty, and insomnia.

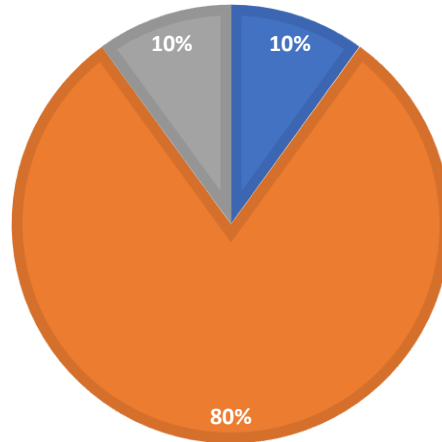
Sixty percent said they had no difficulty obtaining food or water, and this can be explained by the fact that most of the interviewees live in urban areas. They also indicated that they were using sanitizers to clean their hands.



With regards to having difficulty obtaining or putting on personal protective equipment (masks, gloves, and gown), 80% indicated that they did not, while the remaining indicated that they did or that they might have.

### DIFFICULTY OBTAINING OR PUTTING ON PERSONAL PROTECTIVE EQUIPMENT

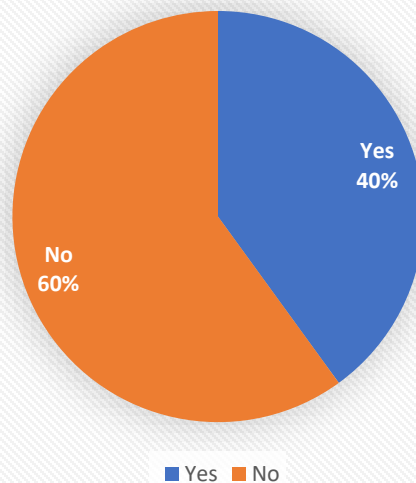
■ Yes ■ No ■ No answer



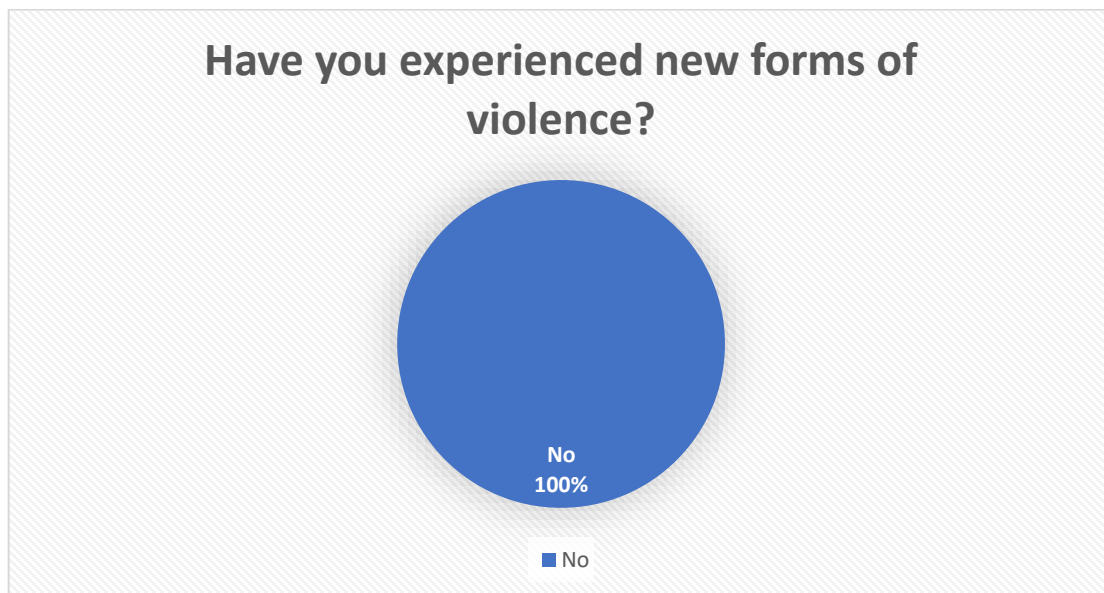
### Security

When asked if they felt more vulnerable or at risk of crime, 60% said no, but the remaining 40% said yes. According to the interviewees, this is due to the unemployment that consequently has generated more crime.

### Have you felt more vulnerable or at risk of crime?

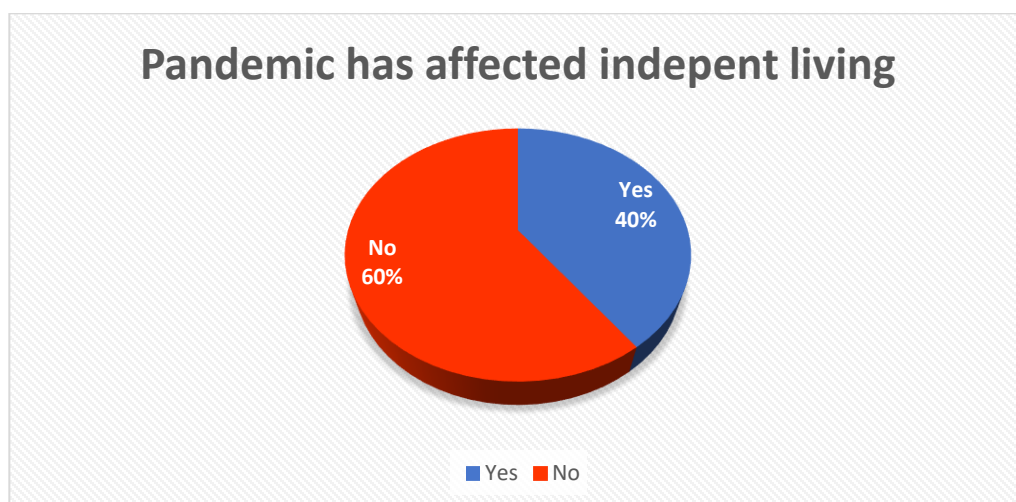


When asked if they were experiencing new forms of violence, 100% said no. This data is interesting, but a wider sample and depth are required to determine what is really taking place in households with people with disabilities. It has been observed that confinement has generated a lot of stress, alcohol consumption, aggressive attitudes and a general emotional disruption that affects all members of the household. For people with disabilities who require some sort of mobility, this has been a serious problem for their families or caretakers as the measures force people to stay at home.



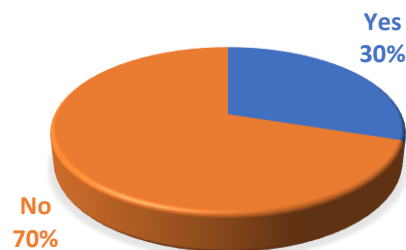
#### Living conditions

Seventy percent indicated that family members' roles had changed and just over half acknowledged that sharing physical space had affected them. Interestingly, 60% said that the pandemic had not affected their independent lives, while 40% said that it had.



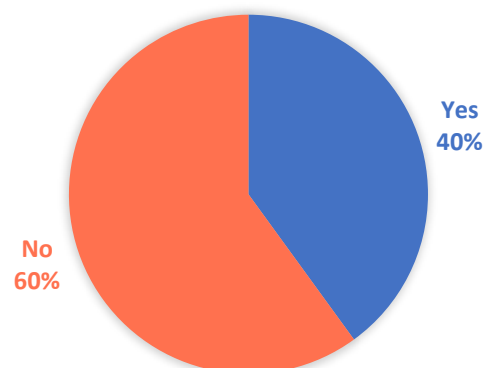
In relation to personal assistants and technical support, again 70% said that vital services, such as personal assistants had not affected them while the remaining 30% said that it had caused them some inconvenience. This has been a real challenge for blind people who use guide dogs since guide dogs also require some space to perform their physiological needs and exercise. The owners of these guide dogs need more flexibility in the COVID-19 restrictions, as they are too often are not considered in the regulations and exceptions.

### PANDEMIC HAS AFFECTED PERSONAL ASSISTANTS



One relevant fact is that most people with disabilities are not aware of the situation of people with disabilities in institutions. In general, they tend to be the most vulnerable within the vulnerable; they lose all contact with the outside world and often cannot even express the treatment and abuses committed against them. This is an issue that has been raised countless times by the Committee of Experts, but which continues to be unresolved, and for this reason, the rights of many persons with disabilities are being violated.

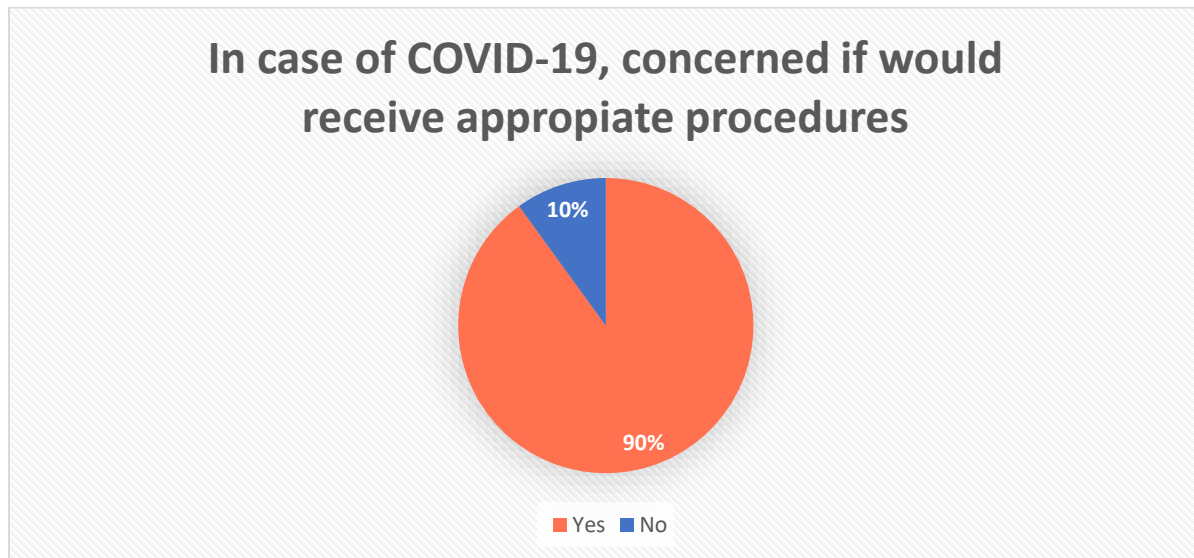
### AWARE OF PERSONS WITH DISABILITIES IN INSTITUTIONS





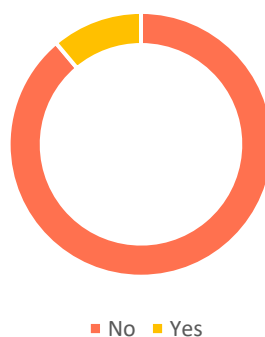
## Health

Ninety percent of the interviewees expressed concern that if they acquired COVID-19, they would not be able to receive the appropriate procedures. This is easily understandable, given the fact that most hospitals do not have adequate protocols or technical assistance to care for people with disabilities. On the other hand, 80% said they were unaware of policies in which they would be affected if they received any treatment under the same conditions as people without disabilities. This point is very important to highlight, because people with disabilities can have pre-existing health conditions that easily could be compromised, if the appropriate treatment is not received.



Sixty percent said they could attend a hospital, even under the restrictions of the pandemic, but 40% said they could not. Regarding access to regular medical services, 60% said they could attend, 30% said they were unsure and 10% said they could not.

Are you aware of any policy that might affect you?



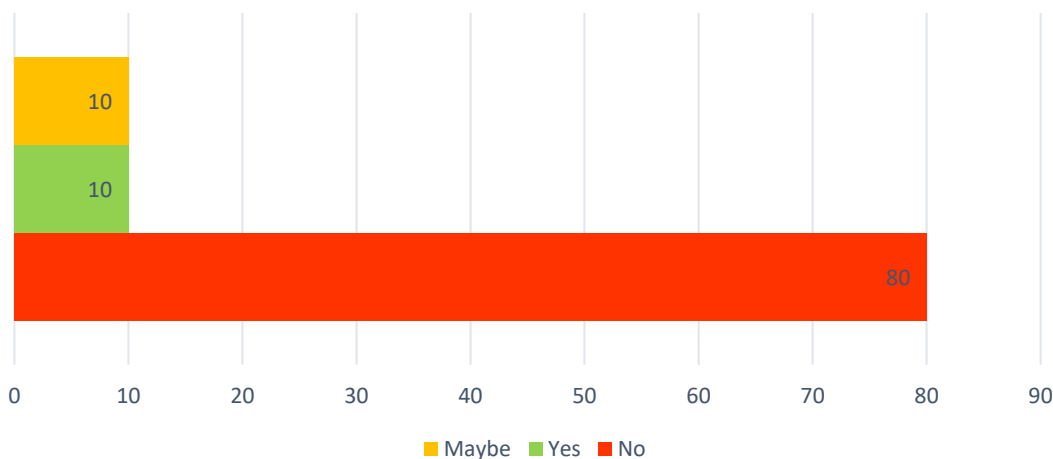
When asked how they obtained their medications, the interviewees indicated that they requested a home service, a family member, or an acquaintance who could assist them. This situation has affected people with disabilities, because social security services have become overloaded. As a result, many people with disabilities have been unable to get their medications on time or at all. Another important point to consider is that many medicines have become scarce or expensive, which has directly impacted people with disabilities.

When asked if in hospitals interviewees could access relevant information, or communicate using sign language interpreters, 100% said no. Eighty percent responded that they did not believe that a personal assistant or interpreter could accompany them. This is a harsh reality for deaf and hard of hearing people who could be negatively impacted by this lack of access to communication and information.

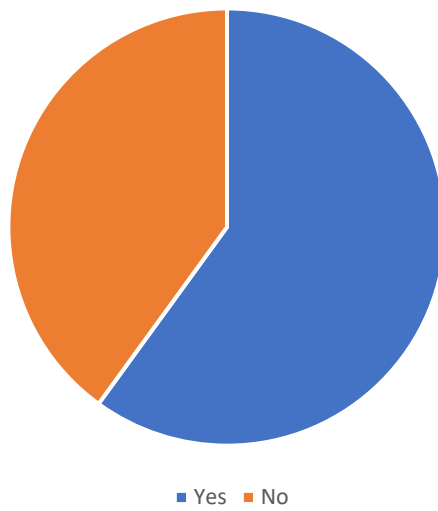
### Access relevant information in hospitals for deaf and hard of hearing persons



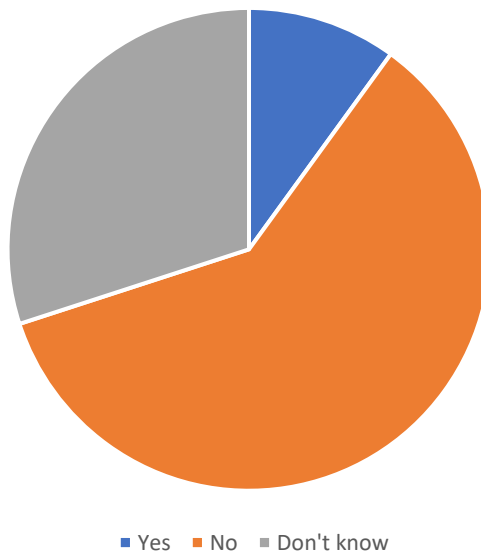
### Personal assistant or interpreter could accompany



Can you go to hospitals for non-elective surgeries or treatments during COVID-19?



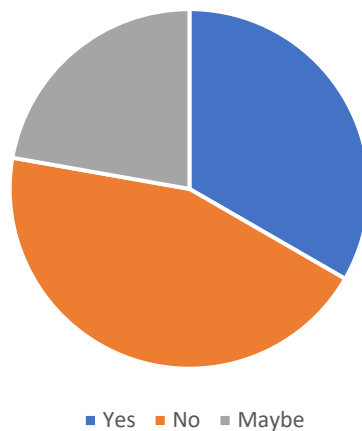
Can you access regular medical services during COVID-19?



## Social protection

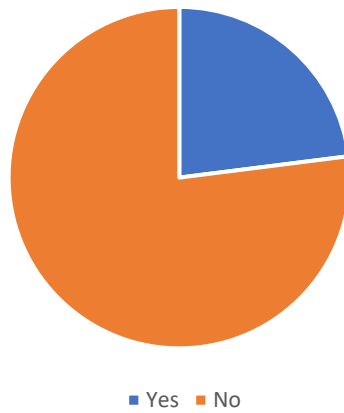
Forty-four percent said that social protection measures had not changed in their country, 33% said they had and 22% said they might have. When asked if social security institutions were providing social protection benefits, 77% said no, and the rest were divided between yes and maybe. This perception confirms that social protection systems have also been seriously impacted, and that many programs have been put on hold or simply not implemented. This is a regrettable response, because this is perhaps the time when State intervention through social programs is most needed.

Have social protection measures changed in your country?

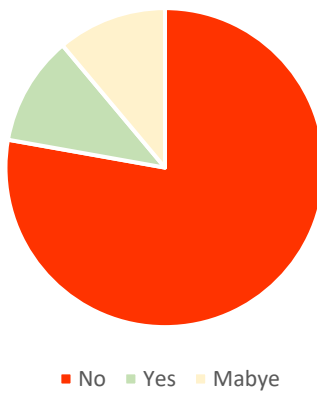


Seventy-seven percent indicated that they had not received any cash benefits related to COVID-19. This can be explained by the slowness shown by the responsible institutions, and the long time it has taken them to respond, due to the development and implementation of new information systems. After this experience, countries will need to prepare and new models of resilience will have to be developed, because, in addition to the high social and human life cost that this pandemic has had, it has devastated the economies of all countries.

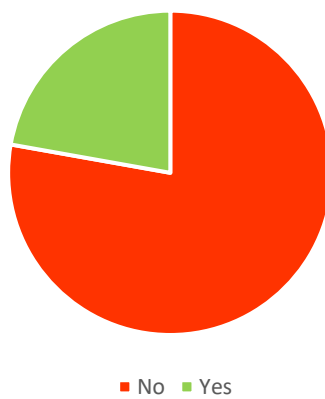
Have you received cash benefits related to COVID-19?



Are social protection benefits provided?

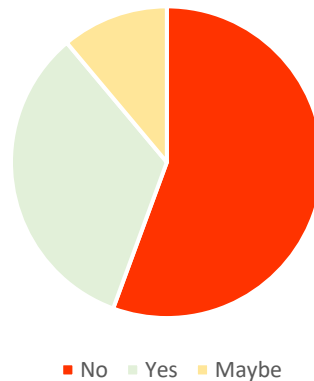


Have new measures been implemented to protect your security?



Regarding local governments (municipal and communal), 55.6% say they have not provided support during the pandemic, while 33.3% indicate that they have and 11.1% that may have received support.

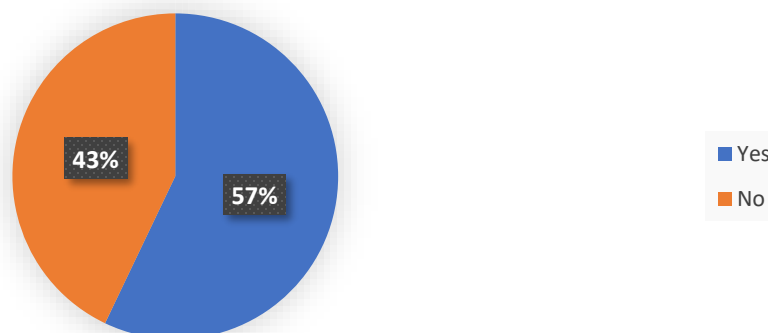
Has local government provided support during the pandemic?



## Employment

Fifty percent said the pandemic had not affected their work, although they did have to change how they were doing it, such as implementing a new form of teleworking. For those that continued to work, 57% said they had found accessibility barriers, compared to 43% who said they had not. The reasons were mainly technological. Computer equipment or the internet were reasons why respondents could not perform their job. A recurring complaint was that there were no fixed working hours. With teleworking, people tended to work longer and transportation times have been reduced, which has had an impact on greater productivity.

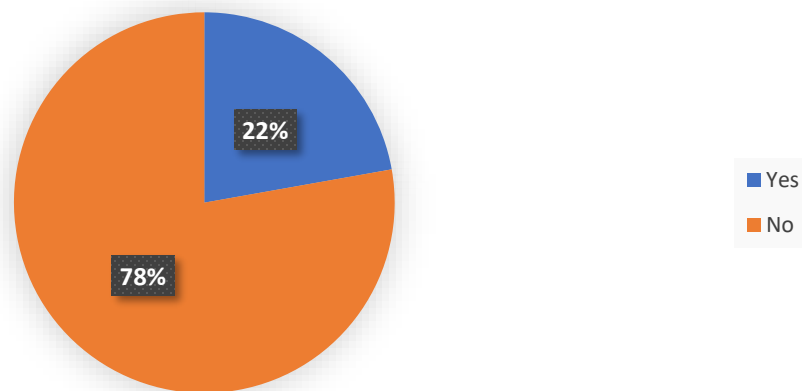
Have you encountered accessibility barriers teleworking?



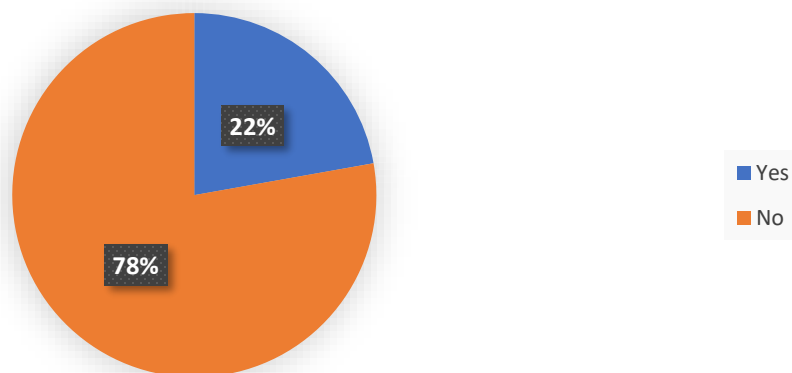
## Emergency plans

Seventy-eight percent of respondents have not been able to access national or local emergency plans, mostly because websites were not accessible for people with disabilities. This situation is regrettable, because considerable investment has been put into setting up emergency and accessibility plans, but they are not fully inclusive.

Access to national or local emergency COVID-19 plans



Are emergency websites accessible for people with disabilities?



## Information

When asked if interviewees were aware of any information or resources available on COVID-19 especially aimed at people with disabilities, respondents expressed they were not aware, and only 10% said they had any information.

In general, many webinars and online workshops have been held allowing people with disabilities to learn new skills and be educated on various topics. WhatsApp groups have been created, and people - in their natural and human need to communicate - have become more participatory. In addition, generally people have been demanding more online content on topics they have not been able to learn or study before. This is a great opportunity for people with disabilities to learn more about issues that concern them, such as the UN Convention on the Rights of Persons with Disabilities.

Are you aware of resources for people with disabilities?

