

‘THIS VIRUS HAS CHANGED US ALL’ EXPERIENCES OF WOMEN WITH DISABILITIES IN THE ASIA-PACIFIC REGION DURING COVID-19

Photo: Subhash Sharma/Sightsavers

The Issue

This paper is based on consultations conducted with women with disabilities from 10 countries across the Asia-Pacific region. The consultations were held in December 2020 and January 2021. At this time, restrictions had been eased or lifted in some of the countries where the participants were based while others still had them in place.

At the time of writing, the COVID-19 pandemic is ongoing, and cases have risen in many of the countries where the consultations took place. This paper intends to provide a better understanding of the experiences of a diverse group of women during the COVID-19 crisis and provide recommendations that will be relevant for the ongoing response and recovery and promote the inclusion of women with disabilities. It will also share recommendations that are applicable far beyond the COVID-19 crisis and that recognise the experiences of the women involved were, in many cases, not unique to the context of COVID-19 but were an amplification of existing experiences resulting from historical and systemic marginalisation and are likely to be experienced in other crises, such the climate crisis.

The full extent of the impact of the COVID-19 pandemic is yet to be fully understood. However, it is clear that the health, social and economic impacts have not been equitably distributed and that the effects will be long-term. It is critical that lessons are learnt from the exclusion of women with disabilities and that more inclusive emergency and long-term responses are developed.

Experiences of women with disabilities during the COVID-19 pandemic

Existing inequalities faced by people with disabilities have been compounded over the last 18 months and particularly for women with disabilities who experience multiple and intersecting inequities. As one woman put it, “women with disabilities always experience a lockdown, when the rest of the country has a lockdown, we experience a double lockdown.”

Discussions highlighted how intersecting forms of discrimination and multiple identities converged. There were significant differences between the experiences of women living in urban areas, where concerns focused on staying safe when going outside, to rural areas where women had less access to information due to limited technology or internet connections.

Most participants emphasised the significant difference in experiences for women with disabilities compared to men, which are explored below. It is worth recognising that this was not a universal experience. One Deaf participant explained that the lack of accessible communication was the biggest challenge she experienced and issues around her gender were less significant.

Women with disabilities who cared for children, with or without disabilities, were highlighted as a group that were significantly affected but not often visible or considered. Patterns of migration within the region also mean that many older women are caring for children with disabilities, and face particular risks and challenges during the pandemic.

POVERTY AND ECONOMIC IMPACTS: The COVID-19 crisis has exacerbated existing levels of poverty for women with disabilities and their ability to meet basic requirements. It is well documented that women with disabilities are less likely to be in employment. When they are, their work is likely to be insecure, informal and low-paid. Women with disabilities explained that their incomes had been affected by COVID-19 and the restrictions, as the sectors where they are over-represented, such as tutoring, were particularly disrupted.

Women with disabilities already experienced a higher cost of living and this was amplified by the increased cost of food, transport and health care during the pandemic. An example was given of one family where the cost of travel increased fourfold. A visit to the hospital would have been financially difficult for them before but was now financially impossible.

A significant concern in relation to the economic impact was the lack of certainty and security about housing, food, health and travel costs which led to an inability to plan. Some women with disabilities were not working prior to the pandemic, due to a lack of reasonable accommodation or their caregiving responsibilities. However, this was made more challenging when other members of the household were also unable to find work.

HEALTH AND SEXUAL AND REPRODUCTIVE HEALTH RIGHTS: Fear around contracting COVID-19 led people to not access health care for other conditions. Even where health services were available, inaccessible or costly transport presented a barrier. The increasing price of medication was also an issue.

Women with disabilities faced particular barriers to accessing their sexual and reproductive rights, including limited access to services and barriers ensuring their autonomy and independence. Pregnant women with disabilities faced additional challenges in accessing the appropriate services.

Menstrual health and management was raised as a particular issue. Cultural norms and requirements about what women can and cannot do whilst menstruating were harder for some people to meet during lockdowns. In some rural areas, there was a shortage of sanitary products, which meant that women with disabilities, who could not travel further afield or ask men to access them on their behalf, went without. A lack of access to clean water was also a particular challenge.

LACK OF INFORMATION AND DATA: Women with disabilities commonly explained that they had lacked understanding about COVID-19. Accessing information was challenging as it was often not accessible or did not consider the specific situations experienced by women with disabilities. One woman from India said, there was also the fear of not knowing what COVID was, little by little the fear increased, and we didn't know about the future."

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A lack of information generates fear and uncertainty about the virus and its impacts. A lack of understanding prevents people from knowing the correct ways to protect themselves from COVID-19. Participants explained that they were told not to touch anyone, but they did not know why, so this impacted their ability to seek the assistance and support that they needed. There were also examples of people with disabilities not seeking medical treatment or leaving the house to access assistance from NGOs or the government because they feared catching COVID-19.

MENTAL HEALTH: The long-term impacts of the COVID-19 pandemic on women with disabilities' psychosocial wellbeing and mental health should not be underestimated and this was a cross-cutting theme across many areas of discussion.

Participants commonly spoke about growing feelings of anxiety and uncertainty. The reasons for increased anxiety and depression and reduced wellbeing are numerous and relate to the direct fear of COVID-19 as well as apprehension about the impacts of the lockdowns.

For women with psychosocial disabilities, this has been particularly acute as they experienced increased frequency and severity of their existing, or previously well-managed, symptoms. One woman said that her anxiety had, "raised up through the roof."

The participants were aware of women with psychosocial disabilities who were being hospitalised due to severe mental health relapses. Whilst in hospital, they then faced increased risks of contracting COVID-19.

One participant said that due to COVID-19 the dosage of psychotropic medication available through the national health insurance had been reduced. This had significant implications on women with psychosocial disabilities, who faced changes to their medication and other forms of support plus the increased stresses of the pandemic.

Existing support structures like peer group meetings and self-help groups were stopped and new online ones were not available or accessible to all. Tensions and changes within families have also impacted people's mental health. The increased incidence of violence and abuse also had significant mental health impacts.

One woman described the long-term impact that COVID-19 had on her and her family. She said, "this virus has changed us all. We are still wondering what will happen in the future."

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Women with disabilities described how existing support systems were being eroded. For example, they were unable to go to church or meet friends and this impacted their wellbeing.

LIMITED MOBILITY AND ISOLATION: In addition to meeting the requirements of lockdowns, women with disabilities felt particularly unable to move around or travel to services. Women with disabilities highlighted the inability to physically distance because they might need to use touch or have support where infrastructure is inaccessible. This meant that they felt even less able to leave their homes.

EDUCATION: The lack of accessible remote learning was raised as a significant challenge. Sign language interpretation or subtitles were not available, and lip-reading was not possible as teachers were wearing masks.

Some resources provided were also not accessible for blind or visually impaired students. The participants also raised that some women with disabilities felt less able to homeschool their children because they had less access to education and the need to educate at home increased the expectations that were placed on them.

INSTITUTIONS: Concerns were raised about the safety of people with disabilities living in institutions. One leader from an Organisation of Persons with Disabilities (OPD) described how they had tried to get information about what was happening, but no data was being collected about COVID-19 rates. Participants had heard of multiple cases of COVID-19 and significant death rates with institutions but it was difficult for them to confirm. One woman explained, "women with disabilities living in the institutions have never been surveyed, they have never been counted."

VIOLENCE AND ABUSE: A common theme throughout all the consultations was an increase in violence and abuse experienced by women with disabilities. This was prevalent in

all geographical areas and a significant concern across women with different impairments.

The request to stay at home was challenging for many because home is not necessarily a safe space. As one woman put it, "violence is coming from the people nearest [to] us."

For some, this lack of safety existed before the pandemic but was amplified by the need to be at home all the time. For others, household dynamics shifted during the pandemic. For example, a loss of family income and tensions around money led to violence.

Violence outside the home was also seen to have increased during COVID-19. In particular, Deaf women and women with hearing impairments particularly shared experiences about women being raped when they left the house during the pandemic. Examples of sexual violence against women with intellectual disabilities were also given.

A couple of examples were also given of violence from the police if they went out or broke lockdown rules, which they often did not understand due to a lack of information.

Participants highlighted that there was a lack of assistance for women who experienced violence and if they were aware of available support mechanisms, such as phone lines, these were often not accessible during the pandemic.

Court systems are often inaccessible and there is a lack of access to financial support, so it is unlikely that women with disabilities will be able to access justice. Participants also highlighted that there was a lack of co-ordination from different agencies, further reducing the likelihood of receiving justice or support.

UNPAID CARE: Participants explained that prior to the pandemic, it was accepted that work inside the home was the responsibility of women. But when this amount of work increased due to restrictions, so did the burden placed on women with disabilities. School closures meant that women were expected to homeschool children whilst continuing with their other household responsibilities.

Responses to COVID-19

The question of access to support, either from the government or other sources, raised interesting and sometimes varied gender dynamics. The participants noted that men with disabilities were better able to access relief packages because it was easier for them to travel to receive them. One reason for this was that women with disabilities are more likely to live with their parents and so may have been overprotected and unable to leave the house. In other cases, there were dynamics around when and where women can go. Alternatively, some people felt that women with disabilities were more likely to leave the house to arrange support for the family but this contributed to the lack of safety, in terms of contracting COVID-19 and the violence that some women experienced.

The lack of accessible communication, such as sign language interpretation, was consistently raised as an issue in responses.

ACCESS TO GOVERNMENT SUPPORT: In some cases, women talked about receiving some government support, at either a local or national level but in multiple countries this was thought to have been slow to arrive. This support included access to essential products such as rice, or a small amount of money. There was also an example of local government providing a circular containing information early in the pandemic. Where women with disabilities had received support, they often had to go to the authorities and specifically ask as they would not have received it automatically. Another positive was the online reporting of gender-based violence which had been introduced. This may have had challenges around accessibility and access to the internet but it was seen as a positive step that did not exist prior to the pandemic.

Other women explained that support did not exist or the participants could not access it. In one country, a government cash transfer for some people with disabilities was supposed to be provided. Participants that spoke about the cash transfer explained it was published in the media so participants were aware but even when they believed they were eligible, they did not receive it. In another country women had heard of government provisions of food but they had not received it and did not know of any other women who had. In another case, a woman explained that cash transfers were distributed from the government through parliamentarians but women with disabilities struggled to access them.

One critical issue that was found across multiple countries, was the classification and registration of people with disabilities by government. This is used for allocating benefits but is not often clear. In some cases, women with disabilities were not entitled to support because they were not correctly registered prior to the pandemic. Participants explained that government lists of people with disabilities had excluded some women as they were not able to travel to register or the support was targeted at household heads

THE ROLE OF OPDS AND WOMEN WITH

DISABILITIES: Participants indicated that women with disabilities have been a huge source of support for each other during the pandemic. As one woman explained, “we called women with disabilities and kept their hope alive.”

OPD leaders explained how they provided information for women in their communities and supported them to access available government provisions.

The sense of solidarity and the power of mutual support between women with disabilities was clear through the answers they gave. This was also shown in the interactions between the women during the consultations.

They also played a crucial role in ensuring that other women with disabilities could access any available support. This was particularly the case for issues such as the provision of sanitary pads, as asking men was culturally inappropriate.

OPDs have given training to their members on using technology and the importance of continuing to go to the hospital. Examples were also given of OPDs supporting access to government benefits. For example, they worked with district officials to ensure that essential food was provided.

OPDs also conducted monitoring reports. In one case, the monitoring led to a government department developing a circular that addressed gaps and challenges in their response.

OTHER FORMS OF SUPPORT: While a lot of discussions focused on the challenges that COVID-19 brought within households, others highlighted that there had been a strengthening of family ties because it has been a hard time for everyone and there was a sense of equity.

Social media, for those who could access it, was identified as a major form of support as it enabled women to connect and express their thoughts on the situation.

INVOLVEMENT IN PLANNING AND RESPONSE: It was consistently said that women with disabilities were not involved in the design or planning of the COVID-19 response and they were also not part of any discussions around the long-term response. Generally, the women said that they felt that the likelihood of them being consulted or involved was low. One woman said, “I’m afraid there is little scope for this.”

Where women with disabilities had been consulted, they were able to give positive examples of how they raised critical issues that needed to be considered in the response.

‘Building back better’

Throughout the COVID-19 pandemic, there has been a call that recovery should not just be about returning to society pre-COVID-19 but should seek to ‘build back better.’ The discussions with women with disabilities across the Asia-Pacific region has highlighted many areas which must be addressed if this is to be realised. This is not a comprehensive list and many specific recommendations could be drawn out in each of the countries in the region, however it provides some indication of the areas where greater efforts are needed to ensure that women with disabilities are not left behind.

Many of the **impacts of COVID-19 on women with disabilities are experienced by other women**, but they are often **amplified by discrimination** or the barriers relating to disability discrimination. This demonstrates the critical importance of ensuring that the experiences of women with disabilities are understood and considered in mainstream responses and by the gender movement.

An intersectional approach that takes into account other factors, such as location, age and ethnicity is critical. It must also consider the specific situations that are more common for women with disabilities and increase their risk of violence, exclusion and poverty. For example, the specific experience of single women caring for children.

Women with disabilities are **carers as well as recipients of care** and their rights and autonomy should be considered from both perspectives. The COVID-19 pandemic has brought discussions around the **disproportionate burden of unpaid care that is placed on women** to the forefront. It is critical that this renewed focus recognises that women with disabilities undertake unpaid care alongside additional challenges such as higher levels of poverty.

Higher levels of poverty and the higher costs of disability underpin many of the experiences of women with disabilities during COVID-19. **The higher costs of disability were also amplified during the pandemic** which highlights the need for this to be built into both emergency response and long-term planning.

There are still significant **challenges and gaps within the policy environment** which mean that the intention of policies is not being realised in practice. This means that many women with disabilities are unable to access their entitlements. There is a need for increased accountability and a specific budget to ensure that existing policies and programmes are put in place.

The impact of COVID-19 has demonstrated the importance of **comprehensive social protection systems**, which provide disability-specific benefits and ensure that people with disabilities can access mainstream social protection benefits. These should take the additional costs of disability into account when setting the benefit level and the barriers that many women with disabilities experience in registering for existing entitlements. Social protection should take **a life course approach** and be **responsive to crisis situations**.

OPDs and organisations of women with disabilities play a critical role in ensuring inclusion and should be meaningfully consulted and included in responses. Women with disabilities should take representative roles on mainstream committees, such as those for disasters.

Many of the gaps in services that were highlighted in the discussions could have been avoided with a strengthened understanding of the lived experience of women with disabilities. However, the burden of ensuring implementation should not sit solely with OPDs.

Despite challenging circumstances, many women with disabilities have been a **critical support to each other during the COVID-19 pandemic**. Spaces (both physical and virtual) which enable mutual support should be supported by governments and development actors.

COVID-19 has highlighted the importance of **working towards de-institutionalisation** and ensuring that people with disabilities can live independently.

The long-term impacts on the **mental health and wellbeing of women with disabilities** should not be underestimated. Providing accessible and inclusive psychosocial support should be a critical element of the recovery from COVID-19. This is essential for all women with disabilities, but particular attention should be paid to the requirements of **women with psychosocial disabilities**.

The COVID-19 pandemic highlighted the importance of **closing the digital divide** which exists within and between countries. Governments and development actors should consider access to the internet as a fundamental human right. Virtual work also offers opportunities for many women with disabilities who may face barriers in travelling for work. Efforts should be made to introduce policies that enable women with disabilities to transition to new forms of work.

Distance learning must be **made available in accessible formats**. But efforts to educate children outside the school setting must recognise that children with disabilities or those living in households with parents with disabilities may also experience higher levels of poverty or additional barriers.

It is vital that **comprehensive, accessible and multi-sectoral approaches are put in place to address gender-based violence** against women with disabilities. This must include ensuring that court and justice systems are accessible and the barriers around poverty and access to resources are addressed.

Increased attention should be paid to ensure that women with disabilities are **able to access their sexual and reproductive health and rights**. There must be particular attention to the intersection between disability discrimination, inaccessibility and cultural norms which create additional and unique barriers for women with disabilities.

Attention should also be given to sectors and policies which can facilitate broader inclusion and access. **Improving access to low-cost, safe and accessible transport** is an enabler for the achievement of many other rights and can facilitate access to services.

National Human Rights Institutions and Disability Commissions should be established or strengthened to ensure that they can play a critical role in accountability. This must complement the role that OPDs can and should play. In some cases, local or district bodies may also play an important role.

Sightsavers

The brief is initiated by a UN-Women led Joint Programme to support countries design and implement disability inclusive response and recovery planning for COVID-19, supported by UN Partnership on the Rights of Persons with

Disabilities (UNPRPD). [Sightsavers](#) served as technical partners on this brief. Sightsavers is an international development organization which works with partners to eliminate avoidable blindness, ensure the provision of quality inclusive education, and promote equality of opportunity for people with disabilities in over thirty low-and-middle income countries.