'*Because of COVID, everything is a mess*' How have people with disabilities experienced the pandemic in Nepal and Bangladesh?

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Executive summary – Easy read English

What we did

- We asked 35 people with disabilities in Bangladesh (20 people) and Nepal (15 people) to tell us about their lives during the COVID-19 outbreak. They had different disabilities such as deafblindness, intellectual disabilities and psychosocial disabilities. We wanted to ask them as they are not often asked about their lives. We also asked parents who had children with disabilities.

What we found out

- The COVID-19 outbreak has made life worse for many people with disabilities as well as many other people.

- To stay safe from COVID-19 people were told to stay at home, which is called a lockdown. This meant some people with disabilities and their families lost their jobs and did not have enough money for food and medicine and other things. This made them very sad and worried.

- They managed by getting money or food from other family members, or by using the money they had saved, or by borrowing money, or by selling things they owned.

- Some people also got some help from the government, or organisations of people with disabilities, or charities. But many people did not get any help or not enough.

- Information provided about the COVID-19 outbreak was not easy to understand. This made it hard for some people to know what they should be doing to keep safe or why they had to stay at home.

- People with visual disabilities use touch to understand the world. But during the COVID-19 outbreak touching things is unsafe as the virus which makes you sick may be on those things. People did not want to help blind people by touching them. This means it was more difficult for them to get around and be independent.

- COVID-19 has changed how everyone lives. This was a shock for many people and made them unsure about what would happen to them and their families. Staying at home all the time was also very boring and made people unhappy. Worries about money caused conflict in families. People felt scared and hopeless and like there was nothing they could do to make things better. People missed their friends, but some kept in touch with each other by phone.

- After a while people were allowed to leave home again. This meant some people could get their jobs back and they felt happier as they now had money to pay for things like food. Other people were happy because of the new COVID-19 vaccine, which can help you to avoid getting COVID-19.

- Some people still did not have work or money to buy food and they were still sad and worried. They did not have any more money and they had to pay back the money they borrowed which was hard for them. The organisations which helped them before had stopped helping them.

- People with different disabilities were affected in different ways. Some said that other people treated them badly, sometimes this was the same as before and sometimes it was worse than before.

- It is important that the government and other organisations help people with disabilities during the COVID-19 outbreak. They should ask people with disabilities about what they need and how this help should be given to them.

Executive summary - English

COVID-19 is deepening pre-existing inequalities. Emerging research suggests that people with disabilities across the world have experienced various rights violations and been disproportionality affected by the health, economic and social impacts of the pandemic and responses to it. The aim of this research was to better understand how people with disabilities who are often excluded from research have experienced the evolving COVID-19 pandemic in Bangladesh and Nepal. In order to better understand how it has affected some of the most marginalised groups of people with disabilities, this study used in-depth qualitative research to focus on people with intellectual, psychosocial, deafblindness and other multiple impairments.

Methodology

A narrative interviewing approach was selected. Telling stories is a natural and universal form of communication and enables participants to make sense of their experiences and focus on what matters to them. Each participant was invited to participate in two interviews, a few weeks apart. This enabled participants to feel more comfortable in sharing their experiences and indicate how these changed as the pandemic progressed. Participants were recruited with the help of organisations of people with disabilities (OPDs) and international and in-country non-government organisations I/NGOs Humanity & Inclusion in Nepal and ADD International and Centre for Disability in Development (CDD) and Sense International in Bangladesh. For safety during the pandemic, the interviews were conducted online or by phone, with reimbursement for data costs and support with technological access. Participants' access and communication support needs were also met. Thematic analysis was conducted online by the IDS team, in-country researchers and some consortium partners and local OPD representatives.

Finally, all interviewees and other key people were invited to a joint online validation workshop which was attended by more than 30 people: participants with disabilities, their supporters, and NGO staff and OPD representatives from both countries. This enabled the participants to meet each other, share their experiences, verify the summary of findings and recommendations to ensure that future pandemic management and mitigations are disability inclusive.

Participants

19 out of 35 participants had multiple impairments, including deafblindness, 11 had intellectual impairments, three had psychosocial impairments, and two participants were parents of children with disabilities. 20 people were interviewed in Bangladesh and 15 in Nepal.

Findings

> "*Everyone has spent their days in misery.*" (Bangladeshi man with deafblindness)
>
> *"Everyone is sad and worried because of the pandemic."* (Nepali woman with psychosocial impairment)

The participants with disabilities and their families experienced major negative economic impacts as they and/or their family members lost their jobs, businesses, or other income as a result of lockdowns and other pandemic restrictions. Families where at least one person was still working were in a slightly better position as they still had some income, while those with pre-existing financial difficulties such as unemployment, struggled the most. Interviewees reported reduced food consumption and hunger as they could no longer afford regular meals, and some feared they and their families would starve. Increased food and transport costs during the pandemic made things more difficult. People also struggled to afford medical costs. This financial crisis caused them significant stress and mental pressure as they struggled to meet their needs. In order to survive during the pandemic lockdown, many interviewees relied on financial support from external family members or friends, used up their savings or business capital, or took out loans.

Government social protection assistance was often only the pre-existing disability assistance, and state support (both COVID-19 specific and from prior programmes) was not provided to many people with disabilities. I/NGOs and in particular OPDs were found to play an important role in supporting people with disabilities during the pandemic. Around half of interviewees in both Bangladesh and Nepal were receiving some financial or other support from OPDs or NGOs, especially from the organisations they already had links with. Such formal support was important to survival for many, however the assistance provided was often inadequate for their family's needs and many people with disabilities did not receive any assistance from any formal sources. Some OPDs also supplied hygiene kits or food packages to people with disabilities, others raised awareness of disability rights. OPDs also played an important role in maintaining mental health by creating opportunities to socialise and discuss problems. Access to essential health and education services was restricted for people with disabilities due to the COVID-19 lockdown. This was on top of pre-existing barriers to services which they faced. Access to information was challenging, and misinformation was found to be of particular concern in Nepal.

The pandemic was particularly challenging for people with visual impairments, due to their reliance on touch, which is discouraged to reduce the spread of the virus. This reduced their independence and increased their isolation, especially as their need for touch was not understood by others. Those with hearing impairment had reduced access to information especially at the beginning of the pandemic. People with deafblindness had increased communication barriers during the pandemic, especially due to the lack of accessible information. Some people with intellectual disabilities or deafblindness found it hard to understand what coronavirus is and why they must remain indoors. The closure of schools and day centres meant children with disabilities (especially those with intellectual impairments and autism) missed out on socialisation, stimulation, and therapy. In Bangladesh, community members believed that people with disabilities were more likely to be carrying the virus and mocking and bullying was reported by several participants.

The abrupt suspension of the 'old normal' life, the dramatic changes, and the need to adapt meant that many participants experienced intense shock and fear as their usual life was completely disrupted. The loss of the stability of their usual life resulted in disorientation and uncertainty about what would happen to them and their families, while the restrictions meant that life was boring and unhappy. The loss of freedom during lockdown and financial difficulties exacerbated tensions between spouses and other family members. People felt hopeless, helpless and depressed in the worst times of the crisis.

As restrictions eased and interviewees or their families were able to find work, life for some participants improved as they were able to meet some of their family's immediate needs. Others also felt happier and more hopeful as they were less worried about COVID-19, especially as a result of vaccine development. However, many still struggled to find work and were still struggling to survive or thrive. Strategies for survival such as taking out loans or using up business capital held people back from restarting their livelihoods. Furthermore, the support from various sources which helped people survive the first lockdown was not necessarily sustained despite the continued need for it. There were serious worries about survival during a possible second lockdown as their resources had been used up during the first one. Whilst the acute distress changed over time as people adjusted to the situation, the pandemic is not over, and so the uncertainty continues.

Conclusions

The COVID-19 pandemic and government responses to it have had devastating and life-changing detrimental effects on people with disabilities from the most marginalised groups in Nepal and Bangladesh. Disability inclusive approaches to the pandemic must be developed together with people with disabilities to ensure that the rights and fundamental freedoms of all persons with disabilities can be realised without discrimination of any kind on the basis of disability.

Executive summaries – Bangla

‘কোভিড মহামারীর কারনে সার্বিক অবস্থার ব্যাপক অবনতি’ মহামারী চলাকালীন সময়ে নেপাল এবং বাংলাদেশের প্রতিবন্ধী ব্যক্তিদের অভিজ্ঞতা কেমন ছিল?

নির্বাহী সারসংক্ষেপ: সহজ পাঠ্য বাংলা

আমরা যা করেছি

বাংলাদেশ (২০ জন) ও নেপাল (১৫ জন) সহ মোট ৩৫ জন প্রতিবন্ধী ব্যক্তির কাছ থেকে কোভিড-১৯ মহামারীর সময় তাদের জীবনযাত্রা কেমন ছিল তা আমরা জানতে চেয়েছিলাম। এসব ব্যক্তিরা বিভিন্ন ধরনের প্রতিবন্ধিতার শিকার ছিলেন, যেমনঃ শ্রবণদৃষ্টি প্রতিবন্ধিতা, বুদ্ধি প্রতিবন্ধিতা, মানসিক প্রতিবন্ধিতা। যেহেতু তাদের কাছ থেকে তাদের জীবন সম্পর্কে তেমন জানতে চাওয়া হয় না, তাই আমরা তাদের কাছ থেকে তাদের জীবন সম্পর্কে জানতে চেয়েছিলাম। এমনকি আমরা যেসব পিতামাতার প্রতিবন্ধী সন্তান রয়েছে তাদের থেকেও জানতে চেয়েছিলাম তাদের অবস্থা সম্পর্কে।

আমরা যা জেনেছিঃ

- কোভিড-১৯ এর প্রাদুর্ভাব অন্যান্য ব্যক্তিদের মত প্রতিবন্ধী ব্যক্তিদের জীবনকেও দুঃসহ করে তুলেছে।
- কোভিড-১৯ থেকে নিরাপদ থাকতে সবাইকে লকডাউন বা ঘরে থাকতে বলা হয়েছিল। যার পরিপ্রেক্ষিতে কিছু প্রতিবন্ধী ব্যক্তিসহ তাদের পরিবারের সদস্যদের কাজ হারাতে হয়েছিল, এছাড়াও তাদের কাছে খাবার,ওষুধ সহ অন্যান্য প্রয়োজনীয় জিনিসপত্র কেনার জন্য পর্যাপ্ত টাকা ছিল না, যার ফলে তারা দুঃখী ও চিন্তিত হয়ে পড়েছিল।
- তারা তাদের পরিবারের অন্যান্য সদস্যদের কাছ থেকে টাকা অথবা খাবার চেয়ে নিয়ে বা নিজেদের সামান্য জমানো টাকা দিয়ে কিংবা টাকা ধার করে অথবা নিজেদের কোন জিনিসপত্র বিক্রি করে চলার চেষ্টা করেছিল। কিন্তু তাদের মধ্যে এমনও মানুষ ছিল যারা কোন ধরনের সাহায্য পায় নি অথবা যে সাহায্য পেয়েছে সেটা অপ্রতুল ছিল।
- কোভিড-১৯ এর প্রাদুর্ভাব নিয়ে যে সকল তথ্য সরবারাহ করা হয়েছিল সেটা অনেকের জন্য সহজবোধ্য ছিল না, যার ফলে নিজেদের নিরাপদ রাখার জন্য কি করা উচিত তা বুঝা মুশকিল হয়ে যাচ্ছিলো এমনকি তারা এটাও বুঝতে পারছিলেন না যে নিরাপদ থাকার জন্য কেন তাদের ঘরে থাকা প্রয়োজন।

- একজন দৃষ্টি প্রতিবন্ধী ব্যক্তি সাধারণত স্পর্শের সাহায্যে তার আশে পাশে যা কিছু আছে তা বুঝার চেষ্টা করে। কিন্তু কোভিড-১৯ মহামারীর সময় স্পর্শ করাটা অনেকটা অনিরাপদ হয়ে পড়ে কারন দৃষ্টি প্রতিবন্ধী ব্যক্তিরা যেসব জিনিস স্পর্শ করবে সেসব জিনিসের উপর মানুষকে অসুস্থকারী এই ভাইরাসের উপস্তিতি থাকতে পারে। এমনকি অন্যান্য মানুষজন শ্রবণদৃষ্টি ও দৃষ্টি প্রতিবন্ধী মানুষদের স্পর্শ করার মাধ্যমে সাহায্য করতে চাইতো না। যার ফলে তাদের পক্ষে স্বাধীন ভাবে চলাফেরা করাটা অনেক কষ্টকর হয়ে পড়ে।

- কোভিড-১৯ মানুষের স্বাভাবিক জীবন প্রক্রিয়া অনেক পরিবর্তন করে দিয়েছিল। এটা অনেক মানুষের জন্য অনেক বড় ধাক্কা ছিল এবং এটা তাদের নিজেদের ও তাদের পরিবারের সাথে ভবিষ্যতে কি হবে সেটা অনিশ্চিত করে তুলেছিল। সবসময় ঘরের মধ্যে আবদ্ধ থাকা মানুষের জন্য অনেক একঘেয়েমিপূর্ণ হয়ে গিয়েছিল এবং এই বিষয়টা তাদের অসুখীও করে তুলেছিল। অপরদিকে টাকা নিয়ে দুশ্চিন্তার কারনে পরিবারের মধ্যে কলহ সৃষ্টি হচ্ছিলো। মানুষজন ভীতসন্ত্রস্ত ও হতাশ হয়ে পড়েছিল এবং তাদের মনে হচ্ছিলো যে পরিস্থিতি আবার স্বাভাবিক করে তোলার জন্য তাদের হাতে আর কিছুই নেই। মানুষজন তাদের বন্ধুবান্ধবদের অভাব অনুভব করছিল, যদিও কিছু মানষ তাদের বন্ধুদের সাথে ফোনের মাধ্যমে যোগাযোগ রাখতে সক্ষম ছিল।

- কিছু সময় পর লকডাউন তুলে নিয়ে পুনরায় তাদের ঘর থেকে বের হওয়ার অনুমতি দেওয়া হয়। যার ফলে কিছু মানুষ আবার তাদের চাকরি ফিরে পেয়েছিলেন এবং অনেক খুশি ছিলেন করণ এখন তাদের কাছে খাবার ও অন্যান্য দ্রব্যসামগ্রীর কেনার মত টাকা আছে। অন্যান্য মানুষজন কোভিড-১৯ এর নতুন ভ্যাকসিনের জন্য খুশি ছিলো কারন ভ্যাকসিন এখন কোভিড-১৯ এর সংক্রমণ কমাতে সাহায্য করবে।

- যদিও কিছু মানুষজনের এখনো কোনো ধরনের কাজ ছিলো না এবং খাবার কিনে খাওয়ার মত টাকাও ছিল না যার কারনে তারা খুবই দুঃখী ও চিন্তিত ছিলেন। এমনকি তাদের কাছে আর কোন টাকা অবশিষ্ট ছিলনা এবং যার ফলে মহামারী চলাকালীন সময়ে বেঁচে থাকার জন্য যে ঋণ নিয়েছিল সেই টাকা ফেরত দেওয়া খুবই কঠিন হয়ে পড়েছিল। যে সংস্থাগুলো পূর্ববর্তী সময়ে তাদের সহায়তা প্রদান করেছিল তারাও সাহায্য করা বন্ধ করে দিয়েছিল।

- বিভিন্ন ধরনের প্রতিবন্ধিতার শিকার ব্যক্তিগণ বিভিন্নভাবে সমস্যার সম্মুখীন হয়েছিলেন। কিছু মানুষের বক্তব্য এমন ছিল যে অন্যান্য ব্যক্তিরা তাদের সাথে অনেক খারাপ আচরণ করতো, কখনো যেটা কোভিড-১৯ এর আগের ব্যবহারের মত ছিল আবার অনেক ক্ষেত্রে সেটা আগের ব্যবহারের থেকে অনেক খারাপ ছিল।
- কোভিড-১৯ মহামারীর মত সময়ে সরকারী ও অন্যান্য প্রতিষ্ঠানের জন্য এটা খুবই গুরুত্বপূর্ণ যাতে তারা প্রতিবন্ধী ব্যক্তিদের সহায়তা প্রদান করেন। তাদের উচিত প্রতিবন্ধী ব্যক্তিদেরকে তাদের প্রয়োজন সম্পর্কে জিজ্ঞেস করা এবং কিভাবে তারা এ সহায়তা লাভ করতে চায় সেই বিষয়েও তাদের মতামত নেওয়া।

সারসংক্ষেপঃ

কোভিড-১৯ মহামারী বিদ্যমান বৈষম্যগুলোকে আরও প্রকট করে তুলেছে। নিত্যনতুন গবেষণা থেকে এ তথ্য পাওয়া যায় যে বিশ্বব্যাপী প্রতিবন্ধী ব্যক্তিরা বিভিন্নভাবে তাদের অধিকার থেকে বঞ্চিত হয়েছেন এবং মহামারীর স্বাস্থ্যগত, অর্থনৈতিক ও সামাজিক প্রভাব এবং এর সাড়াদান কর্মকান্ডের ক্ষেত্রেও অসমভাবে ক্ষতিগ্রস্ত হয়েছেন। এই গবেষণার উদ্দেশ্য ছিল বাংলাদের ও নেপালের প্রতিবন্ধী ব্যক্তিরা যারা প্রায়ই বিভিন্ন ধরনের গবেষণা থেকে বাদ পড়ে যায় তারা এই কোভিড-১৯ এর ফলে উদ্‌ভূত পরিস্থিতিতে কি ধরনের অভিজ্ঞতার সম্মুখীন হয়েছেন তা তুলে ধরা। এই পরিস্থিতি, সবচেয়ে প্রান্তিক জনগোষ্ঠী যেমনঃ প্রতিবন্ধী ব্যক্তিদের কিভাবে ক্ষতিগ্রস্ত করেছে সে বিষয়ে আরও ভালো ধারণা লাভ করার জন্য এই গবেষণাতে বিশদ গুনগত সাক্ষাৎকারের মাধ্যমে তথ্য সংগ্রহ করা হয়েছে যাতে করে বুদ্ধি, মানসিক, শ্রবণদৃষ্টি প্রতিবন্ধিতা এবং অন্যান্য বিভিন্ন ধরনের প্রতিবন্ধিতার উপর গুরুত্ব দেওয়া যায়।

পদ্ধতিঃ

এই গবেষণার জন্য একটি বর্ণনামূলক সাক্ষাৎকার নেওয়ার পদ্ধতি গ্রহণ করা হয়েছে। গল্প বলা যোগাযোগের স্বাভাবিক এবং সর্বজনগ্রাহ্য একটি পদ্ধতি এবং এর মাধ্যমে অংশগ্রহণকারীরা নিজেদের অভিজ্ঞতার কথা সাবলীলভাবে বলতে পারে। একই সাথে তাদের কাছে যেটা প্রয়োজনীয় সেই ব্যাপারেও গুরুত্ব দিতে পারে। প্রত্যেক অংশগ্রহণকারীকে কিছু সপ্তাহের ব্যবধানে দুইটি সাক্ষাৎকারে অংশগ্রহণ করার জন্য আমন্ত্রণ জানানো হয়। যার ফলে অংশগ্রহণকারীরা নিজেদের অভিজ্ঞতাগুলো খুব সহজেই বলে ফেলতে পারতো এবং তারা আরও ভালোভাবে মহামারীর ঊর্ধ্বগতির সাথে তাদের পরিবর্তিত অবস্থা বুঝাতে পারত। অংশগ্রহণকারীদের, প্রতিবন্ধী ব্যক্তিদের নিয়ে কাজ করে এমন বিভিন্ন প্রতিষ্ঠান, বিভিন্ন আন্তর্জাতিক ও স্থানীয় এনজিও, নেপাল ও বাংলাদেশের মানবতা ও অন্তর্ভুক্তি নিয়ে কাজ করে বিভিন্ন সংস্থা, যেমনঃ এডিডি ইন্টারন্যাশনাল এবং সেন্টার ফর ডিজ্যাবিলিটি ইন ডেভেলপমেন্ট (সিডিডি) এর সহায়তায় বাছাই করা করা হয়েছিল ।

কোভিড-১৯ মহামারীর কারনে অংশগ্রহণকারীদের নিরাপত্তার কথা মাথায় রেখে এবং বিভিন্ন ধরনের প্রযুক্তিগত সহায়তার মাধ্যমে বেশিরভাগ সাক্ষাৎকার ফোনে অথবা অনলাইনে নেওয়া হয়েছিল। এছাড়াও অংশগ্রহণকারীদের অভিগম্যতা (Accessibility) এবং যোগাযোগ সহায়ক সরঞ্জামের ব্যবস্থাও করা হয়েছিল। এছাড়াও আইডিএস এর একটি দল, দেশীয় গবেষক দল, কিছু কনসোর্টিয়ামের সদস্যগণ এবং স্থানীয় ওপিডি প্রতিনিধিদের মাধ্যমে বিষয়ভিত্তিক সাক্ষাৎকারগুলো অনলাইনের নেওয়া হয়েছিল ।

সবশেষে, সাক্ষাৎকারে অংশগ্রহণকারী সকল ব্যক্তি ও অন্যান্য প্রধান ব্যক্তিদের তথ্যের শুদ্ধতা যাচাই করার জন্য তাদের একটি অনলাইন কর্মশালায় নিমন্ত্রণ করা হয়, যেখানে ৩০ জনের অধিক মানুষ অংশগ্রহণ করেছিলেন, যাদের মধ্যে ছিলেন অংশগ্রহণকারী প্রতিবন্ধী ব্যক্তিবর্গ, তাদের সাহায্যকারী এবং উভয় দেশের এনজিও ও ওপিডি কর্মীগণ। এর মাধ্যমে অংশগ্রহণকারীরা একে অপরের সাথে সরাসরি সাক্ষাৎ করতে পেরেছিলেন, নিজেদের অভিজ্ঞতা বিনিময় করতে পেরেছিলেন, ফলাফলের সারমর্মের যথাযথতা যাচাই করতে পেরেছিলেন এবং নিজেদের সুপারিশসমূহ তুলে ধরতে পেরেছিলেন, যাতে ভবিষ্যতে মহামারীর ব্যবস্থাপনা ও প্রশমনের ক্ষেত্রে প্রতিবন্ধী ব্যক্তিদের অন্তর্ভুক্ত করা হয়।

অংশগ্রহণকারীগণঃ

৩৫ জন অংশগ্রহণকারীর মধ্যে ১৯ জনের শ্রবনদৃষ্টি প্রতিবন্ধিতাসহ একাধিক ধরনের প্রতিবন্ধিতা ছিল, ১১ জনের বুদ্ধি প্রতিবন্ধিতা, ৩ জনের মানসিক প্রতিবন্ধিতা এবং দুইজন ছিলেন প্রতিবন্ধী শিশুর পিতামাতা। এদের মধ্যে ২০ জনের সাক্ষাৎকার নেওয়া হয়েছিল বাংলাদেশে এবং ১৫ জনের নেপালে।

ফলাফলঃ

"*সকলেই দুঃখ-দুর্দশার মধ্য দিয়ে তাদের দিন অতিবাহিত করেছে” (বাংলাদেশের একজন শ্রবণদৃষ্টি প্রতিবন্ধী পুরুষ)*

"*কোভিড-১৯* মহামারীর কারণে *সকলেই দুঃখী ও চিন্তিত*" (*নেপালের একজন মনোসামাজিক* প্রতিবন্ধী নারী)

লকডাউন এবং মহামারী সম্পর্কিত বিভিন্ন বিধি নিষেধের ফলে শ্রবণদৃষ্টি প্রতিবন্ধী ব্যক্তি এবং তাদের পরিবার গুরুতর অর্থনৈতিক মন্দার সম্মুখীন হয়েছিল যার ফলে অনেকেরই/ তাদের পরিবারের সদস্যদের কাজ, ব্যবসা অথবা আয়ের উৎস হারাতে হয়েছিল। যেসব পরিবারের অন্তত একজন ব্যক্তি কাজ করছিলেন তারা তুলনামূলকভাবে কিছুটা ভালো অবস্থায় ছিল যেহেতু তাদের পরিবারের আয় তখনও চলমান ছিল, অপরদিকে যারা আগে থেকেই বেকারত্বের কারনে অর্থনৈতিক সমস্যার ভিতর দিয়ে যাচ্ছিল তারা সবথেকে কঠিন পরিস্থিতির সম্মুখীন হয়েছিল। এমনকি সাক্ষাৎকারীরা জানিয়েছে যে, নিয়মিত তিনবেলা খাবার যোগাড় করতে না পারার কারনে তারা তাদের খাবারের পরিমান কমিয়ে দিয়েছিল এমনকি অনেক সময় ক্ষুধার্তও থাকত এবং এই শঙ্কায়ও ছিল যে তাদের পরিবারকে অনাহারে থাকতে হবে। মহামারী চলাকালীন সময়ে খাদ্য এবং পরিবহন খরচের মূল্যবৃদ্ধি পরিস্থিতিকে আরও কঠিন করে তুলেছিল। এবং চিকিৎসা খরচ বহন করার জন্য মানুষকে কঠিন পরিস্থিতির মধ্য দিয়ে যেতে হয়েছিল। আর্থিক সংকটের কারনে যেহেতু তারা তাদের মৌলিক চাহিদাগুলো পূরণ করতে পারছিল না, ফলে তারা প্রবল দুশ্চিন্তা এবং মানসিক চাপের ভিতর দিয়ে গিয়েছিল। মহামারীর কারনে প্রদত্ত লকডাউনের সময় বেঁচে থাকার জন্য, অনেক সাক্ষাৎকারীদের তাদের পরিবারের অন্যান্য সদস্যদের অথবা বন্ধুদের আর্থিক সহায়তার উপর নির্ভর করতে হয়েছিল, জমানো টাকা ব্যবহার, অথবা ঋণ নিতে হয়েছিল।

সরকারী সামাজিক সুরক্ষা বিষয়ক সহায়তাগুলো প্রায়শই শুধুমাত্র পূর্ব থেকে বিদ্যমান যেসব প্রতিবন্ধী ব্যক্তিদের তালিকা রয়েছে শুধুমাত্র তাদেরই প্রদান করা হয়ে থাকে, এবং অনেক প্রতিবন্ধী ব্যক্তিকে কোন রাষ্ট্রীয় সহায়তা (কোভিড-19 বিশিষ্ট সহায়তা এবং পূর্ববর্তী প্রোগ্রাম, উভয় ক্ষেত্রেই) প্রদান করা হয়নি। মহামারী চলাকালীন সময়ে বিভিন্ন আই/এন জিও বিশেষ করে ওপিডিগুলো প্রতিবন্ধী ব্যক্তিদের সহায়তা করার ক্ষেত্রে গুরুত্বপূর্ণ ভূমিকা পালন করেছে। বাংলাদেশ এবং নেপালের প্রায় অর্ধেক সাক্ষাৎকারীরা বিভিন্ন ওপিডি কিংবা এনজিও থেকে কিছু পরিমাণে আর্থিক বা অন্যান্য ধরণের সহায়তা পেয়েছে বলে জানিয়েছেন, বিশেষ করে যেসব সংস্থার সাথে তারা আগে থেকে জড়িত ছিলেন তাদের থেকে এই সহায়তাগুলো পেয়েছিলেন। এই ধরনের আনুষ্ঠানিক সহায়তা অনেকেরই বেঁচে থাকার জন্য গুরুত্বপূর্ণ ভূমিকা পালন করেছে, তবুও প্রদত্ত সহায়তা প্রায়শই তাদের পরিবারের প্রয়োজনের তুলনায় যথেষ্ট ছিল না এবং এমনকি অনেক প্রতিবন্ধী ব্যক্তিই কোনো আনুষ্ঠানিক উৎস থেকে কোনো সহায়তা পাননি। কিছু কিছু ওপিডি প্রতিবন্ধী ব্যক্তিদের জন্য স্বাস্থ্যবিধি মেনে চলার সুরক্ষা সরঞ্জাম অথবা খাদ্য সামগ্রী সরবরাহ করেছিল, অপরদিকে অন্যান্য ওপিডিরা প্রতিবন্ধী ব্যক্তিদের অধিকার নিশ্চিত করতে সচেতনতামূলক কর্যক্রম চালিয়ে গিয়েছে । সামাজিকীকরণ এবং বিভিন্ন সমস্যা সম্পর্কে আলোচনার মাধ্যমে মানসিক সুস্থতা বজায় রাখতে ওপিডিগুলো গুরুত্বপূর্ণ ভূমিকা পালন করেছে। কিন্তু, কোভিড-১৯ মহামারীর দরুন প্রদত্ত লকডাউনের কারণে প্রতিবন্ধী ব্যক্তিদের প্রয়োজনীয় স্বাস্থ্য এবং শিক্ষা সেবায় প্রবেশগম্যতা (Accessibility) সীমাবদ্ধ ছিল, ফলে সেবা নেয়ার ক্ষেত্রে তারা আগে থেকেই যেসব বাধার সম্মুখীন হয়ে আসছিল তার মধ্যে উক্ত সমস্যা সবার শীর্ষে ছিল। তবে এই সময়ে তাদের জন্য কোন তথ্য যোগাড় করা সত্যিই অনেক কষ্টসাধ্য ছিল, এবং ভুল তথ্যের প্রচার নেপালে একটি বিশেষ উদ্বেগের কারণ ছিল।

এই মহামারীর সময়কাল শ্রবণদৃষ্টি ও দৃষ্টি প্রতিবন্ধী ব্যক্তিদের জন্য বিশেষভাবে কষ্টকর ছিল, যেহেতু তারা স্পর্শের উপর বিশেষভাবে নির্ভরশীল, এবং ঐ সময়ে ভাইরাসের সংক্রমণ কমাতে স্পর্শ করা থেকে বিরত থাকতে বলা হয়েছিল। যেহেতু তাদের স্পর্শনাভূতির প্রয়োজনীয়তা সকলের দ্বারা বোধগম্য ছিল না, ফলে তাদের স্বাধীনতা অনেকাংশেই লোপ পায় এবং তাদের একাকী থাকার প্রবণতা বৃদ্ধি পায়। মহামারীর শুরুর দিকে শ্রবণ প্রতিবন্ধী ব্যক্তিদের তথ্যের প্রবেশগম্যতা খুবই সীমিত ছিল। এবং সীমিত তথ্যের প্রবেশগম্যতার কারনে শ্রবনদৃষ্টি প্রতিবন্ধী ব্যক্তিরা মহামারীর সময়ে যোগাযোগের ক্ষেত্রে অনেক বাধার সম্মুখীন হয়েছিল।কিছু কিছু বুদ্ধিবৃত্তিক প্রতিবন্ধী অথবা শ্রবনদৃষ্টি প্রতিবন্ধী ব্যক্তিদের পক্ষে করোনা ভাইরাস কী এবং কেন এর সংক্রমণ কমানোর জন্য বাসায় থাকা প্রয়োজন এটা বুঝতে পারা বেশ কঠিন ছিল। এমনকি বাংলাদেশে বিভিন্ন কমিউনিটির মানুষেরা মনে করত যে প্রতিবন্ধী ব্যক্তিদের দ্বারাই ভাইরাস বহন করার সম্ভাবনা বেশি এবং অনেক সাক্ষাৎকারীরা এর কারনে বিভিন্ন ধরনের উপহাস এবং হেনস্তার শিকার হয়েছিল।

যেহেতু তাদের স্বাভাবিক জীবন একেবারেই ব্যাহত হয়ে গিয়েছিল, একইসাথে পুরানো স্বাভাবিক জীবন এভাবে 'হঠাৎ করে স্থির হয়ে যাওয়া, মারাত্মক পরিবর্তন এবং নতুন পরিস্থিতির সাথে মানিয়ে নেওয়ার ক্ষেত্রে অনেক সাক্ষাৎকারীই বড় ধরনের ভয় এবং ধাক্কার সম্মুখীন হয়েছিল। তাদের স্বাভাবিক জীবনধারার স্থায়ীত্ব লোপ পাওয়ার কারনে তাদের জীবন বিশৃঙ্খল হয়ে গিয়েছিল এবং তার পাশাপাশি তাদের ও তাদের পরিবারের কী হবে তা নিয়ে অনিশ্চয়তাও বৃদ্ধি পেয়েছিল এবং চলমান নিষেধাজ্ঞার কারণে জীবন একঘেয়েমিপূর্ণ এবং অসুখী হয়ে উঠেছিল। লকডাউন চলাকালীন সময়ে তাদের স্বাধীনতা লোপ পাওয়ার ফলে এবং আর্থিক সমস্যার কারনে স্বামী-স্ত্রী এবং পরিবারের অন্যান্য সদস্যদের মধ্যে দুশ্চিন্তার পরিমান অনেক গুন বেড়ে গিয়েছিল। সংকটকালীন সময়ে অনেক মানুষই এ কারনে অসহায় এবং হতাশাগ্রস্ত বোধ করছিল।

অপরদিকে, যেহেতু বিধিনিষেধগুলো তুলে নেয়া হয়েছে এবং সাক্ষাৎকারীরা বা তাদের পরিবারের সদস্যেরা আবার কাজ খুঁজে পেতে সক্ষম ছিল, সেহেতু কিছু কিছু সাক্ষাৎকারীর জীবন আগের থেকে উন্নত হতে শুরু হয়েছিল, কারণ এখন তারা তাদের পরিবারের প্রধান চাহিদাগুলো পূরণ করতে সক্ষম ছিল। এছাড়াও, ভ্যাকসিনের আবিষ্কারের ফলে অন্যান্য মানুষেরাও আগের থেকে অনেক বেশি খুশি এবং আশাবাদী ছিল কারন তারা এখন আর কোভিড-১৯ নিয়ে অত বেশি চিন্তিত ছিল না। কিন্ত, এখনও অনেক মানুষ কাজ খুঁজে পেতে লড়াই করে চলছিল এবং বেঁচে থাকার জন্যে বা জীবনমান উন্নয়নের জন্য সংগ্রাম করছিল। যেসব মানুষ মাহামারী চলাকালীন সময়ে বেঁচে থাকার জন্য ঋণ নিয়েছিল অথবা তাদের ব্যবসায়িক মূলধন ব্যবহার করেছিল, তাদের স্বাভাবিক জীবনে ফিরে আসার জন্য তুলনামুলকভাবে বেগ পেতে হয়েছিল। এছাড়াও, প্রথম লকডাউনের সময় বেঁচে থাকার জন্য মানুষেরা বিভিন্ন উৎস থেকে যে সহায়তাগুলো পেয়েছিল, সেগুলোর চাহিদা থাকা সত্ত্বেও আর চলমান ছিল না। একারনে, সম্ভাব্য দ্বিতীয় লকডাউনের সময় বেঁচে থাকার বিষয়ে সবাই গভীরভাবে চিন্তিত ছিল, কারন ইতিমধ্যে তাদের যা সঞ্চয় ছিল তা তারা প্রথম লকডাউনের সময় ব্যবহার করে ফেলেছিল। যদিও মহামারীর প্রভাব এখনও শেষ হয়নি এবং একে ঘিরে অনিশ্চয়তা এখনও চলমান রয়েছে, কিন্ত তারপরও সাধারণ মানুষেরা পরিস্থিতির সাথে মানিয়ে নিয়ে ভোগান্তির মাত্রা কমিয়ে আনতে সক্ষম হয়েছে।

উপসংহার

কোভিড-১৯ মহামারী এবং এর প্রতি সরকারের যা পদক্ষেপ ছিল তা নেপাল এবং বাংলাদেশের সব থেকে প্রান্তিক গোষ্ঠীর সদস্য, যেমনঃ প্রতিবন্ধী ব্যক্তিদের উপর ধ্বংসাত্মক এবং জীবন পরিবর্তনকারী ক্ষতিকর প্রভাব ফেলেছে। এ কারনে, মহামারী চলাকালীন সময়ে প্রতিবন্ধী ব্যক্তিদের অধিকার এবং মৌলিক স্বাধীনতা নিশ্চিত করার জন্য কোন প্রকার বৈষম্য ছাড়া সকল প্রতিবন্ধী ব্যক্তিদের উপস্থিতি নিশ্চিত করে প্রতিবন্ধিতা অন্তর্ভুক্তিমূলক পদ্ধতিগুলো তৈরি করতে হবে।

Executive summaries – Nepali

‘*COVID को कारणले, सबै कुराहरू गडबड छन्* नेपाल र बङ्गलादेशमा अपाङ्गता भएका व्यक्तिले महामारीको कस्तो अनुभव गर्नुभएको छ?

कार्यकारी सारांश – सहज पठन

हामीले के गऱ्यौं

- हामीले बङ्गलादेश (20 जना मानिस) र नेपाल (15 जना मानिस) मा अपाङ्गता भएका 35 जना व्यक्तिलाई कोभिड-19 को प्रकोपको समयमा आफ्नो जीवन बारे हामीलाई बताउन अनुरोध गऱ्यौं। उहाँहरूलाई वणदृष्टिविहीन, बौद्धिक अपाङ्गता र मनोसामाजिक अपाङ्गता जस्ता विभिन्न अपाङ्गता थिए। उहाँहरूलाई प्रायः आफ्नो जीवन बारे नसोधिने भएकोले हामी उहाँहरूलाई सोध्न चाहन्थ्यौं। हामीले अपाङ्गता भएका बालबालिकाका आमाबुवाहरूलाई पनि सोध्यौं।

हामीले के फेला पाऱ्यौं

- कोभिड-19 को प्रकोपले अपाङ्गता भएका धेरै मानिसका साथसाथै अन्य धेरै मानिसको जीवनलाई अझै खराब बनाएको छ।

- कोभिड-19 बाट सुरक्षित रहन, मानिसलाई घरमा बस्न भनिएको थियो जसलाई लकडाउन भनिन्छ। यसको मतलब अपाङ्गता भएका केही मानिस र उहाँहरूका परिवारहरूले आफ्ना जागिरहरू गुमाउनुभयो र खाना तथा औषधि र अन्य कुराहरूको लागि पर्याप्त पैसा भएन। यसले उहाँहरूलाई एकदमै उदास र चिन्तित बनायो।
- उहाँहरूले अन्य पारिवारिक सदस्यहरूबाट पैसा वा खाना लिएर वा आफूले बचत गर्नुभएको पैसा प्रयोग गरेर वा पैसा सापटी लिएर वा आफ्नो स्वामित्वमा रहेका कुराहरू बिक्री गरेर व्यवस्थापन गरिरहनुभएको छ।

- केही मानिसले सरकार वा अपाङ्गता भएका मानिसहरूका संस्था वा च्यारिटीहरूबाट पनि मद्दत प्राप्त गर्नुभयो। तर धेरै मानिसले कुनै मद्दत प्राप्त

गर्नुभएन वा पर्याप्त भएन।

- कोभिड-19 को प्रकोप बारे उपलब्ध गराइएको जानकारी बुझ्नको लागि सजिलो थिएन। यसले केही मानिसलाई आफू सुरक्षित रहनको लागि के गर्नुपर्छ वा आफू किन घरमा बस्नुपर्‍यो भन्ने कुराहरू बुझ्न कठिन बनायो।

- दृष्टिसम्बन्धी अपाङ्गता भएका मानिसले संसारलाई बुझ्नको लागि स्पर्श प्रयोग गर्नुहुन्छ। तर कोभिड-19 को प्रकोपको अवधिमा वस्तुहरूमा हुन सक्ने भाइरसले तपाईंलाई बिरामी बनाउन सक्ने भएको हुँदा तिनीहरूलाई छुन असुरक्षित थियो। मानिसले दृष्टिविहीन मानिसलाई छोएर मद्दत गर्न चाहेनन्। यसको मतलब उहाँहरूलाई वरिपरि हिड्न र स्वतन्त्र रहन एकदमै कठिन थियो।

- कोभिड-19 ले सबैजनाको जिउने तरिकालाई परिवर्तन गर्‍यो। यो धेरैजना मानिसको लागि झट्का थियो र उहाँहरूलाई आफू र आफ्ना परिवारहरूलाई के हुन्छ भन्ने कुरामा अनिश्चित बनायो। हरेक समय घरमा बस्दा पनि एकदमै दिक्कलाग्दो हुन्थ्यो र मानिसलाई निराश बनायो। पैसा बारे चिन्ताहरूले परिवारहरूको बीचमा झगडा भयो। मानिस डराए तथा आशाहीन भए र उहाँहरूले कुराहरूलाई अझ राम्रो बनाउन गर्ने सक्ने कुराहरू केही पनि नभएको जस्तो भयो। मानिसले आफ्ना साथीहरूलाई सम्झिनुभयो तर केही फोनद्वारा एक अर्कासँग सम्पर्मा रहनुभयो।

- केही समयपछि मानिसलाई फेरि घरबाट निस्कन अनुमति दिइएको थियो। यसको मतलब केही मानिसले आफ्ना जागिरहरू फिर्ता पाउन सक्नुहुन्थ्यो र उहाँहरूसँग अब खाना जस्ता कुराहरूको लागि भुक्तानी गर्न पैसा भएकोले उहाँहरू खुशी हुनुहुन्थ्यो। अन्य मानिस नयाँ कोभिड-19 खोपको कारणले खुशी हुनुहुन्थ्यो जसले तपाईंलाई कोभिड-19 हुनबाट बचाउनमा मद्दत गर्न सक्छ।

- केही मानिससँग अझै पनि खाना खरिद गर्नको लागि काम वा पैसा थिएन र उहाँहरू अझै पनि निराश र चिन्तित हुनुहुन्थ्यो। उहाँहरूसँग कुनै थप पैसा थिएन र उहाँहरूले आफूले सापटी लिएको पैसा फिर्ता दिनुपर्थ्यो जुन उहाँहरूको लागि कठिन थियो। उहाँहरूलाई पहिले मद्दत गरेका संस्थाहरूले उहाँहरूलाई मद्दत गर्न रोक्यो।

- विभिन्न अपाङ्गता भएका मानिस विभिन्न तरिकाहरूले प्रभावित हुनुभएको थियो। केहीले अन्य मानिसले उहाँहरूलाई नराम्रोसँग व्यवहार गरेको र कहिलेकाहीँ यो पहिले जस्तै एउटै हुन्थ्यो र कहिलेकाहीँ पहिले भन्दा एकदमै खराब हुन्थ्यो भनी बताए।

- सरकार र संस्थाहरूले कोभिड-19 को प्रकोपको अवधिमा अपाङ्गता भएका मानिसलाई मद्दत गर्न महत्त्वपूर्ण हुन्छ। उहाँहरूले अपाङ्गता भएका मानिसलाई के आवश्यक छ र यो मद्दत उहाँहरूलाई कसरी उपलब्ध गराउने भनी सोध्नुपर्छ।

कार्यकारी सारांश

कोभिड-19 ले पूर्व-विद्यमान असमानताहरूलाई गहिरो बनाइरहेको छ। उदयमान अनुसन्धानले संसारभरिका अपाङ्गता भएका मानिसले विभिन्न अधिकारहरूका उल्लङ्घनहरूको अनुभव गरेको र महामारीको स्वास्थ्य, आर्थिक र सामाजिक प्रभाव र यसका प्रतिक्रियाहरूले असमानुपातिकतामा प्रभावित भएको सुझाव दिन्छ। यो अनुसन्धानको लक्ष्य भनेको अनुसन्धानबाट प्राय: वर्जित गरिने अपाङ्गता भएका मानिसले बङ्गलादेश र नेपालमा बढिरहेको कोभिड-19 महामारीको कस्तो अनुभव गर्नुभएको छ भनी अझ राम्ररी बुझ्नको लागि थियो। यसले अपाङ्गता भएका मानिसका केही सीमान्तकृत समूहहरूलाई कसरी प्रभावित पारेको छ भनी राम्ररी बुझ्नको लागि, यो अध्ययनले बौद्धिक, मनोसामाजिक, वणदृष्टिविहीन र अन्य बहु कठिनाइहरू भएको मानिसमा केन्द्रित गर्न गहन गुणात्मक अनुसन्धान प्रयोग गऱ्यो।

कार्य-प्रणाली

विवरणात्मक अन्तर्वार्ता लिने पद्धति चयन गरिएको थियो। कथाहरू सुनाउने भनेको सञ्चारको प्राकृतिक र विश्वव्यापी रूप हो र सहभागीहरूलाई आफ्ना अनुभवहरूको अर्थ लगाउन र उहाँहरूको लागि के महत्त्वपूर्ण छ भनी ध्यान दिन सक्षम गराउँछ। प्रत्येक सहभागीलाई केही हप्ताको अन्तरालमा, दुईवटा अन्तर्वार्तामा सहभागी हुन निमन्त्रणा गरिएको थियो। यसले सहभागीहरूलाई आफ्ना अनुभवहरू साझा गर्नमा थप सहज महसुस गराउन सक्षम गरेको छ र महामारी बढ्दै गएपछि यिनीहरू कसरी परिवर्तन भयो भनी सङ्केत गर्छ। सहभागीहरूलाई नेपालमा अपाङ्गता भएका मानिसका संस्थाहरू (OPDs) र अन्तर्राष्ट्रिय तथा राष्ट्रिय गैर-सरकारी संस्थाहरू/NGOs मानवता तथा समावेशन र बङ्गलादेशमा ADD अन्तर्राष्ट्रिय र अपाङ्गता विकास केन्द्र (CDD) र विवेक अन्तराष्ट्रियको मद्दतद्वारा नियुक्ति गरिएको थियो। महामारीको अवधिमा सुरक्षाको लागि, अन्तर्वार्ताहरू डाटा शुल्कहरूको प्रतिपूर्ति र प्राविधिक पहुँचको सहायतामा अनलाइन वा फोनद्वारा सञ्चालन गरिएको थियो। सहभागीहरूको पहुँच र सञ्चार सहायताका आवश्यकताहरू पनि पूरा गरिएको थियो। विषयक्षेत्रसम्बन्धी विश्लेषण IDS टोली, राष्ट्रिय अनुसन्धानकर्ता र केही संकाय साझेदार र स्थानीय OPD प्रतिनिधिहरूद्वारा अनलाइनमा सञ्चालन गरिएको थियो।

अन्त्यमा, सबै अन्तर्वार्ता दिने व्यक्तिहरू र प्रमुख मानिसलाई संयुक्त अनलाइन मान्यता कार्यशालामा निमन्त्रणा गरिएको थियो: अपाङ्गता भएका सहभागी, उहाँहरूका समर्थकहरू र NGO कर्मचारू र दुवै देशबाट OPD प्रतिनिधिहरू। यसले सहभागीहरूलाई भावी महामारी व्यवस्थापन र घटावहरू अपाङ्गता समावेशी हो भनी सुनिश्चित गर्नको लागि एक अर्कालाई भेट्न, आफ्ना अनुभवहरू साझा गर्न, खोज र सिफारिसहरूको सारांश प्रमाणित र्न सक्षम गरायो।

सहभागीहरू

35 जना सहभागी मध्ये 19 जनालाई वणदृष्टिविहीनतासहित बहुविध अपाङ्गता थियो, 11 जनालाई बौद्धिक अपाङ्गता, तीन जनालाई मनोसमाजिक अपाङ्गता थियो र दुई जना सहभागीहरू अपाङ्गता भएका बालबालिकाका आमाबुवाहरू हुनुहुन्थ्यो। 20 जना मानिसलाई बङ्गलादेशमा र 15 जना मानिसलाई नेपालमा अन्तर्वार्ता लिइएको थियो।

परिणामहरू

> *"सबैजनाले आफ्नो दिन दु:खमा बिताउनुभएको छ"* (वणदृष्टिबिहीनता भएको बङ्गलादेशी मान्छे)

> "*सबैजना महामारीको कारणले उदास र चिन्तित हुनुहुन्छ।*" (मनोवैसामाजिक अपाङ्गता भएको नेपाली महिला)

अपाङ्गता भएका सहभागी र/वा उहाँहरूका परिवारहरूले लकडाउन र अन्य महामारीका प्रतिबन्धहरूको परिणाम स्वरूप आफ्ना जागिर, व्यवसाय वा अन्य आम्दानीहरू गुमाउनुभएको कारणले उहाँ र उहाँका परिवारहरूलाई प्रमुख नकारात्मक आर्थिक प्रभाव परेको छ। अझै पनि काम गरिरहेको कम्तीमा एक जना व्यक्ति परिवारहरूमा हुनाले अझै पनि केही आम्दानी हुने हुँदा थोरै राम्रो थियो भने, बेरोजगारी जस्ता पूर्व-विद्यमान वित्तीय कठिनाइहरू भएका ती परिवारहरूले एकदमै संघर्ष गर्नुभयो। अन्तर्वार्ता दिने व्यक्तिहरूले अब उपरान्त नियमित खानाहरू वहन गर्न नसक्ने हुँदा खानाको उपभगोग र भोकालाई घटाएको र केहीले आफू र आफ्ना परिवारहरू भोकै रहने भनी डराएको बताउनुभयो। महामारीको अवधिमा बढ्दो खाना र यातायात खर्चहरूले कुराहरूलाई थप कठिन बनायो। मानिसले चिकित्सा खर्चहरू वहन गर्न पनि संघर्ष गर्नुभयो। उहाँहरू आफ्ना आवश्यकताहरू पूरा गर्न संघर्ष गरिहनुभएको हुँदा यो वित्तीय संकटले उहाँहरूलाई महत्त्वपूर्ण तनाव र मानसिक चाप दियो। महामारीको लकडाउनको अवधिमा बाँच्नको लागि, धेरै अन्तर्वार्ता दिने व्यक्तिहरू बाह्य पारिवारिक सदस्य वा साथीहरूका बचतहरू वा व्यवसाय पुँजी प्रयोग प्रयोग गरेर वा ऋणहरू लिएर उहाँहरूको वित्तीय सहायतामा निर्भर रहनुभयो।

सरकारी सामाजिक सुरक्षा सहायता प्राय: पूर्व-विद्यमान अपाङ्गता सहायता मात्र थियो र राज्य सहायता (दुवै कोभिड-19 विशिष्ट र पूर्व कार्यक्रमहरूबाट) अपाङ्गता भएका धेरै मानिसलाई उपलब्ध गराइएको थिएन। I/NGO र विशेष अवस्थामा OPD हरूलाई महामारीको अवधिमा अपाङ्गता भएका मानिसलाई समर्थन गर्न महत्त्वपूर्ण भूमिका निर्वाह गरेको फेला पारिएको थियो। दुवै बङ्गलादेश र नेपालमा लगभग आधा अन्तर्वार्ताकर्ताहरूले OPD वा NGO हरूबाट केही वित्तीय वा अन्य सहायता प्राप्त गर्दै हुनुहुन्थ्यो, विशेषगरी उहाँहरूको पहिले नै लिङ्क भएका संस्थाहरूबाट। उक्त औपचारिक सहायता धेरैजनाको उत्तरजीवीको लागि महत्त्वपूर्ण थियो, यद्यपि उपलब्ध गराइएको सहायता उहाँहरूका परिवारका आवश्यकताहरूको लागि प्राय: अपर्याप्त थियो र अपाङ्गता भएको धेरै मानिसले कुनै औपचारिक स्रोतबाट कुनै सहायता प्राप्त गर्नुभएन। केही OPD हरूले अपाङ्गता भएका मानिसलाई सरसफाइका किटहरू वा खाद्य प्याकेजहरू पनि पूर्ति गर्नुभयो, अन्य व्यक्तिहरूले अपाङ्गता अधिकारहरूको चेतना फैलाउनुभयो। OPD हरूले पनि समस्याहरूलाई सामाजिक बनाउन र समस्याहरूको छलफल गर्न अवसरहरू सिर्जना गरेर मानसिक स्वास्थ्यलाई कायम राख्न महत्त्वपूर्ण भूमिका निभायो। महत्त्वपूर्ण स्वास्थ्य र शैक्षिक सेवाहरूमा पहुँच कोभिड-19 लकडाउनको कारणले अपाङ्गता भएका मानिसको लागि प्रतिबन्धित गरिएको थियो। यो उहाँहरूले सामना गर्नुभएका सेवाहरूमा पूर्व-विद्यमान अवरोधहरूको शीर्षमा थियो। जानकारीमा पहुँच चुनौतीपूर्ण थियो र गलत जानकारी नेपालमा विभिन्न चिन्ता भएको पेला पारिएको थियो।

महामारी दृष्टिसम्बन्धी अपाङ्गता भएका मानिसको स्पर्शमा निर्भरताको कारण भाइरस फैलनबाट कम गर्न निरूत्साहित भएकोले उहाँहरूको लागि विशेषगरी चुनौतीपूर्ण थियो। विशेषगरी, उहाँहरूको आवश्यकता अन्य व्यक्तिहरूले नबुझेकोले यसले उहाँहरूको स्वतन्त्रतालाई घटायो र उहाँहरूको आइसोलेसनलाई बढायो। विशेषगरी महामारीको सुरुवातमा सुनुवाईसम्बन्धी अपाङ्गता भएका ती व्यक्तहरूले जानकारीमा पहुँच कम गर्नुभयो। वणदृष्टिविहीनता भएको मानिसले विशेषगरी पहुँचयोग्य जानकारीको कमीको कारणले महामारीको अवधिमा सञ्चारका अवरोधहरूलाई बढाउनुभयो। केही बौद्धिक अपाङ्गता वा वणदृष्टिविहीनता भएको केही मानिसलाई कोरोना भाइरस के हो र उहाँहरू किन घरभित्र बस्नुपर्छ भनी बुझ्न कठिन भयो। विद्यालय वा डे सेन्टरहरू बन्द हुनु भनेको अपाङ्गता भएका बालबालिका (विशेषगरी बौद्धिक अपाङ्गता र स्वलीनता भएका ती मानिसहरू) को सामाजिकीकरण, उत्तेजना र थेरापी छुट्नु हो। बङ्गलादेशमा, सामुदायिक सदस्यहरूले

अपाङ्गता भएका मानिसले भाइरस बोक्ने थप सम्भावना थियो भनी विश्वास गर्नुभयो र जिस्काउने र दुर्व्यवहार विभिन्न सहभागीहरूद्वारा रिपोर्ट गरिएको थियो।

'पूरानो सामान्य जीवन' को आकस्मिक निलम्बन, आकस्मिक परिवर्तनहरू र अनुकूल बनाउने आवश्यकता भनेको धेरै सहभागीहरूले आफ्नो सामान्य जीवन पूर्ण रूपमा अवरोध भएकोले तीव्र झट्का र डरको अनुभव गरेको हो। आफ्नो सामान्य जीवनको स्थिरता गुम्नाले उहाँहरू र उहाँहरूका परिवारहरूलाई के हुन्छ भन्ने आत्मविस्मृति र अनिश्चिततालाई निम्त्याएको छ भने प्रतिबन्धहरूको मतलब जीवन दिक्कलाग्दो र दुःखी थियो। लकडाउनको अवधिमा स्वतन्त्रता गुम्नाले र वित्तीय कठिनाइहरूले जीवनसाथी र अन्य पारिवारिक सदस्यहरूको बीचमा तनावहरू बढाएको छ। मानिसले संकटको खराब समयमा आशाहीन, असहाय र तनावग्रस्त महसुस गरेका छन्।

प्रतिबन्धहरू सहज हुँदै गर्दा र अन्तर्वार्ता दिने व्यक्ति र उहाँहरूका परिवारहरूले काम फेला पार्न सक्षम हुँदा, केही सहभागीहरूले आफ्ना परिवारका तत्कालीन आवश्यकताहरू पूरा गर्न सक्षम हुँदा उहाँहरूको जीवनमा सुधार आयो। विशेषगरी खोप विकासको परिणाम स्वरूप, अन्य व्यक्तिहरू पनि कोभिड-19 को खोप बारे कम चिन्तित भएकोले खुशी र थप आशावादी हुनुहुन्थ्यो। यद्यपि, धरै अझै पनि काम फेला पार्न संघर्ष गरिरहेका छन् र बाँच्न वा उन्नति गर्नको लागि अझै पनि संघर्ष गरिरहेको थिए। ऋणहरू लिने वा व्यवसायको पुँजी प्रयोग गर्ने जस्ता बाँच्ने रणनीतिहरूले मानिसलाई आफ्ना जीवनयापनहरू फेरि सुरु गर्नबाट पछाडि पारेको छ। साथसाथै, पहिलो लकडाउनमा मानिसलाई बाँच्न मद्दत गरेको विभिन्न स्रोतहरूको सहायता यसको निरन्तर आवश्यकताको वावजुद आवश्यक रूपमा स्थिर थिएन। पहिलो लकडाउनको अवधिमा उहाँहरूका स्रोतहरू प्रयोग भएको कारणले सम्भावित दोस्रो लकडाउनको अवधिमा बाँच्ने बारे गम्भिर चिन्ताहरू थिए। मानिस अवस्थामा समायोजित हुँदै गर्दा तीक्षण कठिनाई समय अनुसार परिवर्तन हुने भएकोले, महामारी समाप्त भएको छैन र त्यसकारण अनिश्चितता जारी रहन्छ।

निष्कर्षहरू

कोभिड-19 महामारी र यसमा सरकारका प्रतिक्रियाहरूले नेपाल र बङ्गलादेशका धेरैजसो सीमान्तकृत समूहहरूबाट अपाङ्गता भएका मानिसमा भयानक र जीवन परिवर्तन हुने अहितकर प्रभावहरू परेको छ। महामारीमा अपाङ्गता समावेशी पहुँचहरू अपाङ्गता भएका सबै व्यक्तिहरूका अधिकार र आधारभूत स्वतन्त्रताहरूलाई अपाङ्गताको आधारमा कुनै पनि प्रकारको भेदभावबिना सिद्ध गर्न सकिन्छ भनी सुनिश्चित गर्न अपाङ्गता भएका मानिससँग एकसाथ विकास गरिनुपर्छ।

Introduction

The COVID-19 pandemic is deepening pre-existing inequalities, including those faced by people with disabilities (UN, 2020). At the beginning of the COVID-19 pandemic, serious concerns were raised about the possible impacts of the pandemic for people with disabilities and their families, and whether the national and local support for populations during the pandemic would be sufficiently disability inclusive (IDA, 2020; UN, 2020). Guidelines were produced by key organisations suggesting ways to avoid the predicted exacerbation of the disadvantaged position of people with disabilities in many contexts (IDA, 2020; IDA and IDDC, 2020; ILO 2020a, ILO, 2020b, Inclusion International, 2020; OHCHR, 2020; WHO, 2020;).

Initially, information about the situation for people with disabilities was scarce, but as the pandemic has progressed, emerging evidence indicates that they have experienced various rights violations and been disproportionality affected by the health, economic and social impacts of COVID-19 (COVID-19 DRM, 2020). People with disabilities are especially at risk of catching and dying from COVID-19, due to a combination of lack of accessible information about COVID-19 prevention, increased barriers to health care, reduced support or care, or, for some, increased clinical vulnerability (Webster, 2020; HI, 2020a; Goyal et al., 2020; COVID-19 DRM, 2020; i2i, 2020; HI, 2020b). Barriers to education that were already present for some children with disabilities have increased with school closures and the move to online learning has generally not considered their access needs (Goyal et al., 2020; COVID-19 DRM, 2020; Nagari, 2020). Various surveys have found that the pandemic has negatively affected the incomes of people with disabilities and their households as they have lost their jobs, resulting in increased food insecurity (HI, 2020b; HI, 2020a; Goyal et al., 2020; i2i, 2020; Ahmed et al, 2020; Christensen, 2020a; Christensen, 2020b). Pre-existing disability related stigmatisation, discrimination and violence are reported to have increased during the outbreak (HI, 2020a; UN, 2020; Goyal et al., 2020; COVID-19 DRM, 2020; Christensen, 2020a, WEI 2020; Christensen, 2020b), and some people with disabilities' mental health has been severely affected by the enforced isolation of lockdowns and other restrictions (COVID-19 DRM, 2020; Sale et al 2020; Goyal et al., 2020). These emerging findings suggest the global pandemic has led to the predicted negative consequences for people with disabilities. However, more evidence is needed to fully understand what has happened to people from different impairment groups and living in diverse situations across the world during the pandemic. In particular, there is limited in-depth understanding about how people with disabilities in low-and-middle income countries have experienced the evolving COVID-19 situation, from their perspective.

The Disability Inclusive Development (DID) programme, the flagship disability inclusion programme of the UK's Foreign, Commonwealth, and Development Office (FCDO), involves a consortium of 11 organisations working in six countries over six years (2018-2024) to improve the long-term wellbeing and inclusion of people with disabilities. The programme has responded to the ongoing COVID-19 pandemic in a variety of ways. Through collaboration with international and local partners, including Organisations of Persons with Disabilities (OPDs[2]), and in line with UNCRPD principles, this response has included our research, which aimed to better understand the experiences of some of the most marginalised groups of people with disabilities. The study did not aim to sample the views of a full range of people with different impairments, but focuses on people with intellectual, psychosocial, deafblindness and other multiple impairments and their priorities, in two of the DID programmes.

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[2] Organisations of Persons with Disabilities (OPDs) are also sometimes referred to as Disabled People's Organisations (DPOs)

This report highlights the findings of this in-depth qualitative research with these groups in Bangladesh and Nepal. The study explored their lived experiences over two different phases of the COVID-19 pandemic using a narrative interviewing approach, which involved them directly in communicating their experiences and focused on their priorities and perceptions, as well as gathering their own recommendations on more disability inclusive pandemic responses.

Country contexts

Nepal country context

The first case of COVID-19 was seen in Nepal in January 2020, and on 24th March 2020, the state went into the first lockdown. However, there was a huge influx of people into the country from neighbouring India, as well as from migrant workers returning from around the world. By May 2020, the number of cases reached 1,000 and, in the same month, the first death was registered - a postnatal woman in her late 20s. The infection tally at the beginning of January 2021 totalled 262,784 (122,273 just in Kathmandu Valley) with 5,225 active cases and 1,893 deaths (Post Report, 2021).

At the start of the pandemic, most people were not easily able to access COVID-19 information, given language barriers and limited action from the government and non-governmental bodies. Thus, misinformation and disinformation about the spread of the virus and its consequences was quite common. The Ministry of Health did provide information and data on the situation through national television and radio programmes, but this did not reach those who do not have access to media technology, and other marginalised groups such as people with disabilities and rural populations. Alleged mismanagement, delays and corruption in the procurement process of COVID-19 medical equipment have affected testing and quarantining facilities (Sharma, 2020). There are also anecdotal concerns about the prevalence of caste-based discrimination in government run quarantine centres.

The pandemic and resulting lockdown hit Nepal’s tourism, entertainment, and transport sectors hard, knocking projected economic growth and pushing three in every five people working in small or micro enterprises out of jobs in both the formal and informal sectors (UNDP, 2020a; UNDP, 2020b). The widespread loss of income and jobs, as well as reduced overseas remittances, and increased living costs has made people highly vulnerable to descending into or falling back into poverty (UNDP, 2020b). A survey of 4,416 households in April 2020, found that 1 in 10 had lost jobs due to COVID-19, 3 in 10 had lost some income, and 23% had inadequate food (Regmi et al, 2020). Daily wage labourers, migrant workers and households with a disabled person were most likely to experience a loss in income (Regmi et al, 2020; MALD and WFP, 2020). A second round of this survey in August 2020 found food insecurity slightly decreased (20.2%) (MALD and WFP, 2020). There was a small increase in households reporting job losses (11%) and a reduction in income (31.2%), although this was greater for households reporting severe (11.1%) and moderate (16.5%) income loss in August than April (severe 3.7%; moderate 9.3%), suggesting that the situation was worsening over time (MALD and WFP, 2020). A UNDP study found that women were more likely to lose their jobs than men, and their care responsibilities were increased due to school closures (UNDP, 2020b). The closure of schools and universities meant that an estimated 9 million students were affected in early May, with the switch to e-learning being challenging for poor households and those living in rural areas, who lack access to the internet (Dawadi et al, 2020). The majority of private health care services halted their services, severely affecting ‘reproductive, maternal, and child health services and those with chronic health conditions and non-communicable diseases’ (Singh et al, 2020: 2). There has been an increase in gender-based violence, including online (WOREC, 2020). The impact of the pandemic is clearly visible among those who are already at the margins in the society based on their economic status, geographic location, and caste, gender, disability and other identity factors.

Some surveys have looked at the specific experiences of people with disabilities in Nepal. Humanity and Inclusion (HI) (2020b: 1) conducted a rapid assessment in April 2020 and found that 'persons with disabilities face significant barriers to protecting themselves and their family from the COVID-19 and its broader impacts'. Almost half had no protective materials such as masks or soap (HI, 2020b). 'The lockdown has negatively affected 76% of the respondents' family income, 49% in personal income, while 27% have seen an interruption in medical and assistive devices' services, 17% mention interruption of therapeutic services' (HI, 2020b: 1). Services provided by caregivers had stopped for 32% of respondents (HI, 2020b). Almost 40% mentioned the need for specific sanitary/hygiene materials (HI, 2020b). More than 40% of respondents reported food insecurity, with many borrowing money to buy food, buying cheaper food, and eating less (HI, 2020b). A household survey carried out in April also found that households with a person with disabilities were more likely to have a loss of income in comparison with other households (Regmi et al, 2020). 13.1% of households with a person with disabilities on average experienced job loss, compared to 11.3% of households without a person with disabilities (Regmi et al, 2020). This increased in the second round of the survey in August, when 16.8% of households with a disabled household member experienced job loss, compared to 10.6% of households without (MALD and WFP, 2020). Households with people with disabilities also were found to be more food insecure (29.5% compared to 19.5% of households without a person with disabilities) (MALD and WFP, 2020). Other research found that people with disabilities were experiencing elevated levels of anxiety and depression (KOSHISH 2020). The negative effects of the virus are further compounded for marginalised groups within the disability community, such as indigenous women (Santos, 2020).

Persons with disabilities were found to be amongst those more commonly receiving COVID-19 assistance, in comparison with other households; although receipt of COVID-19 assistance was still very low for them (Regmi et al, 2020; MALD and WFP, 2020). According to the HI rapid assessment, very few persons with disabilities were accessing relief programmes from local government for persons with disabilities (HI, 2020b). In addition, the government discontinued some of the usual disability benefits during the pandemic (NDWA, 2020). Organisations such as the National Federation of the Disabled Nepal (NFDN) have been working to support people with disabilities in various different ways, including providing relief items and advocating for a disability inclusive response (UNDP, 2020b).

Between our two rounds of interviews (October and November/December 2020), regulations around inter and intra country travel restrictions were lifted. Similarly, the public services that were open only a few days a week for a certain number of allocated hours have changed to fully functioning institutions, in most cases. Schools have resumed in many districts and state-run exams including entrance exams for medical schools have taken place. People in the community seem to be more at ease given the removal of the mobility restrictions and life seems to be going back to how it was before the pandemic.

There are concerns that the Health Ministry's claims in December 2020 that the infection rate has been reducing since October were inaccurate and it was criticised for being careless with citizen's health, with concerns that a second wave will emerge (Poudel, 2020). Since the dissolution of The House of Representatives and the announcement of elections in April 2021 by the Prime Minister in December 2020, the country has been in turmoil, with protests from the civilians and political parties, however this election has now been cancelled (March 2021). Now that international travel has resumed and that Kathmandu Valley is going back to its usual routine, there is said to be fear that COVID-19 cases will inevitably rise.

Bangladesh country context

COVID-19 was confirmed to have spread to Bangladesh in March 2020. The first three known cases were reported on 8 March by the country's Institute of Epidemiology Disease Control and Research, (IEDCR) (Paul, 2020). To protect the population, the Government declared a national lockdown starting on 23rd March. Initially it was due to finish after 10 days but was soon extended to 30th May. Infections remained low until the end of March but saw a steep rise in April (Nabiand Shovon, 2020). In the week ending on 11th April, new cases grew by 1,155 percent, the highest in Asia, ahead of Indonesia with 186 percent (Devulapalli & Dantewadia, 2020). As of 18th January 2021, there have been 527,632 confirmed cases of COVID-19 with 7,906 deaths in Bangladesh (WHO 2021). Bangladesh is the second most affected country in South Asia, after India.

In the early stages of the crisis, Bangladesh was slow to respond to demands for testing. By the end of March (a week into the national lockdown), only 1,185 people had been tested for COVID-19 in Bangladesh. By the same date, neighbouring India had carried out 27,688 tests and Pakistan 14,336 (Alif, 2020). Newspaper reports and social media continued to report deaths of patients with COVID-19 symptoms. Some of the deceased were treated at COVID-19 isolation centres at hospitals in the districts, though no tests were conducted to confirm infection (Maswood, 2020). In the early days, testing remained centralised at the IEDCR, which is based in the capital Dhaka, although patients with symptoms were reported all around the country. The IEDCR created a series of hotline numbers, email address and social media pages for people to contact them if they had COVID-19 symptoms and to provide information.

Bangladesh has faced significant challenges in combating COVID-19, as it is a densely populated country, and also houses a million Rohingya refugees in sprawling refugee camps conducive to the spread of disease. It also has significant migrant populations living in various countries, including China and Italy, which were badly affected by COVID-19 in early 2020. Religion is an important part of Bangladeshi culture, and mass religious events and communal prayers may have helped to spread the virus (Nooruddin & Shahid, 2020).

The economy in Bangladesh has been badly affected by the pandemic. Exports from the ready-made garment industry are a major part of Bangladesh’s economy, and demand for this industry has been particularly badly hit. COVID-19 has caused unemployment, job losses, reduced incoming remittances, food insecurity and poverty in Bangladesh. The socio-economic and development impacts have been severe, and the health sector is under considerable strain. The pandemic will have a detrimental impact on working towards the targets of Sustainable Development Goals. In addition, quality education will be hampered in the country, although institutions are now open and some are exams going ahead. Some are not and students have been protesting about this. The government of Bangladesh has mobilised a stimulus package to support the affected industries and communities. However, it is not yet clear how services such as education and health will be strengthened and supported.

As of January 2021, there are no lockdown measures in place. There is concern that natural disasters which are common in Bangladesh, including cyclones, tidal floods, flash floods, and landslides are likely in the coming months and could add to the challenges posed by COVID-19 and further aggravate the humanitarian needs of the most vulnerable groups in the country.

Research process and methods

The aim of this research was to better understand how people with disabilities have experienced the evolving COVID-19 pandemic in Bangladesh and Nepal. In particular, this study focussed on involving participants from the most marginalised impairment groups, who are often excluded from research. This included people with intellectual, psychosocial, deafblindness and other multiple impairments.

With the UNCRPD as a guiding framework for an inclusive approach, a research design was developed using qualitative methodologies, as these are most appropriate for generating subjective knowledge from within a context (Tracey, 2013; Braun and Clarke, 2012; Hammet et al, 2015). A narrative interviewing approach was selected for several reasons:

- Telling stories is a natural and universal form of communication - this method is accessible to everyone regardless of education level, language competence or communication mode (Jovchelovitch and Bauer, 2000).
- By recollecting and sequencing experiences as stories, participants make sense of their experiences.
- As a *teller-focused* method, evidence about what matters to participants is generated, rather than using pre-determined questions to investigate topics that may be of less concern to them (Hydén, 2014).
- This approach can generate insights on situational, emotional and relational aspects, that may not emerge from researcher-directed interviews.

Each participant was given the opportunity to take part in two rounds of interviews, separated by 1-2 months. The purpose of interviewing people twice was first to gain deeper insight as trusting relations and thus openness developed between participants and researchers, and because the narratives were anticipated to flow more easily as the interviewees' expressive confidence increased. Second, this provided an additional processual lens, to enable some insight on *how* disabled participants interpreted and responded to Covid-19 as the pandemic progressed over time.

Experienced participatory researchers from the two countries led the data collection process, and we recruited two researchers with disabilities in Nepal and Bangladesh, who were paired with these more experienced interviewers to increase their research skills. The Institute of Development Studies (IDS) team developed the research processes and materials, provided training and supervisory accompaniment for the local researchers, and led the analysis process. Extra researcher training on dealing with sensitive issues and communication needs for people from different impairment groups was provided by the wider team and partners.

Support from the DID in-country consortium partners, and key organisations of people with disabilities (OPDs) in each country, were crucial to reaching marginalised participants as intended, such as youth with intellectual disabilities, and people with deafblindness and multiple disabilities. The local researchers therefore worked with HI and OPD representatives in Nepal and ADD International and Centre for Disability in Development (CDD)/Sense International in Bangladesh to purposively recruit interviewees beyond those usually asked to participate, to ensure inclusion of participants from the targeted impairment groups, as well as to achieve a gender-balance, a range of ages, and the inclusion of some parents /carers when relevant.

To ensure that both the participants and researchers remained safe during the research process, all the narrative interviews were undertaken online or by phone, which is an accepted approach (Holt, 2010). Researchers were encouraged to use online communication platforms use the video function when possible. This was both to aid relationship building and effective communication, which was particularly important for those such as those with intellectual disabilities, who may rely more on visual cues such as body language, gestures, or facial expressions. In both countries there was reimbursement for data costs, and the in-country consortium partners also supported technological access, with some participants and their assistants coming to the partners offices to conduct the interview by computer in a socially distanced way where it was locally safe to do so. However, the choice of platform was ultimately informed by each individual participant's preferences, capacities and access to technology.

Ethics approval for this work was obtained from the IDS Ethics Committee. To mitigate heightened ethical risks compared with face-to-face interviewing (such as the additional difficulties of reading dynamics or responding supportively if strong emotions arose), the research process involved three calls with each participant during the first interview round:

On the first call the research purpose and process were explained, including consent and anonymisation, the right to withdraw, and the analysis and reporting plans. The participants' access and communication support needs were also discussed, which enabled necessary accommodations to be planned for. For example, tactile interpreters accompanied the interviewees with deafblindness. Some parents were also interviewed for additional insight when communication needs warranted it, but researchers prioritised hearing directly from the participants.

At the beginning of the second call participants were asked or their verbal consent to being involved. This gave them time and space after the first call to decide whether to participate, reducing any perceived pressure to participate. The participants confirmed that they felt secure and their access needs were being met. The interview was then conducted. After an initial introduction, a narrative interview proceeds by asking one very general and open question (Jovchelovitch and Bauer, 2000):

> ***Participants were asked to share how the COVID-19 situation had developed for them and impacted on their lives.***

The interviewers reassured them that they could share experiences in any way they liked but encouraged a story format by suggesting they start at the beginning, when they first heard about the pandemic, and then relate what happened afterwards up to the present. Prompts and follow-up questions were used to ask for specific examples, or to expand on the key aspects that interviewees chose to talk about.

Finally, there was a third call to ensure that the participant was feeling alright and still happy to be involved.

The second round of interviews 1-2 months later followed a similar process. It was anticipated that the second round of interviews would involve greater openness and narrative flow due to the previous meetings between the researcher and participant and so more familiarity with each other.

A face-to-face participatory thematic analysis process had been planned, ideally involving the researchers and some participants from both countries. However, this had to be adapted due to ongoing COVID-19 meeting and travel restrictions. To minimise risk and comply with regulations, a series of collective analysis sessions were undertaken online. These involved the IDS team, in-country researchers and some consortium partners. Prior to undertaking the analysis, the researchers were provided with thematic analysis training.

The analysis sessions included an initial reading of the first interviews, and the sharing of selected interview narratives. From the data, themes were generated by the team and compared across countries. Following discussion and debate, the themes were then clustered to produce a first-level analysis. Overarching themes, such as gender, impairment specific aspects, emotions and economic/financial impacts emerged. The IDS team-members each analysed the remaining interviews using one of these lenses. After the second round of interviews had been conducted, a second analysis session was held, where additional themes were generated based on the current situation in each country at that time. New insights were compared with the detailed first round analysis. This validated previous themes and indicated data saturation, but there were also changes in impacts and feelings, as well as some additional overarching themes.

The linkages between themes were explored to produce a conceptual map, showing the main themes and exploring how they related to each other. Collectively generating overarching meanings and interpretations, ensured that this synthesis was grounded in local perspectives.

Finally, 3 months later a participants' validation workshop was run online, to which all interviewees, researchers and in-country INGO and OPD partners from both countries were invited. More than 30 people attended with support from local OPDs and NGOs.

Participants

A table detailing the characteristics of the participants can be found in Annex 1. In total 35 participants took part in the study. Gender parity was achieved, with 18 males and 17 females. 19 out of 35 participants disclosed that they had multiple impairments, including deafblindness. A further 11 identified having intellectual impairments, three had psychosocial impairments. Two participants were parents of children with disabilities and some other parents were also asked for their brief contributions after the main interview ended. Most of the participants were young or middle aged, with only three being over 50 years of age. Just over a quarter of participants had attained primary, secondary, or tertiary education each, while five participants had no education. Half the participants were unemployed. Only 7 participants had jobs, and the same number were students. The majority of the participants (57 percent) were married. 15 lived in a rural area, 14 in an urban area and six in a semi-urban location. 17 participants reported having family members or others who depended on them. Six participants reported that they depended on others. The vast majority of participants (91 percent) agreed to be interviewed twice.

Findings

We present key themes which emerged from the narrative interviews in Bangladesh and Nepal. Two different types of interlinked themes emerged: 'concrete' material impacts and overarching 'subjective' experiences.

Concrete (material) themes illustrating the tangible impacts of the pandemic were clearly identified. These fall into two main types, with overlaps between them. There are individual (and intersecting) identity related experiences linked to people's gender and/or impairment type and disability status. Then, there are the economic/financial impacts and people's experience of the structures, systems and civil society responses to the pandemic.

The ‘subjective’ experience themes broadly reflect the participants’ feelings and experiences during the initial COVID-19 crisis and its continuation over a couple of months. These emotions arose in response to the loss of the stability of known life, the ‘old normal’, the pandemic risks and the lockdown restrictions, and the uncertain journey towards a ‘new normal’. We interpreted these emotions as ‘floating above’ or ‘weaving through’ participants’ experiences expressed as more ‘concrete’ or material themes. Overall, strong themes of de-stabilisation, disorientation and uncertainty emerged, due to the extraordinary situation, with subthemes of shock, confusion, fear loss, stress, conflict, anxiety, despair and depression in various forms.

We describe these two major types of themes and bringing to the fore the voices of the participants through the use of selected quotes. We have drawn on examples from both countries throughout, as to a large extent the themes were very similar in both contexts. We have not undertaken a separate analysis per country here.

Quotes are identified as from individuals by country, gender and impairment type, and interview ID number (A or B before the number indicate whether the quote comes from the first (A) or the second (B) interview).

Economic impacts

Similarly to people globally, our interviewees with disabilities and their families in Bangladesh and Nepal experienced major negative economic impacts due to lockdowns and other pandemic restrictions and descended into (deeper) poverty as they or those they were dependant on lost their jobs, businesses, or other income. Participants were usually part of family/household units that relied on more than one source of income, especially in Bangladesh. Generally, most of the income earners in families had lost their job. Families where at least one person was still working were in a slightly better position as they still had some income on which to survive.

> “*At the March 25, 2020, Bangladesh Government declared the lockdown which creates a thunderstorm on my head as I am totally dependent on my small shop.*” (Bangladesh, man, multiple, DIDCOVBDA3)

> *“The overall economic condition of my family totally fell down. We passed a miserable life during the pandemic situation”*. (Bangladesh, man, multiple, DIDCOVBDA1)

Interviewees reported reduced food consumption and hunger as they no longer had the money to pay for regular food, and some feared they would starve.

> “*At this time of the epidemic, no one could work, so we could not afford food, rent, medical treatment properly*”. (Bangladesh, woman, intellectual, DIDCOVBDA16)

> “*It was a really bad dream for all of my family members. In that time we were not able to take our 3 regular meals. We did not have any type of good food in that time during the corona.*” (Bangladesh, woman, deafblindness, DIDCOVBDA9)

> “*Great problems have arisen because of corona. Some people could not get food to eat*.” (Nepal, man, intellectual, DIDCOVNEPB3)

The situation was not helped by increased food and transport costs during the pandemic.

> *“Things are expensive to buy, they have hiked the price of daily necessity like vegetables and milk.”* (Nepal, man, deafblindness, DIDCOVNEPA9)

Medical costs for those with medical needs in their family, their own or other family members, were also major concerns as people with disabilities and their families struggled to pay for them.

> *"My mother is still sick and my younger sister is also sick. They need regular medicine which is really burdensome for my family as we did not have the money."* (Bangladesh, woman, multiple, DIDCOVBDB4)

This financial crisis caused the interviewees and their families significant stress and mental pressure as they struggled to meet their and their families' needs, especially in relation to food security.

> *"I was totally mentally broken in that time as all the financial source of our family was stopped."* (Bangladesh, man, multiple, DIDCOVBDA5)

> "*It gave me lot of mental pressure as we the adults could live without food, but my son could not*." (Bangladesh, woman, deafblindness, DIDCOVBDA6)

Especially affected by the economic impacts were those with existing financial pressures prior to the outbreak. These circumstances included already being unemployed, common amongst many people with disabilities due to existing barriers (Wickenden et al 2020), those needing to pay for ongoing medicine, those with family dependants and single parents.

In order to survive during the worst phase of the pandemic lockdown, many interviewees relied on financial support from external family members or friends, used up their savings or business capital, or took out loans that generated further pressure.

> "*If our aunt had not helped us in this situation, we would not have eaten.*" (Bangladeshi woman, deafblindness, DIDCOVBDB14)

> "*I had used many of my savings to run my family members and had to take a lot of money as a loan from my relatives. This loan was like a thorn for me in the throat.*" (Bangladeshi male, multiple, DIDCOVBDA5)

Some managed to survive the economic shock as a result of more formally provided relief from government, INGOs, NGOs or, OPDs, whereas others received no such assistance as discussed next.

Structures, systems and services

Experiences of and opinions about support for people with disabilities from their respective governments during the pandemic were mixed. Some interviewees were provided with state social protection assistance, which was seen as crucial:

> "*I received government relief during the epidemic. And if I did not get this relief then I would not have eaten.*" (Bangladesh, man, deafblindness, DIDCOVBDB12)

However, government social protection assistance was often only the pre-existing disability assistance, and state support (both COVID-19 specific and from prior programmes), was not provided to many people with disabilities. In addition, in Bangladesh, for people already receiving disability assistance, this was used as an excuse to deny people access to COVID-19 specific social protection, while in Nepal it was provided late.

> "*When I ask for help, they tell me that people with disabilities get allowances from the government that will help them again. But the average person who has a home who is not disabled like us gets help from many places*." (Bangladesh, woman, intellectual, DIDCOVBDA19).

Corruption was also a concern (reportedly at local and national levels), as one participant with multiple impairments reported:

> *"Many of the PWDs did not get the support due to the lack of support from government and also for corruption."* (Bangladesh, man, multiple, DIDCOVBDB5)

International and local NGOs and in particular OPDs were found to play an important role in supporting people with disabilities during the pandemic. Around half of interviewees in both Bangladesh and Nepal were receiving some financial or other support from organisations of people with disabilities or (I)NGOs, especially from the organisations they already had links with, such as ADD International and CDD in Bangladesh, and Koshish, in Nepal. These were important to survival for many.

> "*I did not get any help from the government. The help I received from an organisation during this time of the epidemic has benefited me immensely*." (Bangladesh, woman, intellectual, DIDCOVBDA19)

> "*We have been getting support from NGOs for food and supplies since the pandemic. We are in a better place because of the support and relief we have got so far".* (Nepal, man, deafblindness, DIDCOVNEPA11)

> "*I always felt helpless all the time during the lockdown. If the INGO, union parishad (local government) and one of relative did not support in that time, maybe we will be dead now. I am still frightened thinking the worst situation I had ever led in my life.*" (Bangladesh, woman, multiple, DIDCOVBDA4)

In addition to financial support, some OPDs supplied hygiene kits or food packages to people with disabilities, with the support of (I)NGOs. Others worked to raise awareness of disability rights and particular support that was needed. OPDs also played an important role in maintaining mental health by, providing emotional support, creating channels (by phone and though support groups) and platforms to allow people with disabilities to socialise and discuss their problems. In Nepal, some OPDs are providing training to get people back to work However, some OPDs were forced to shut during the height of restrictions, although the second round of interviews indicated that most had by then re-opened and resumed their activities.

While the assistance provided by (I)NGOs, OPDs, and government was crucial to those who received it, a number of interviewees noted that the assistance provided was inadequate for their family's needs.

> "*The disability allowance we received was not enough to buy the daily necessary items of ours*." (Bangladesh, woman, multiple, DIDCOVBDA4)

> "*An organisation ….. helped me which was not enough for me. ……………………* (Bangladesh, woman, deafblindness, DIDCOVBDA13)

In addition, it was clear that many people with disabilities slipped through the net and did not receive any assistance from any formal sources.

> "*At this time of the pandemic, I have many disabled brothers and sisters who haven't received any help neither from the government and an organisation*." (Bangladesh, man, deafblindness, DIDCOVBDA11)

In terms of other essential services, (including health and education), access was restricted for people with disabilities due to the COVID-19 lockdown itself and its financial impact which made it harder to afford travel and medicine costs, some of which had increased in price. This was on top of pre-existing barriers to services which they faced.

> *"I could not visit any doctor due to financial crisis and scarcity of the doctor" (Bangladesh, woman, multiple, DIDCOVBDA2)*

> *"I haven't been able to meet any doctor since a while. Koshish (OPD) used to bring doctors but since the pandemic we haven't been able to meet doctors." (Nepal, woman, psychosocial, DIDCOVNEPA15)*

Another interviewee faced discrimination from hospital staff and was denied entry.

> *"I went to hospital but hospital denied to admit me….. One thing is I am disabled, and another thing is that I did not have educated assistant. For example, for a blood test, we have to ask room number and where is it located. My assistant was uneducated. So they denied me".* (Nepal, man, deafblindness, DIDCOVNEPB2)

The restricted access to health services resulted in a lot of anxiety for people with disabilities, especially for people with psychosocial disabilities and their families in Nepal. Parents of children with disabilities reported extreme stress and frustration at the lack of the usual support services. In addition, the situation for people with disabilities who contracted COVID-19 was particularly challenging, with limited support to procure medicine and supplies.

Not many participants were in still in education, but those that were, were unhappy that it had stopped and worried for their future opportunities.

> "*I do not know when government will open the school. I really felt bad to stay at home all the time. The pace of the education is also lost. I am doing my study irregularly*." (Bangladesh, male, multiple, DIDCOVBDB8)

> "*I was thinking that after I completed my diploma I will be able to start some job but due to the session jam may be my dream will be unfulfilled"*. (Bangladesh, woman, multiple, DIDCOVBDA4)

Finally, we found that some people had received inaccurate information about the virus and preventative measures. Misinformation was found to be of particular concern in Nepal, where several participants were dismissive of the seriousness of the disease.

> *"It is just simply a common cold and cough"* (Nepal, man, intellectual, DIDCOVIDNEPB3)

It is unclear as to where this misinformation originated from but highlights the importance of supporting people with disabilities with factually correct information in an accessible format. This was a particular issue for those with intellectual, hearing and visual impairments. Whilst responses demonstrated that generally people with disabilities are being left behind in the pandemic interventions, there was concern that people with visual impairments or with deafblindness were at particular risk of being neglected by government responses. This highlights the need to understand and address impairment-related issues and impacts.

Impairment impacts

The pandemic has been particularly challenging for people with visual impairments, due to their reliance on touch. During the pandemic, touch increases the risk of infection and is discouraged to reduce the spread of the virus. For example, one participant in Nepal with deafblindness stated:

> *"There is a threat that we can get the virus easily as we have to touch around to walk and navigate"* (Nepal, man, deafblindness, DIDCOVNEPA9)

Similar sentiments were expressed by those in Bangladesh, with one participant with deafblindness commenting:

> *"I have to touch everything to identify [things] - this is not acceptable in society. Everyone fears that maybe I am contagious."* (Bangladesh, woman, deafblindness, DIDCOVBDB6)

As well as challenges relating to mobility, COVID-19 resulted in increased isolation for interviewees with visual impairments who may require guidance or support, as other members of society are uncomfortable touching them or being touched. Some participants with visual impairments had touched other people by accident as they could not see them. This resulted in anger from others and a lack of understanding. In addition, undertaking domestic tasks, such as shopping, has become much harder during the pandemic. One participant in Bangladesh with a visual impairment explained that they used touch to select food at the market. Without being able to do this, they were sold rotten vegetables.

In both Bangladesh and Nepal, people with deafblindness were highlighted as being particularly vulnerable during the pandemic. As well as relying on touch more than others, like others with visual impairments, there were increased challenges due to the added communication barriers and the support they require, both of which were affected by the pandemic and lockdown. As previously noted, not all the information provided by the governments on the virus was provided in an accessible format. For people who have hearing impairment, lack of accessible information in a visual (e.g. signed, written or pictorial) form was also problematic. Those families who do not use a standard sign language had limited ways to convey the information to their family member. Due to this, it was hard for people with these impairments to gain knowledge on the disease and how to prevent its spread. One participant in Nepal with deafblindness reported that in the early stages of the pandemic, they did not know what the rules were. They were moving around during the lockdown and ended up being harassed by the police.

In Nepal, it was reported that some people with intellectual disabilities found it hard to understand what coronavirus is and what the risks are. It can be hard for people to comprehend how everyday life has changed and why they must stay indoors. Interviewees thought people with intellectual impairments may need tailored guidance and support to ensure their safety and the safety of others. They also faced stigma as people assumed that they didn't understand (see below section on stigma).

For people with complex or multiple impairments who require a high level of care or support, the pandemic has created many problems. For example, if the person who supports them is exposed to the virus, they may be too sick to help or need to self-isolate, leaving the person with disabilities without support. As one parent to children with intellectual impairments in Nepal stated:

> *"We were worried if something happens to us what will happen to the kids"* (Nepal, parent of woman with intellectual disabilities, DIDCOVNEPA7)

In both countries, the pausing of education had an impact on all students. However, those with intellectual impairments have been particularly badly affected, as it may take them longer to catch up than other students and the specific support they need may not be available. Students with multiple impairments are also at a disadvantage with regards to education. There were predicted impacts on educational progress, as one participant from Bangladesh reflected:

> "*There is still an education gap and I am afraid that maybe I will have to suffer the academic year loss*." (Bangladesh, woman, multiple, DIDCOVBDB4).

The two parents of children with deafblindness and autism interviewed in Nepal observed that the closure of the day care centres their children attended placed great pressure on them and their children. At least one parent had to remain at home to take care of their child and could not work, and their children missed out on socialisation, stimulation, and therapy, and struggled to understand why they were being kept at home.

> "*In day care, they get to meet their friends and teachers. The teachers teach them new things and play with them. They feel different there. So it was easier for us when the day care was running. It quite difficult for us to teach them new things*." (Nepal, parent of child with deafblindness, DIDCOVNEPA16)

This resulted in exacerbated tension in this family as the child was upset and confused, but there was increased family discord in other cases that can be interpreted from a gender perspective.

Gender impacts

The evidence suggests that men and women with disabilities, like those in the wider community, were impacted by the pandemic and lockdown in different ways. Traditional gender norms in both countries were found to result in particular challenges. Interviewees observed that the lockdown meant that men in their communities were spending more time at home than they normally would.

> "*Men are not used to of staying a long time at home which increase their financial burden as well as their mental pressure."* (Bangladesh, man, multiple, DIDCOVBDA3)

> "*It has affected women. Men are also affected who are going out to earn money. In case of women, more workload has been added as they spend more time in house because of lockdown*." (Nepal, mother of a child with autism, DIDCOVNEPA5)

This put a lot of pressure on some relationships, resulting in women suffering from increased mental stress, shifts in gender relations in the home and in some cases gender-based violence. Households with people with disabilities without a male member found it particularly difficult to undertake necessary domestic tasks, as well as sourcing food. This problem was exacerbated for women and girls with disabilities, and particularly those with impairments that impacted on mobility (as above). Some women worried about what would happen to their children if they caught the virus as they were the main or sole carers. In addition, interviewees observed that the situation in Bangladesh resulted in some girls in their community being forced by their parents to get married to ease the financial situation. Some respondents perceived that girls may also have been particularly impacted with regards to education provided to them, although it is not clear why this would be the case, perhaps again because of increased financial stresses on the family income? Women and girls were found to have to stay at home far more than men and boys, resulting in depression, boredom, isolation and frustration. The situation was acutely felt by the young women with disabilities in this study.

The experiences of men were not found to be as extreme, although men were more worried about the financial situation if they were the household breadwinner. The predominant culture in Bangladesh is that the men are responsible for running the household financially. As a result, during the pandemic they some faced particular stress in considering the needs of all family members and bringing in sufficient funds. There was a suggestion from interviewees that the impact of this mental pressure was manifesting itself in increased conflict and in some cases possible gender-based violence within the house and more widely in their communities.

> *"Many of the men did not have any other income source. This actually irritates them all the time and increase the domestic violence."* (Bangladesh, man, multiple, DIDCOVBDA3)
>
> "*The tension level of the men was comparatively high as they had to manage the family and they faced the financial crisis during that time. Due to unable to perform their regular responsibility, many men suffered from frustration*". (Bangladesh, woman, multiple, DIDCOVBDA4)
>
> "*What I have seen around is women are affected more in family and society. Some are affected due to their husband and some because of their in-laws*". (Nepal, woman, psychosocial, DIDCOVNEPB15)

The second round of interviews revealed that as the pandemic progressed the situation was improving in both countries. It became easier for everyone to move around, and the renewed freedom was felt more by women with disabilities. As many people went back to work their financial situation improved, although in Bangladesh it was reported that both women's and men's salaries were less than they were in before the pandemic due to the weaker economy. Reports on the levels of gender-based conflict within the home and violence vary and contrast with some people reporting it has decreased in their communities as the pandemic has progressed, but other people saying it is continuing.

Exacerbated Stigma

In Bangladesh, negative stereotyping with regards to COVID-19 and people with disabilities was reported. Mocking and bullying was reported by several participants, both as something they experienced normally and something that was connected to the pandemic. Some people in their communities believed that people with disabilities were more likely to be carrying the virus either due to their impairment, or due to inadequate hygiene practices. This resulted in some people with disabilities being ostracised by members of the community.

> "*Many people thought that we the people with disabilities actually carry the coronavirus with us*." (Bangladesh, man, multiple, DIDCOVBDA3)

This negative stereotyping resulted in challenges around mobility. In Bangladesh, rickshaw drivers would avoid picking up people with disabilities. In addition, people with disabilities reported feeling anxious that if members of society contracted the virus that they would be unfairly blamed for it.

The second interviews revealed that negative stereotyping, mocking and bullying has continued even as restrictions have been lifted and some aspects of life were returning to how they were before. The negative attitudes towards people with disabilities is deeply ingrained within both societies, but the study suggests that the pandemic may have exacerbated the stigma experienced by some people with disabilities. Stigma is experienced as very hurtful, but during the pandemic this was compounded by a range of other emotional impacts, as is explored next.

Emotions/feelings (internal) effects

As is illustrated in discussing the more concrete themes so far, like many other people worldwide, the participants with disabilities in this study went through and may be continuing to experience difficult emotional journeys due to the COVID-19 pandemic. This was in response to the abrupt suspension of the ‘old normal’ life, the dramatic changes, and the need to adapt many aspects of normal routines.

Initially many participants experienced intense shock and fear as their usual life was completely disrupted.

> “*It was really shocking news for my family*.” (Bangladesh, woman, deafblindness, DIDCOVBDA9)
>
> “*Everyone at the time [of the pandemic] was terrified*”. (Bangladesh, woman, intellectual, DIDCOVBDA16)
>
> “*I got frightened about it. It created havoc for me as well as my husband. We were totally tensed about how we will run my family*”. (Bangladesh, woman, deafblindness, DIDCOVBDA6)

The loss of the stability of usual lives, resulted in disorientation and uncertainty about what would happen to them and their families.

> *“I felt bad by thinking the overall situation. It was totally uncertain for me and my family*.” (Bangladesh, woman, multiple, DIDCOVBDA2)
>
> *“Because of COVID, everything is a mess”*. (Nepal, woman, intellectual, DIDCOVNEPB7)

Whilst most interviewees understood the need to protect themselves and the need to stay at home due to lockdown, restrictions were experienced as making life boring and unhappy.

> *“All in all, the epidemic days have made us [disabled classmates] all miserable”*. (Bangladesh, woman, intellectual, DIDCOVBDA16)
>
> “*Everyone has spent their days in misery*”. (Bangladesh, man, deafblindness, DIDCOVBDA11)
>
> *“Continuously remaining at home is boring*.” (Nepal, woman, intellectual, DIDCOVNEPA1)

Some participants felt imprisoned or caged, and one perceived this was a form of social violence.

> *“Now there is a restriction, I feel like a bird in a cage”*. (Nepal, woman, psychosocial, DIDCOVNEPA15)
>
> *“I felt like I was stuck in a prison because I did not have the habit to stay long time at home without any work*.” (Bangladesh, man, multiple, DIDCOVBDA3)
>
> *“I have been sad. It almost feels like violence. I am not able to go to places. I am worried that I will get infected.”* (Nepal, man, deafblindness, DIDCOVNEPA9)

As previously mentioned, the loss of freedom during lockdown exacerbated tensions between spouses and other family members.

> “*It increased the tension and hassle in our life*”. (Bangladesh, man, multiple, DIDCOVBDA1)

> "*At this time of the epidemic, when my father and brother had no work, everyone in our family was frustrated*." (Bangladesh, woman, intellectual, DIDCOVBDA19)

However, the situation was especially hard for some participants with specific impairments. For example, parents reported that their children with deafblindness or autism really struggled to understand why they were no longer allowed to go out, which resulted in feelings of frustration.

> *"Our family, relatives, neighbours have understood about how corona is transmitted and how we can be safe from it, but my daughter thinks 'why are my family members not letting me to go outside, why are they not taking me to visit the places?'*." (Nepal, parent of child with autism, DIDCOVNEPA5)
>
> *"She is not herself. They are sceptical if they are being locked down due to COVID-19 or if it is going to be like that forever*." (Nepal, parent of woman with intellectual disabilities, DIDCOVNEPA6)
>
> *"For them it's very hard. For them everything is mundane, same room, same kitchen and all. So, they get very irritated when they have to stay in the same place for long time and get aggressive*." (Nepal, parent of child with deafblindness, DIDCOVNEPA16)
>
> "*She says you keep only me in the house. Other friends are going to school. She feels like only she is staying at her home and her friends are going to school. We also took her to school to prove that school is completely closed and no one is coming to read.*" (Nepal, mother of young woman with intellectual impairment, DIDCOVNEPB6)

In one case, the anger and aggression was so extreme that discord was perceived to be always present in the home.

> "*There is never peace in the family…. For us, when we are feeling sad, we can express it or share it with others, which cools us down, but it's not the case for them. For them slamming things or shouting is the way to express their emotions. But for us, when they destroy stuff or shout, there is economic damage and mental pressure*." (Nepal, parent of child with deafblindness, DIDCOVNEPA16)

The pandemic lockdowns and other restrictions clearly created much worry and distress for people with disabilities. Inevitably, due to the economic problems they faced, the initial acute fear of the virus was taken over by fear of hunger. People felt hopeless, helpless and depressed in the worst times of the crisis.

> "*Everyone is sad and worried because of the pandemic.*" (Nepal, woman, psychosocial, DIDCOVNEPA15)
>
> *"Different feelings frighten and swallow me all the time. I was crying at home all the time. No one was there to help me and my family in that time. I was stuck in my wheelchair all the time and felt mentally traumatised*." "*I always thought that I will die due to the mental pressure*." "*I always felt helpless all the time during the lockdown*." (Bangladesh, woman, multiple, DIDCOVBDA4)

It is important to understand the emotional impacts of the pandemic, as subjective feelings such as frustration or lack of hope are a barrier to people's agency, which is needed in the COVID-19 circumstances to adapt to the 'new normal'.

Changes over time – material impacts and emotional responses

Comparing the first and second interviews, we observed feelings changing for particular interviewees, such as the level of fear and emotional distress either decreasing or being perpetuated, the difference being related to individual material circumstances.

The second interviews indicated that life for some participants and people in their communities did improve a little as restrictions eased and family members, or interviewees themselves, were able to find work again. This covered some of their family's immediate needs and eased their mental stress and worries for these respondents.

> "*My family is doing well and we could manage our livelihood without that much difficulty*". (Bangladesh, man, multiple, DIDCOVBDB1)
>
> "*Dad and I were both very helpless when I had no job at this time of the epidemic. There was no money in the house and not enough food. Now I got my job back again and we are all safe and good*." (Bangladesh, woman, intellectual, DIDCOVBDB18)
>
> "*We couldn't market for lack of money after the epidemic started but now we do not have to do these troubles. Nowadays we can eat three meals a day properly*." (Bangladesh, man, deafblindness, DIDCOVBDB11)

However, we identified a clear difference between those who had family income coming again, and those who didn't. In addition, many of the interviewees with disabilities were unable to find employment, including as a result of disability discrimination, and the conditions of those who found work again were often worse than before, with lower wages and fewer hours, especially in Bangladesh. This meant many people were still struggling to survive or thrive.

> "*All the community members financial condition has changed but my family condition has not changed that much*." (Bangladesh, woman, multiple, DIDCOVBDB2)
>
> "*My brother is able to work again after the lockdown is over but he is not being paid as before. Now the wages are much lower than before*." (Bangladesh, woman, intellectual, DIDCOVBDB19)

Interviewees noted that it was hard for people with disabilities who had businesses prior to the pandemic to restart because they had used up their capital to survive.

> "*Any of the people with disabilities in my community who used to do street hawker jobs still struggle to come back to their normal life as they have already used their principle amount of business to lead their livelihood in the lockdown time*." (Bangladesh, man, multiple, DIDCOVBDB1)
>
> "*Many of these small business persons with disabilities had used their principle amount to run their family. Now, they are totally in the edge of the financial crisis*." (Bangladesh, man, multiple, DIDCOVBDB3)

The repayment of loans taken to survive over lockdown was also a major concern and burden for people with disabilities in Bangladesh.

> “*It is really difficult for me to manage the daily livelihood as well as pay the loan with interest but I tried to repay one by one*.” (Bangladesh, man, multiple, DIDCOVBDB3)

> “*But we have some loan and I have repaid that loan in every month which is very burdensome for us. As the income we had is not enough to run the family, how could we repay the loan with interest* (Bangladesh, woman, deafblindness, DIDCOVBDB6)

In Bangladesh, some people with disabilities faced further challenges during this time due to damage caused by flooding.

Furthermore, the support from various sources which helped people survive the first lockdown in Bangladesh and Nepal has not necessarily been sustained as lockdowns and restrictions eased, and opportunities for employment emerge, even though people’s actual material conditions have not improved by much or at all.

> “*During the lockdown, many people support us in that time but right now the level of support has decreased as many of them may have thought that the situation may improve for many of the cases. But our condition has not improved a little bit. Still we have to depend on others for our daily livelihood*.” (Bangladesh, woman, multiple, DIDCOVBDB4)

Not surprisingly, the subjective emotions experienced were related to the participants’ particular situation. Some people felt happy and hopeful again by the time of the second interview. This was either because their material circumstances had improved after the initial negative economic shock, as they or their family members were earning again, or because they were less worried about COVID-19, especially as a result of the news about vaccine development.

> “*Recently I got my job back and I am so happy now*.” (Bangladesh, man, intellectual, DIDCOVBDB17)

> “*Now everyone can work and eat as before. Tell me what could be better than this. Everyone wanted to get back to a healthy life. Slowly now everything is the same as before. We are very happy now.*” (Bangladesh, woman, intellectual, DIDCOVBDB15).

> “*The effect of coronavirus has not that much which was before. Before, I and my family were afraid about coronavirus but currently we do not have the fear anymore. We adjusted with the current situation*.” (Bangladesh, man, multiple, DIDCOVBDB1)

> *“I had fear. People used to say corona has come. Now fear has gone…Now we are in hope because vaccines are being developed and is coming in January and then we can meet and gather*.” (Nepal, man, intellectual, DIDCOVNEPB4)

> “*Now no one has to die because scientists have developed a coronavirus vaccine. Everyone used to be afraid of coronavirus but now no one is afraid of coronavirus*.” (Bangladesh, man, intellectual, DIDCOVBDB20)

In Nepal, some were no longer worried as a result of misinformation about COVID-19.

> “*Before 1-2 months, there was more fear and risk. We did not go outside also. Now it is felt that corona is nothing. It is just simply common cold and cough.*” (Nepal, man, intellectual, DIDCOVNEPB3)

People adapted to new routines and felt less frustration. Some interviewees also observed that generally in their communities, people's improved circumstances had led to a return of peace in people's families.

> *"Although she did not know about COVID but staying at home since longer time, it is easier to maintain her activities"*. (Nepal, parent of child with autism, DIDCOVNEPB5)

> "*The mental pressure is less than before. Now, they could manage their livelihood in a well manner like before. In every family, there is peace again*". (Bangladesh, man, deafblindness, DIDCOVBDB10)

Despite these people feeling more optimistic about their situation in the second interviews, some interviewees expressed concerns and sometimes great fear for the future due to the duration of the pandemic and the uncertainty about how it is evolving.

> "*The pandemic situation is getting longer so it's been challenging for people*". (Nepal, woman, deafblindness, DIDCOVNEPA10)

With the possibility of a second lockdown, there were renewed serious worries.

> "*I do not know if the 2nd wave of coronavirus hits us, what will happen to my family. We are already have a lot of difficulties and I do not know how I will manage the situation*". (Bangladesh, man, multiple, DIDCOVBDB3)

Some people wondered how they would survive as their savings and other resources they used to survive the first lockdown were now gone.

> "*We already used the savings. Now, we are totally dependent on our daily wage income. If the situation arises, government will again announce the lockdown then our life will be worse than before*." (Bangladesh, woman, deafblindness, DIDCOVBDB9)

> "*It's been challenging now, compared to how it was before. It's like devices, you can charge things for some time, but then once the charge finishes, the problem is still there. The savings I had have finished. The relief support I used to get from organisations and people in the past has now reduced*". (Nepal, man, deafblindness, DIDCOVNEPB11)

Overall, whilst the acute distress changed over time as people adjusted to the situation, the pandemic is not over, and so the uncertainty continues.

Participant's validation meeting

This provided a chance for more than 20 of the 35 interviewees and their families to meet each other, share experiences, verify the emergent themes from the analysis, ask each other questions and look at the combined recommendations. See Annex 2 for details.

Achievements and limitations of the study

The use of narrative interviewing as a specific type of very flexible qualitative interview allowed for a focus on interviewees' own concerns and helped generate insights on situational, emotional, relational and dynamic aspects that can be missed by researcher-directed interviews. However, this approach was harder for inexperienced researchers than more conventional interviews, which are more structured. This resulted in more direct questioning prompts than intended, especially to some participants with intellectual impairments when the researchers struggled to get communication flowing. Despite this, the study generated rich and deep evidence on the interviewees' feelings, and some insight into the nuances of contextual impacts by gender, impairment and other intersecting influences such as relative poverty or access to assistance. We were pleased to be able to recruit and employ two women with disabilities to work as researchers. Both were relatively inexperienced, but both fed back that they had enjoyed and learnt from the experience. Whether they shared their identity as having a disability with the participants is not clear, so we do not know if this made a difference to how the interviews went. We hope to work with these or other young disabled researchers in subsequent projects in order to build up their experience and research capacities, and indeed we aim to model an inclusive approach to building research teams more widely.

The gap between interview rounds was shorter than planned but nevertheless we were able to identify changes in people's circumstances and feelings. Researchers found interviewees communicated more openly in the second round due to the established relations between them, as we had hoped. We thought this was also due to both the researchers and participants developing confidence in the research approach and what was expected.

We focused on and successfully recruited interviewees from the most marginalised groups of people with disabilities with the help of the DID OPD and NGO partners: people with deafblindness, intellectual, and psychosocial disabilities. However, due in part to their connections with these organisations, they were not necessary amongst the most marginalised and excluded of these groups (e.g. by economics, impairment or geography), as evidenced in part by the fact that many of them accessed assistance from OPD and NGO which helped in their survival of the pandemic. The most marginalised people with disabilities are likely to unsupported by these organisations. In addition, despite carrying out two interviews with each person giving us the opportunity to understand how experiences of the pandemic changed over time, it still is ongoing, so what is presented cannot be the full story of our interviewees' experiences of COVID-19, which is something that comes across clearly in the expression on future worries from some. Uncertainty continues.

Additionally, interviewing people remotely using online platforms or phones to ensure safety, is inevitably limiting and unsatisfactory for some participants and for the interviewers, and restricts the process to those with access to the relevant technology. Those living very remotely were less likely to be able to join the research, due to the lack of technology, infrastructure and connectivity. Although we made great efforts to ensure that the process was inclusive and accessible, including by providing sign language or tactile interpreters and paying for the data used so that people could afford to take part, we recognise that it was less inclusive and accessible than a face-to-face process would be, and some participants had to drop out of the second round, due to travel or technology difficulties in the first round.

Recommendations from our interviewees

Existing pandemic responses have been criticised for not directly including the perspectives of people with disabilities in their design and implementation, therefore interviewees were asked for their recommendations for responses to COVID-19 and future pandemics. Below are the main recommendations from the participants. They suggest that more disability inclusive responses to the current situation and in future pandemics or other crises are needed. There was a greater focus in the Bangladesh interviews on gathering recommendations, than in the Nepal ones, hence the discrepancy in the number provided for each country. In Bangladesh recommendations for different agencies and stakeholders were asked for.

As well as participants making recommendations that were pandemic related and disability-specific there were also suggestions that were rather general, arguably relevant to non-pandemic or crisis situations, and indeed some were not necessarily disability specific. This should be recognised, and in response we have combined and edited the recommendations to some extent.

Bangladesh

For the DID programme

- More counselling, sensitisation, and advocacy is required to ensure employers don't respond to the challenges of COVID-19 by terminating the contracts of people with disabilities. Employers need support to recruit people with disabilities as the economy rebounds. Improved advocacy with employers about reasonable accommodation and accessibility would improve job seeking and retention for people with disabilities.
- Advocacy at the local and national-level government should be increased to improve relief and social protection services for people with disabilities. More direct financial assistance should be given to people with disabilities to rehabilitate them and support them to build back better.
- More awareness generation meetings/seminars/workshops for people with disabilities should be implemented providing emotional support and development opportunities. Training could help people to be mentally prepared to deal with future pandemics, to overcome the challenges and minimise the losses.
- Awareness campaigns could be arranged at the community level to improve the attitude of the general population towards people with disabilities. More awareness should be generated at the community level to reduce the current stigma about disability.
- Advocacy should be undertaken with banks, social welfare authorities, and other stakeholders to provide interest free loans to people with disabilities. People should be encouraged to increase savings to overcome the challenges of future pandemics.
- Medical staff should be trained and counselled to better treat people with disabilities.
- Soft and hard skills training should be offered to youth with disabilities. Training should be based on the requirements of the current demands of the job market.
- An awareness campaign should be undertaken specifically for people with disabilities focused on the health measures and precautions relevant to COVID-19.

For local agencies including OPDs

- OPDs, private organisations and the government should work together to support people with disabilities. OPDs can increase the interaction between people with disabilities so that they do not feel isolated. OPDs can help to increase the mass awareness among the person with disabilities, their family, and the community about the safety measures for COVID-19.
- Employers should be flexible towards people with disabilities and restore any jobs lost due to the pandemic. An awareness campaign and advocacy with employers could be

undertaken to remove discrimination in recruitment, remuneration, and others due to disability and gender.

For national government

- The government should analyse the impact of the pandemic and deliver initiatives like providing financial assistance, job opportunities, and small enterprise/entrepreneurship support so that everyone (especially people with disabilities) could get back to their normal life.
- The government should undertake initiatives to minimise the impact on the education of students; in particular, the education of girls with disabilities must be improved.
- Medical services should be improved to be more accessible and to deliver the services people with disabilities need. The trust of people with disabilities in the medical sector must be revived.
- Contingency plans should be prepared and implemented by the government for current as well as future disasters.
- The distributions of the different services should be given on a priority basis, making sure that people with disabilities are considered at the grassroots level. The local government could play a vital role in ensuring that benefits of support reach people living remotely (benefitting the grassroots level).
- A disaggregated database should be prepared to determine the losses affecting specific subgroups of the population due to COVID-19 focusing on marginalised groups.
- All types of accessibility should be ensured for people with disabilities.
- A one-stop service centre should be developed to reduce harassment of people with disabilities.
- More training should be provided to increase disability inclusion. This includes training for teachers to ensure inclusive education for all.
- Corruption should be addressed. The relief distribution should be done fairly, minimising power misuse. Monitoring and evaluation will help to maintain discipline and cut corruption. Transparency should be increased.
- The price of essential products should be kept within the limits of what the general population can afford.
- Priority should be given to people with disabilities for medicine, and the COVID-19 vaccine in particular.
- The entire development plan initiated by the government should be inclusive of people with disabilities.
- Public-Private Partnership (PPP) should be made to provide services to marginalised and disadvantaged groups.

For the international audience

- Increase advocacy by and on behalf of people with disabilities with international and Bangladeshi stakeholders to provide special priority on the different development plans and services provided under the response to COVID-19 and other development programs.
- Provide more funds to help people with disabilities to build back better.

Nepal

- Communication about the pandemic and precautions to prevent the spread of COVID-19 should be provided in accessible formats, especially for people with intellectual disabilities and deafblindness. This includes countering misinformation about the pandemic.
- Access to health should be prioritised, including by making existing facilities and service providers inclusive and disability friendly, and through the provision of free medicine and services to those who cannot afford it.
- COVID-19 tests should be provided for free (nb this has now happened) https://www.reuters.com/article/health-coronavirus-nepal/nepal-to-provide-free-covid-19-tests-and-treatment-as-cases-surge-idUSKBN27Q0PA?edition-redirect=uk
- Quarantine facilities, including toilets, should be disability accessible.
- The government should respond to food insecurity and provide food supplies or cover the costs for three meals a day for those who are struggling.
- Local government should identify, approach, and provide support directly to those in their communities who are in need but who cannot access local government offices. Work should be done to make local government disability aware and friendly.
- Existing social protection payments should be topped up during the pandemic and social protections payments to people with disabilities should not be stopped. Parents of children with disabilities should not be forgotten and support should be provided to them.
- People with disabilities should be provided with skills and employment opportunities so that they can become self-sufficient, especially those currently dependent on aging parents.
- The disability movement should be united and coordinated in its advocacy and cooperation with government.

Conclusion

This research has shown that the COVID-19 pandemic has had devastating and life-changing detrimental effects on people with disabilities' lives in both Nepal and Bangladesh. The 35 participants who took part in the narrative interviews illustrated that the impact of the COVID-19 pandemic has been wide-ranging and extreme in some cases. The data shows similar key themes emerging in the lives of people with disabilities due to COVID-19 in the two countries. These include a negative impact on emotional wellbeing, finances, relationships, access to services and opportunities.

Some of the impacts were found to differently affect men and women, and people with specific impairments also appeared to be affected in distinctive ways. Many of the impacts were found to interact with each other (for example, losing employment - leading to financial concerns – leading to deteriorating mental health). Some of the impacts affected the whole community, but for people with disabilities the impacts often seem to be exacerbated or compounded. The interaction between disability and poverty appeared to increase the disadvantage for those living rurally, and those with particular impairments.

People with visual impairments have experienced particular challenges linked to reliance on touch. Touching people (e.g. guides and assistants) and surfaces during the pandemic has become problematic due to the increased risk of infection, but also due to how people react and respond to being touched during this time. This has had a negative impact on mobility, but also on feelings of isolation and lack of support. Some people felt less autonomous as touching became increasingly disapproved of. People with deafblindness were highlighted as facing particular issues during the pandemic. As well as relying on touch, many struggled to engage with information about the pandemic and lockdown as it was not accessible. People with intellectual, complex or multiple impairments have been negatively impacted by the pandemic as there has been disruption to their usual support and routines, which in some cases they were not able to understand. While it is recognised that COVID-19 has had a negative impact on the education of nearly all children and youth, those with intellectual impairments have been particularly affected and their needs have not been fully considered in the response planning.

Despite the challenges highlighted and the hard times people have endured, interviewing the majority of participants twice enabled us to see that the situation is improving for many people. During the first interviews most people were very anxious, worried and depressed about many aspects of their lives including their finances, their access to food and their health. The second interviews indicated that the situation for many had improved. Worries about food security had abated, and these people felt more positive, happier and hopeful for the future. In some cases, financial or health concerns remained, or had worsened and they were feeling more desperate. Nevertheless, the underlying dread of the virus and the isolation the national lockdowns brought, appeared to have lifted, although there were some concerns about the possibilities of future lockdowns.

Stigma or negative stereotyping was found to be prolific both during the national lockdowns and after. Many people with disabilities reported experiencing negative discrimination due to their impairment at either the same or increased levels since the pandemic began. There was some evidence of bullying and violence, within and outside the home. Gender based violence in the wider community was a particular concern highlighted during the initial lockdown, although there are mixed reports about whether that situation has improved or not.

The main material effects of the situation included extreme financial stress and poverty, lack of access to essential services (including education, health, social protection and relief). A lack of accurate accessible information was reported, and government responses were found to be largely exclusive of people with disabilities. Rumours and misinformation about the virus were common and was a barrier to people understanding the situation. Corruption was reported as a major problem. OPDs were found to play an important role in making sure that people with disabilities were not left behind in support and relief efforts and recovery. The emotional affects such as the sense of loss (of opportunities, freedom and social relations), anxiety and depression, resulted from the lockdown restrictions and consequent material impacts. However, these are also important to recognise and address as emotional factors such as frustration and hopelessness affect people's agency and thus their ability to adapt and recover after the pandemic.

To conclude, the data showed that people with disabilities from the most marginalised groups in Nepal and Bangladesh have been marginalised by the pandemic and government responses to it. Inclusive approaches must be developed to ensure that the rights and fundamental freedoms of all persons with disabilities can be realised without discrimination of any kind on the basis of disability.

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Annex 1 – Participant table

Theme	**Gender**		**Impairment**							**Age**			**Education***					**Occupation****				**Marital status**			**Location**			**Dependence*****			**Interviewed**	
Category	**Male**	**Female**	**Physical**	**Visual**	**Hearing**	**Intellectual**	**Psychosocial**	**Other**	**Multiple**	**<29**	**30 to 49**	**50>**	**None**	**Primary**	**Secondary**	**Tertiary**	**Other**	**Employed/ works**	**Unemployed**	**Student**	**Other**	**Married**	**Single**	**Other**	**Rural**	**Urban**	**Semi**	**Depends on others**	**Others depend on them**	**Neither**	**Once**	**Twice**
Bangladesh	10	10	0	0	0	6	0	0	14	11	9	0	5	7	3	4	1	5	6	7	2	4	16	0	10	8	2	0	8	12	0	20
Nepal	8	7	0	0	0	5	3	2	5	4	8	3	0	2	7	6	0	2	12	0	1	9	4	2	5	6	4	6	9	0	3	12
Totals	**18**	**17**	**0**	**0**	**0**	**11**	**3**	**2**	**19**	**15**	**17**	**3**	**5**	**9**	**10**	**10**	**1**	**7**	**18**	**7**	**3**	**13**	**20**	**2**	**15**	**14**	**6**	**6**	**17**	**12**	**3**	**32**
Percent	**51**	**49**	**0**	**0**	**0**	**31**	**9**	**6**	**54**	**43**	**48**	**9**	**14**	**25**	**29**	**29**	**3**	**20**	**51**	**20**	**9**	**37**	**57**	**6**	**43**	**40**	**17**	**17**	**49**	**34**	**9**	**91**

* Education categories standardised across the two countries. College education included under 'tertiary'. Other includes religion-based education and informal education.

** The occupation category of 'other' included volunteers, and those with caring responsibilities who were not actively seeking employment.

*** The dependence category was open to interpretation by data collectors, but an attempt at standardising the categories across the countries has been made.

Annex 2

Notes from online participant validation meeting

Participants were welcomed and a short summary of the project and the main findings were provided in English. The findings were presented in Nepali and Bangla during breakout groups (split into one Nepal group and two Bangladesh groups with translators, sign language and tactile interpreters, facilitators and notetakers)

Breakout session 1 participants were asked to discuss the summary findings and add extra points.

Feedback from Nepali group

- Fear of police – threatening behaviour/restrictions on movement/abuse
- People with disabilities treated with pity rather than having their right to information realised
- General lack of concern from government for people with disabilities
- Access to health services inadequate

Feedback from Bangladesh groups

Group 1

- People with deafblindness faced a lot of challenges – e.g. attending online classes
- People with intellectual impairment and people using wheelchairs faced a lot of challenges
- No specific relief for people with disabilities. Those who received disability allowance did not receive further relief services from government
- Domestic violence increased

Group 2

- People with disabilities (particularly deafblind) became isolated
- People with sensory impairments were put at a particular disadvantage due to people wearing masks and the impact this had on communications
- Loss of earnings/income – loss of capital – had to take loans with high interest. Decent loans harder to secure due to loss of income.
- Access to services and information was a challenge
- Increased health risks (including mental health risk)

Breakout session 2

Participants were asked to think of questions they would like to ask people from the other country (i.e. Nepalis ask Bangladeshis, Bangladeshis ask Nepalis). In plenary these questions were fed back and translated into English and both languages. Answers were then provided from each country and translated for the whole group.

Nepali questions for Bangladesh

1. During COVID what was the reaction of the society towards the PWDS in Bangladesh?

2. Did the PWDS make any approaches to the government?

3. People with deafblindness – did they receive any assistive devices during the pandemic?

4. Women with disabilities – how did they manage their health needs – e.g. assistive devices and equipment and medication – from government or elsewhere?

5. Children with developmental disability e.g. autism. How did the parents engage the children during lockdown - any different activities, any special help?

Bangladeshi questions for Nepal

Group 1

1. What was the support from government of Nepal for people with disabilities?

2. Those who didn't receive relief from government – how did they survive?

3. Those who lost work – how have they come back to their previous work or a new normal?

4. Was information accessible for people with disabilities, e.g. health/hygiene messages?

5. How did other people manage these practices despite their poverty or other challenges? hygiene etc

6. Since communication for people with deafblindness is mostly tactile –not being able to touch things e.g. when shopping is difficult – did they have same problem in Nepal – how did they manage?

Group 2

1. Same as question 1 above – was there support enough from government?

2. Lost work – did government provide any work for PWD who lost their job?

3. Is the education system open again in Nepal? Is it inclusive for PWDs?

4. Has the covid vaccine started in Nepal? If so, is there any restriction for PWDs to take the vaccine?

The final part of the meeting

presented the summarised recommendations and the plans for dissemination of these in various formats and languages.