



## Nepal Health Sector Support Programme III (NHSSP – III)

**Case study on access to essential health services and care of people living with severe disabilities  
during lockdown and COVID-19 emergency**



# **Access to essential health services and care of people living with severe disabilities during lockdown and COVID-19 emergency**



Government of Nepal

**Ministry of Health and Population**

**Department of Health Services**

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## Executive Summary

### Background

With more than 144,000 people in Nepal infected, the economy in shock and the health system stretched, the COVID-19 pandemic threatens to reverse Nepal's economic and human development gains. Globally and in Nepal, the pandemic has hurt the poorest, the least empowered and most vulnerable the hardest. Across the world and in Nepal, people with disabilities and women have been severely impacted by the health, economic and social fall-out of the pandemic.

### Objectives of the study

This study documents the impact of the pandemic on access to essential health services and care of people with severe and complete disabilities as defined by the Rights of Persons with Disabilities Act, 2017, and presents recommendations to address the gaps.

The study focuses on five target groups: people with spinal cord injury, people with hemophilia, people with psychosocial disabilities, people with intellectual disabilities and people with multiple disabilities.

### Methodology

The study was implemented under the leadership of the Population Management Division of the Ministry of Health and Population. It was undertaken by National Federation of the Disabled Nepal with guidance from Population Management Division, Policy, Planning and Monitoring Division and Epidemiology and Disease Control Division. Technical support was provided by the UK-aid funded Nepal Health Sector Support Programme.

A qualitative case study methodology was used. This method allowed rich data to be collected from primary respondents in a timely manner given the constraints of working in the COVID-19 context.

Primary data was collected in three provinces plus Kathmandu. This included interviews with 55 persons with severe and complete disability, and 18 related care givers. A sample of health providers, municipalities, Provincial Ministry of Social Development and Provincial Health Directorate in the three focal provinces were interviewed. National stakeholders from Ministry of Health and Population, Ministry of Women, Children and Senior Citizens, and Rural Municipality Federation were also consulted.

### Policy context

The study found that the policy provisions and disability related health strategies and technical guidelines that have been introduced, have created an ambitious agenda of new service delivery commitments. However, implementation of the various policy provisions falls below expectations, and is hindering access to essential health services and rehabilitation.

### Key findings

The study found a number of common experiences across the target groups. The findings are separated into two main categories: (i) common experiences across the sample, and (ii) the particular experiences of people with specific types of disabilities.

#### Common experiences

The majority of persons with severe and complete disabilities included in this study are socially and economically dependent on their family: 82% need full time or part time support to meet their daily living needs such as food, clothing, toileting, bathing, mobility and participation in the community.

**Family income:** Two-thirds of respondents reported that the lockdown situation has affected their own or family income sources to the extent of a financial crisis. Small shops are closed, jobs have been terminated and agricultural products couldn't be sent to the market due to travel restrictions. Over 10 respondents noted how they are now forced to consume cheaper and less nutritious food.

I am fully dependent to the support and income of my family. My family's income is based on the agriculture. Vegetable farming is main source of income, but due to the pandemic the market and transportation are closed. We could not send the product to the market for a long time. It gave a big loss to our family. All products are damaged. The suddenly imposed financial crisis has created problems also in my regular treatment.

*Experience of 46 years man living with hemophilia who belongs to Janajati community.*

**Access to health services:** Out of the 55 study respondents, 71% said that they need some form of regular health service - medical check-up, medicine and supplies, counselling, psychosocial therapy - and 27% said that they need such services sometimes. COVID-19 has severely impacted access to the regular and occasional health services needed with 37 (67%) reporting that very few services have continued, and 13 (24%) saying that their regular health services have been completely interrupted.

Out of 55 respondents, 87% said that they were not provided with personal protective hygiene materials such as face masks, sanitizer, gloves and soap, or had access to public health information on how to stay protected from the risk of infection.

**Hygiene materials:** More than 15 respondents reported how the closure of markets and restrictions on public transportation is impacting their access to health and hygiene materials. Some products such as catheters are also not available in village markets.

**Assistive devices:** 31 respondents depend on different types of assistive devices for their mobility but have not been able to get their assistive devices repaired or replaced since lockdown.

**Worry:** COVID-19 is fueling fears and anxiety. Most worry about how they will be treated at hospital, who will take care of them if they are admitted, and whether caretakers and helpers are allowed to accompany them.

**Social assistance:** Out of the 34 (61%) respondents that were receiving social assistance in the form of cash or in-kind support from government, NGOs, private organizations and personal donors, before the

pandemic, 19 people have had this vital source of support completely interrupted since the onset of COVID-19.

#### Persons with spinal cord injury

**Medical supplies and hygiene materials:** Persons with spinal cord injury typically need a range of medical supplies and hygiene materials - such as catheter, urine bag, Clean Intermittent Catheterisation (CIC) pipe, jelly, diaper, sanitary and menstrual pads - to manage urine, menstruation, pressure sore and defecation. Access to these supplies has become very difficult since COVID-19 because of travel restrictions, financial hardship and materials not being available in the local market.

**Pressure sores** are a very common health problem, and regular care at a hospital or health facility is needed to avoid the sores becoming severe and complicated. Respondents shared that since COVID-19 they have not been able to access a hospital or health facility for treatment of their bed sores. For six respondents, the number of sores has increased and they are experiencing extreme pain, and resorting to strong pain killer or sleeping tablet for relief.

**Additional health complications:** The limited availability of medical supplies and hygiene material and the lack of access to essential health care since the pandemic, has caused additional health complications, including:

- Extreme pain in the body
- Worsened personal hygiene and sanitation
- Urine infection
- Problem of blood pressure, headache and stomach pain
- Anxiety and depression
- Constipation

I use CIC pipe to manage my urine. I cannot use one for a long time. I need to replace it but it is hard to get CIC pipe in my local area. Now I have only one. I have to go a bit far to bring this but there is lockdown and travel restrictions. I cannot go and I am also afraid of the infection of COVID. On the top of that after COVID pandemic I am also suffering with financial problems.

*Experience of 52 years male living with Spinal Cord Injury in Kathmandu District.*

#### Persons with hemophilia

**Supply of anti-hemophilic factor:** The Rights of Persons with Disabilities Act, 2017, ensured provision of anti-hemophilic factors to persons with hemophilia free of cost. Prior to COVID-19, the factor was not on the essential drugs list or being supplied by Government. The only source of anti-hemophilic factor available was from the NGO, Nepal Hemophilia Society, which was collecting a very limited number from international donors and providing it to persons in need.

With the introduction of lockdown, the stock of factor with Nepal Hemophilia Society was exhausted and fresh supplies could not be sourced. In response, the Federal Ministry of Health and Population allocated NRs 20.6 million for factor procurement for financial year 2020/21 and some Provincial Ministries of Social Development (Province 1, Bagmati Province, Gandaki Province and Sudurpaschim Province) followed suit.

The Provincial Government of Province 1 bought an amount of anti-hemophilic factors using the fast track process in coordination with NFDN and Nepal Hemophilia Society, and this helped to save the lives of people who were in a serious condition in that province. Other provinces have not yet used their budget allocations and the supply problem remains.

**Complications faced by persons with hemophilia during the pandemic:** The shortages of factor have left persons living with hemophilia facing serious complications, including:

- Extreme pain for a long time in joints.
- Damages in joints and additional physical limitations.
- Gradually they are compelled to use crutches and wheelchair to walk due to the damages in joints.
- The body cannot work due to the pain and regular bleeding.
- Use of strong pain killer and sleeping tablet to get relief.
- Problem of blood pressure and mental torture and stress.

There was an internal bleeding in my hands during lockdown. I could not go to see the doctor and therapist because of the travel restriction and I was also afraid of the risk of COVID infection. I used ice to relief from pain, put some bandage for one week. I went through an extreme pain and I had to use some strong medicine to get relief from the pain. Me and my family had to face a mental stress too.

*Experience of 27 years old male.*

#### Persons with psychosocial disabilities

**Access to health services:** seven out of the nine respondents with psychosocial disabilities reported that access to regular doctors, medicine, treatment, counseling and psychiatrists which they had been seeing before COVID-19 has been interrupted. Medicine is not available in the market, and travel restrictions and fear of COVID-19 infection has added to their troubles.

**Additional health complications:** Respondents shared that they are experiencing additional health problems since the pandemic, including:

- Increased level of depression.
- Feeling pain in heart and something scary.
- Uneasy feeling and less sleep.
- Anxiety and stress have increased.
- No interest in food and less sleep.

Five out of nine respondents shared how the loss of their own or family's income source has increased their mental stress and they are living in the fear that there will be more problems in the future.

This situation is panicking me. Every time I am scared of COVID infection. I am feeling that the level of depression has increased. I also have some other health problems which I need to check-up in regular basis. But I cannot go to see the doctor in this situation. My husband also has physical disability. He was engaged in tailoring before COVID and we had some income to run the family. After COVID he is not able to for work. My family is running out of income for a long time.

*Experience of 30 years female living with psychosocial disabilities who belongs to the Dalit community*

## Persons with intellectual disabilities

**Access to health services:** Parents of children with intellectual disabilities reported how their children cannot understand the risks and implications of COVID-19 and it is very hard to get them to physically distance, use face mask and sanitizer. They noted how services at hospitals are difficult to access due to travel restrictions, and the requirement of a PCR test first, which is difficult to organize for persons with intellectual disabilities. Pre-COVID-19, some doctors, therapist and rehabilitation workers had delivered care at home, but since COVID-19 this was not available.

In my family, first I was infected with COVID. My son has intellectual disabilities who always live and sleep with me. Every time he wants me to care and love him. After COVID infection I tried my best to get him keep away from me but I could not do it. He was also infected from COVID. After this he mixed up with other family members and they were also infected. Now my whole family is infected with COVID.

Experience of parent with a child with intellectual disabilities taking part in FGD.

Parents shared how health staff lacked training in how to interact and care for persons with intellectual disabilities, and how they felt this led to doctor's dispensing without a proper diagnosis, and abuse by staff when their children's behavior was challenging.

## Persons with multiple disabilities

**Access to health services:** Services needed by people with multiple disabilities are only available in urban areas. Those from rural areas face the extra burden of travel and accommodation, in addition to treatment cost. For services required on a regular basis, for instance, treatment of bed sore, therapy, psychosocial counseling, urine infection, the out of pocket and opportunity costs are very high. Most of the health-related services they were taking before COVID-19 have been interrupted.

The high dependency of persons with multiple disabilities and their need for intensive care and support if they are admitted to hospital raises concerns for how they would be cared for in the COVID-19 context. Normally, hospitals are unable to provide essential caregiver services to persons with disabilities and patients are supported by the helpers they bring with them. But in the COVID-19 situation, hospitals may not provide permission to helpers due to the risk of infection. Their main concerns are:

- Is there provision for helper at hospital who could provide intensive care to severe and complete persons with disabilities, if they get infected?
- Are they allowed to bring their own helpers to the hospital and is the hospital ready to provide personal protective equipment to the helper?
- Do the health professionals know about the requirements of persons with disabilities?
- Will we receive care without any discrimination on the basis of our disabilities?

I know a little bit about how to be prepared to fight with COVID if I get infected but I really don't know about how the health worker will support me during the time of treatment if I am admitted at hospital for treatment. I don't know, whether I am

allowed with my helper or not and I also don't have any information about how much the health workers know about needs of people like us.

Experience of 22 years male living with multiple disabilities.

### Experience of family members

Parents and family members interviewed shared the challenge of balancing their responsibilities caring for those with disability and their other family responsibilities such as household work, income generation and social commitments.

**Care burden:** Parents and family members (mainly mother or women) spend between three to eight hours per day caring for the person with disabilities. They noted that they frequently have to compromise on the quality of care they provide due to other family responsibilities and how this increases their stress and worry. Poor families who cannot afford to stay home are forced to leave the family member with disabilities at home alone. Parents worried about the risk of sexual violence, rape and abuse in such a situation.

### Reflections of health professionals and government authorities

Health professionals and government authorities agreed that persons with disabilities have faced significant challenges in accessing essential health care during the COVID-19 pandemic and lockdown, and are especially vulnerable to infection and experiencing severe COVID-19. However, the response of the health service to prepare for COVID-19 cases among people with disability has been limited. Critical preparations such as introduction of guidelines or training of staff on how to respond to the specific needs of people with disability in the event that they are admitted to a COVID-19 isolation centre, have not been introduced.

Provincial and municipality responses to the special needs of people with disability during lockdown and the pandemic situation have been piecemeal. No instructions have been given to local health facilities to ensure they regularly contact persons with severe and complete disabilities by phone or in person given their vulnerability. No special efforts were made to check up on their health, to ensure they have sufficient supply of medicines, health and hygiene material, or respond to their fears and worries.

Province 1 supplied health and hygiene products to persons with spinal cord injury and distributed them in cooperation with NFDN and local DPOs. In addition, Province 1 procured and supplied anti-hemophilic factor to people with hemophilia.

National stakeholders recognize that the policy foundations to provide essential health care to persons with disabilities, are yet to be fully operationalised, and significant gaps in services remain at all levels. Health workers and management lack training in disability inclusive health care, resources have not been provided to address accessibility barriers at facility level or provide special services to persons with severe and complete disabilities. The plan to establish at least one Spinal Injury and Disability Rehabilitation Centre in each province has not been implemented.

## Recommendations

Two sets of interconnected recommendations are made. The first set of recommendations aim to address the immediate situation and improve access to essential health services of people with complete and severe disabilities. The second set of recommendations focus on the longer term strengthening of the health system to provide disability inclusive health services and deliver the Government's policy provisions.

### *Recommendations to reduce the immediate impact of COVID-19 on access to essential health care and daily living needs of persons with severe and complete disabilities*

#### **1. Access to essential health care, public health information, medicines, assistive devices and health and hygiene related supplies:**

- a. Ministry of Health and Population (MoHP) and Provincial Health Directorate to ensure adequate supplies of essential drugs for persons with severe and complete disability at hospitals and local health facilities.
- b. MoHP in cooperation with Ministry of Federal Affairs and General Administration (MoFAGA) to develop and issue instructions to municipalities and local health facilities to provide persons with spinal cord injury, hemophilia, psychosocial disabilities, intellectual disabilities, and multiple impairments:
  - i. regular weekly health check-up service from local health workers either through in person visits or phone-based check-up.
  - ii. all essential medicines needed on a regular or occasional basis to manage their health needs, provided as required and free of cost.
  - iii. all health and hygiene materials as required including catheter, urine bag, Clean Intermittent Catheterisation pipe, jelly, diaper, sanitary and menstrual pads be provided free of cost. The municipality health fund is one option to fund these inputs.
- c. Hospitals to provide ambulance transport to persons with complete and severe disabilities that need to use hospital services, and free of cost.
- d. Interrupted psychosocial counseling and psychiatric service at provincial and district hospitals to be restarted, and essential drugs for persons with psychosocial disabilities made available at provincial and district hospitals and local health facilities, once prescribed by an authorized prescriber (psychiatric doctor, medical officer and health assistant).
- e. Local government to ensure that all persons with severe and complete disabilities have full access to public health materials to protect them from COVID-19 infection, including face mask, sanitizer, gloves, soap and COVID-19 related public information to stay safe from the infection. Distribution of materials may be in collaboration with DPOs and NGOs.
- f. Ministry of Women Children and Senior Citizen (MoWCSC) in cooperation with NDFN and other NGOs, map the need for assistive devices for spinal cord injury, multiple disabilities and other severe and complete disabilities, in each province. MoWCSC contract out the supply, repair and maintenance of assistive devices of people with complete and severe disabilities to local DPOs or NGOs.

- g. COVID-19 related public information produced and disseminated by MoHP, provincial government and local municipalities to be made in accessible format such as easy-to-read, audio, pictorial, sign language, and local language.

**2. Disability inclusive COVID-19 testing and treatment:**

- a. Ministry of Health and Population in cooperation with the Ministry of Women Children and Senior Citizen, to develop interim guidelines on how COVID-19 testing and treatment services in each province are to respect the needs, and provide special care to persons with disability. This guideline will be targeted towards hospital management, doctors and health staff and accompanied by virtual or in-person orientation. It will allow persons with severe and complete disabilities to be accompanied by one helper/assistant when seeking diagnostic services or treatment for COVID-19. This helper/assistant will be supplied with personal protective equipment as per that provided to health workers in the hospital.
- b. Provincial government and local municipalities to ensure that isolation centres and quarantine facilities are accessible and safe for persons with profound and severe disabilities.

**3. Anti-hemophilic factors for persons with hemophilia:**

- a. Provincial Ministry of Social Development to assess the prevalence of hemophilia in each province and calculate the supplies required.
- b. MoHP to allocate conditional grant to each province, to be supplemented by provincial government as required, to procure sufficient supplies of anti-hemophilic factors for the province. Procurement to be expedited using the fast-track process. In financial year 2022/23, the Provincial Government to take full responsibility for funding anti-hemophilic factors.
- c. At least one provincial hospital in each province to be designated to provide services to persons with hemophilia.

**4. Information and social support to be provided to persons with disability and their families in each hospital:**

- a. Hospital based Social Service Units (SSU) to support persons with disabilities to access hospital care. MoHP to instruct SSUs on how to serve and support persons with disabilities and their parents, and the Provincial Ministry of Social Development, Health Directorate to monitor implementation.
- b. In hospitals without SSU, MoHP and Provincial Ministry of Social Development to coordinate establishment of a disability focal desk in provincial and district hospitals as a contingency plan, and until a SSU is established.

**5. Social protection of persons with severe and complete disability to offset the impact of the pandemic:**

- a. Public Health Service Act provision for the Ministry and Provincial Governments to establish an emergency health treatment fund to be activated to finance gaps in the care of people with complete and severe disabilities<sup>1</sup>.
- b. Ministry of Women Children and Senior Citizen in coordination with municipalities to develop and provide a new Livelihood Allowance for persons with complete and severe disabilities who are experiencing economic crisis due to COVID-19; to be distributed by municipalities.
- c. Local government to prepare a database of persons with severe and complete disabilities. Data to be disaggregated by gender, age, disability, government allowances and provisions currently received. This will provide evidence to inform local government relief and recovery plans and help ensure people with severe and complete disabilities are not left out.
- d. MoFAGA to facilitate local government's continued distribution of the disability ID card which has been interrupted by the COVID-19 situation.

*Recommendations to support the Government's longer-term objective of providing disability inclusive health services*

**1. Dissemination of federal policies and acts:**

- a. Ministry of Women Children and Senior Citizen to disseminate the Rights of the Persons with Disability Act, 2017 and related bylaws to provincial and local level authorities.
- b. Federal MoHP to disseminate disability specific health policies and plans to provincial and municipality stakeholders including Disability Prevention and Rehabilitation Strategy 2016-2026, and National Guideline on Disability Inclusive Health Services, 2019-2030.
- c. MoHP to socialize the National Guideline on Disability Inclusive Health Services to provincial, district and local level stakeholders so that they understand their responsibilities.
- d. Federal MoHP and Provincial Ministry of Social Development, Health Directorate to provide orientation to health facility managers, and hospital and health facility staff to support implementation of the National Guideline on Disability Inclusive Health Services, 2019-2030.

**2. Federal level health systems strengthening to support disability inclusive health services:**

- a. Federal MoHP to define the location and responsibilities for providing essential and specialist health services to persons with severe and complete disabilities. Based on this commitment, MoHP to calculate the human resources needed to provide these services, and develop a medium term human resource development plan to meet these commitments.
- b. In line with the Government of Nepal's (2013) national standards on accessibility of public physical infrastructure and communication services, the MoHP and MoWCSC plan and undertake regular Accessibility Audits of health-related infrastructures in collaboration and

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<sup>1</sup> Government of Nepal, Public Health Service Act, 2018, Section 33 states "The Ministry and Provincial Government shall set up an emergency health treatment fund to make arrangements for bearing the expenses of treatment of the poor and destitute, the person whose house and address is not traced, the family members of a martyr who sacrificed life in the course of popular movement, armed struggle and revolution, the family of the enforced disappeared person, the warrior of democracy, conflict victim and the displaced, the disabled, the wounded and the victim, in the case of not being able to bear the expenses incurred in treatment."

- cooperation with local DPOs and accessibility experts. The reports from the Accessibility Audits to be submitted to the National Steering Committee chaired by the Minister of MoWCSC, and Disability Coordination Committees at Provincial and Municipality levels.
- c. Social health insurance to insure all persons with complete and severe disabilities into the scheme, and to raise awareness of this provision. The social health insurance package to cover the costs of providing essential and specialized health care to this target group. Until social health insurance is in a position to cover the costs of persons with severe and complete disability, free services at government facilities should be provided at the point of delivery with costs reimbursed to the facility by MoHP.

**3. Provincial level health system strengthening to support disability inclusive health services:**

- a. Provincial governments to establish a comprehensive rehabilitation centre and centre of excellence for spinal cord injury, intellectual disabilities, hemophilia, multiple disabilities, autism and other forms of impairment specific services. The centre of excellence to support capacity development of district and local level health workers on disability-related services provided at their level.
- b. Provincial government to ensure disability-related specialized services are provided at provincial hospitals. Provincial hospitals to be equipped and enhanced with additional facilities, special care units, and human resources to provide specialized services, treatment, and rehabilitation to persons with spinal cord injury, hemophilia, multiple impairments, intellectual disabilities, psychosocial disabilities, severe physical disabilities, and autism.
- c. Provincial government to ensure that all provincial health institutions are accessible to persons with disabilities and health workers are well trained to provide treatment, support, and special care to them as they come to take services.
- d. Provincial Government and Ministry of Social Development to allocate adequate budget for rehabilitation services, specialized services, and medicines for persons with disabilities.
- e. Provincial Government to provide capacity building to health workers at provincial, district and municipal level on disability issues, essential health services to be provided to spinal cord injury, psychosocial disability, intellectual disabilities, hemophilia, multiple disabilities and other disability category and the provision of respectful, empathetic and client-centred care to persons with disabilities.

**4. Strengthening the role of local governments to protect and meet the rights of people with severe and complete disability:**

- a. Local government to ensure that health institutions are accessible to persons with disabilities, and persons with severe and complete disabilities are prioritized in service delivery.
- b. Essential health care and primary treatment of persons with spinal cord injury, psychosocial disabilities, multiple impairments, and severe physical disabilities is available at local health facilities; with referral to higher level. Psychiatric services, counseling, therapeutic services, basic level rehabilitation services to be available at the district hospital.
- c. Municipalities to provide mental health and psychosocial disability awareness raising program at the community level on a regular basis.

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## Acronyms

CIC	Clean Intermittent Catheterisation
CRPD	Convention of the Rights of Persons with Disabilities
DFID	UK Department for International Development
DoHS	Department of Health Services
DPO	Disabled Peoples Organisation
EDCD	Epidemiology and Disease Control Division in Department of Health Services
GDP	Gross Domestic Product
MoFAGA	Ministry of Federal Affairs and General Administration
MoHP	Ministry of Health and Population
MoSD	Ministry of Social Development
MoWCSC	Ministry of Women, Children and Senior Citizens
NFDN	National Federation of the Disabled Nepal
NGO	Non-Governmental Organisation
NHSSP	Nepal Health Sector Support Programme
NHRC	Nepal Health Research Council
OHCHR	Office of the High Commissioner of Human Rights
PMD	Population Management Division in Ministry of Health and Population
PPMD	Policy, Planning and Monitoring Division in Ministry of Health and Population
RPD Act	Rights of the Persons with Disabilities Act
SRH	Sexual and Reproductive Health
UNDP	United Nations Development Program
WASH	Water, Sanitation and Hygiene

# Chapter 1: Introduction and Background

## 1.1 The global impact of COVID-19

The whole world has deeply been affected by the pandemic of the novel Corona Virus ([SARS-CoV-2](#)) known as COVID-19<sup>2</sup> which was first identified in Wuhan, China in December 2019. The transmission of this deadly virus from human to human expanded rapidly throughout the world and has taken the lives of more than 1.1 million people as of now<sup>3</sup>. More than 43.8 million have been infected by the virus and to date there are 10.4 million active cases in the world<sup>4</sup>. The impact of the pandemic has spread beyond health and desperately paralyzed the world's economy as countries have imposed lockdown, social distancing, curfews, travel and mobility restrictions, to break the chain of infection. COVID-19 has affected industries, transportation, trade, education and social life. Hundreds of millions of people have lost their source of income and many have been confined inside their home. COVID-19 is more than a health crisis; it is affecting societies and economies at their core<sup>5</sup>. The vulnerability of low- and middle-income countries has been exacerbated by the pandemic as they contend with crisis in their health systems, reductions in remittances and trade, and have to manage infected people with limited resources. COVID-19 has resulted in a number of global shocks impacting economic and social sectors and causing deep recession in many countries. The World Bank estimates a contraction of 5.2% in the global GDP in 2020, and significant shrinkage in the per capita income of many developing economies; it calls for urgent policy action to address all these issues<sup>6</sup>.

## 1.2 Impact of COVID-19 in Nepal

Nepal has not been left untouched. So far more than 144,000 have been infected, 791 have died and 99,000 recovered<sup>7</sup>. The first case of infection was identified in Nepal on 21<sup>st</sup> February 2020, and the second case on 22<sup>nd</sup> March. The following day, on March 23<sup>rd</sup>, the government imposed a nationwide lockdown to break the chain of infection and all people were told to stay at home. All markets beside a few designated pharmacies, hospitals and shops selling essential goods, schools, colleges, religious places, offices, entertainment centres, sports activities were strictly closed. All public and private transportation and travel were banned. Construction sites and factories were closed and waged labourers were terminated from their job. The strict nationwide lockdown continued for over three months. After some 80 days, the government reopened local markets and permitted local transportation according to strict rules. However, the virus was not brought under control, but grew rapidly. As of September 2020,

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<sup>2</sup> Coronaviruses are a large family of viruses which may cause illness in animals or humans. In humans, several coronaviruses are known to cause respiratory infections ranging from the common cold to more severe diseases such as Middle East Respiratory Syndrome (MERS) and Severe Acute Respiratory Syndrome (SARS). The most recently discovered coronavirus causes coronavirus disease COVID-19. <https://www.who.int/emergencies/diseases/novel-coronavirus-2019/question-and-answers-hub/q-a-detail/q-a-coronaviruses>

<sup>3</sup> <https://www.worldometers.info/coronavirus/> 1,165,461 as of 27th October 2020.

<sup>4</sup> <https://www.worldometers.info/coronavirus/> retrieved on 27th October 2020

<sup>5</sup> <https://www.undp.org/content/undp/en/home/coronavirus/socio-economic-impact-of-covid-19.html>

<sup>6</sup> Global Economic Prospects. A World Bank Group, Flagship Report. <https://www.worldbank.org/en/publication/global-economic-prospects>

<sup>7</sup> <https://covid19.mohp.gov.np/> dated 21<sup>st</sup> October 2020

nationwide lockdown has been lifted but provincial governments and local municipalities are imposing lockdowns and various restrictions in most parts of the country, to control transmission at the local level.

A Rapid Assessment of the Socio-Economic Impact of Covid-19 in Nepal by UNDP (2020), claims that accommodation and food; art, entertainment and recreation; and transport are the three sectors that have been the worst affected by the COVID-19 pandemic. Tourism which is one of the main pillars of Nepal's economy, is expected to decline by 60% this year. Similarly, remittance from foreign employment which is another important source of the national economy, is projected to fall by 15-20% this fiscal year. Pre-COVID-19, the projected GDP rate was 8.5%, it is estimated to decline to 2.5%<sup>8</sup>.

### 1.3 International evidence of the impact of COVID-19 on persons with disabilities

Based on experience and evidence from previous humanitarian, emergency and disease outbreak situations, it is well documented that persons with disabilities face a high risk of vulnerability in such conditions. In the case of COVID-19, persons with disabilities experience both a high risk of infection and face the risk of discriminatory behaviour of health professionals during the course of treatment<sup>9</sup>. Many persons with disabilities also have secondary conditions (such as pressure sores, contractures, urinary tract infections, and depression<sup>10</sup>) and suppressed immune systems or respiratory complaints that COVID-19 could worsen. Moreover, these underlying conditions increase the risk of experiencing a severe form of COVID-19 if infected<sup>11</sup>.

Emerging research on COVID-19 shows that the coronavirus pandemic and the indirect effects of lockdowns on the economy, social interaction and stress is increasing the prevalence of psychosocial problems and gender-based violence, and women and vulnerable populations including persons with disabilities are at high risk. The strict rules for social distancing, travel restrictions, lockdowns and curfew imposed frequently for a long time, are worsening people's mental health. People with disabilities have to face multiple barriers to access medical supplies even outside of emergency settings, but these challenges have been amplified by the pandemic. They are more likely to face a higher level of isolation in the name of protection and shielding, and experience an intensified feeling of loneliness<sup>12</sup>. In the case of COVID-19 infection, research shows an increased likelihood of discrimination towards people with disability from health workers and hospital management during treatment, this includes withholding scarce resources (such as ventilators) for more able persons, and putting patients with disability in isolation because health professionals are unaware or unsure of the accessibility requirements to be ensured in isolation centres or hospitals, or lack the capacity to provide appropriate accommodations.

WHO considers persons with disabilities as a group-at-risk of COVID infection for the following key reasons<sup>13</sup>:

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<sup>8</sup> Rapid Assessment of Socio-Economic Impact of COVID-19 in Nepal, UNDP, 2020

<sup>9</sup> <https://www.apa.org/topics/covid-19/research-disabilities>

<sup>10</sup> <https://www.nap.edu/read/1579/chapter/9>, accessed 27<sup>th</sup> October 2020

<sup>11</sup> <https://www.apa.org/topics/covid-19/research-disabilities>

<sup>12</sup> <https://www.apa.org/topics/covid-19/research-disabilities>

<sup>13</sup> <https://www.who.int/docs/default-source/documents/disability/covid-19-disability-briefing.pdf>

- Barriers to follow basic hygiene measures such as hand-washing, because WASH facilities are often inaccessible to them.
- Difficulty in enacting social distancing because of the need for additional support (personal attendants, helpers, human guides, care takers) or because they are institutionalized.
- The need to touch things to obtain information from the environment or for physical support.
- Barriers to accessing public health information.
- Barriers to accessing health care.

UNICEF acknowledges that persons with disabilities are disproportionately represented among the elderly who are at high risk of experiencing severe COVID-19, and estimates that 46% of the population above 60 years are living with some form of disabilities<sup>14</sup>. UNICEF further states that the limited availability of disaggregated data results in an inability of surveillance systems to determine the impact of the pandemic on people with disabilities. Barriers to accessing public health information and accessible communication means that many people with disability, particularly those with hearing, visual, intellectual or physical disabilities, are not able to access public information and messages issued for prevention.

The OHCHR<sup>15</sup> has analyzed the impact of COVID-19 on the lives of persons with disabilities in regard to health services, institutional based settlement, community settlement, livelihood and protection from violence. On health-related issues, persons with disabilities were found to face even greater inequalities in accessing healthcare including sexual and reproductive health information and services, during the pandemic than normal. This was due to inaccessible health information and environments, as well as selective medical guidelines and protocols that may magnify the discrimination persons with disabilities face in healthcare provision. In institutional environments, OHCHR notes there is a very high risk of contracting COVID-19 due to underlying health conditions, difficulty in enforcing social distancing amongst residents and staff, and abandonment by staff. Persons with disabilities living in institutions also face greater risks of human rights violations, such as neglect, restraint, isolation and violence. In the community setting, persons with disabilities often have to face multiple forms of barriers in their daily life which have increased during the pandemic. Lockdown and stay-at-home approaches do not consider the needs of people with disabilities, and create additional barriers and new risks to their autonomy, health and lives. Those who rely on others for daily living (through formal support by service providers or informal support by relatives/friends) find themselves without support due to movement restrictions and physical distancing measures. This may leave them at high risk without access to food, essential goods and medicine, and prevented from carrying out basic daily activities such as bathing, cooking, or eating. OHCHR found most COVID-19 related information and communication materials issued for the public are neither systematically communicated nor disseminated in accessible formats and means to reach all persons with disabilities including the use of sign language interpretation, captioning, and Easy to Read format.

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<sup>14</sup> [https://www.unicef.org/disabilities/files/COVID-19\\_response\\_considerations\\_for\\_people\\_with\\_disabilities\\_190320.pdf](https://www.unicef.org/disabilities/files/COVID-19_response_considerations_for_people_with_disabilities_190320.pdf)

<sup>15</sup> OHCHR. COVID-19 and the Rights of Persons with Disabilities. [https://www.ohchr.org/Documents/Issues/Disability/COVID-19\\_and\\_The\\_Rights\\_of\\_Persons\\_with\\_Disabilities.pdf](https://www.ohchr.org/Documents/Issues/Disability/COVID-19_and_The_Rights_of_Persons_with_Disabilities.pdf)

A survey in India undertaken by the National Centre for Promotion of Employment for Disabled People<sup>16</sup>, found that over 73% of persons with disabilities interviewed faced particular challenges due to lockdown. Some 57% said they were facing a financial crisis, 13% spoke of challenges in accessing rations, while 9% were facing obstacles in access to healthcare and medical aid. The study found that health care workers were not equipped to serve people with disability. The lockdown has put people with severe disabilities, such as those with thalassemia, at great risk. People with spinal cord injuries reported a huge shortage of medical kits as well as medical services such as fixing catheters. Persons who need diapers, catheters, urine bags, disposable sheets, bandages, cotton, antibiotic medicines etc. are unable to procure these either due to lack of funds, unavailability of these items, or inability to physically get them oneself or through the help of another.

#### 1.4 Impact of COVID-19 on the health of persons with disabilities in Nepal

Nepal's public health system and facilities are weak and struggle to deliver essential health services to persons with disability even outside of an emergency situation. Persons with disabilities in Nepal face significant problems in accessing essential health related support, services and facilities such as therapy, health counseling and advice, early identification and interventions, referral services, basic rehabilitation, corrective surgery, medicine, assistive devices, psychosocial counseling, and health equipment. The barriers to health have been magnified by COVID-19, and the lockdown and special measures introduced by the Government.

National Federation of the Disabled Nepal (NFDN) (2020), rapid assessment of the impact of COVID-19 and lockdown on persons with disabilities, found a lack of accessible information and awareness raising strategies<sup>17</sup>. The study found that 41% of persons with disabilities reported little awareness, and 6% were completely unaware of COVID-19 and the global pandemic. Similarly, 42% reported little knowledge and 7% complete lack of knowledge of the measures to be taken to stay safe from infection. The report further found that around 60% of the total number of persons with disabilities who were 'less aware and completely unaware' of the measures to be adopted to stay safe from COVID-19 experienced 'complete disability' or 'severe disability'. The study showed that the greater the severity of impairment, the greater the barriers people face in getting access to information.

The NFDN, 2020 report found that 7.5% of persons with disabilities need psychosocial support and 45% are in urgent need of hygiene materials such as catheter, tube, mask, sanitizer, urine bag, and diaper. Some 3% suffer different forms of violence and abuse. The regular health services or medicines of 45% had been interrupted by lockdown, and 36% were not receiving adequate services. The report calls for an immediate response to ensure that such essential services are not interrupted.

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<sup>16</sup> LOCKED DOWN AND LEFT BEHIND (A Report on the Status of Persons with Disabilities in India During the COVID – 19 Crisis), National Centre for Promotion of Employment for Disabled People (NCPEDP), 2020, accessed 27<sup>th</sup> Oct 2020 from [https://www.ncpedp.org/sites/all/themes/marinelli/documents/Report-locked\\_down\\_left\\_behind.pdf](https://www.ncpedp.org/sites/all/themes/marinelli/documents/Report-locked_down_left_behind.pdf)

<sup>17</sup> <https://nfdn.org.np/ne/impact-of-covid-19-pandemic-and-lockdown-on-persons-with-disabilities-a-rapid-assessment-report>

A COVID-19 rapid need assessment by Humanity and Inclusion (2020) found that in terms of severity of disability, red card holders seem to have less awareness overall than blue, yellow and white card holders<sup>18</sup>. The study found that around 36% of persons with disabilities were facing barriers to access COVID-19 related information, and 40% reported dire need of sanitary and hygiene materials such as sanitary pads, catheter, adult diapers for people who are suffering from spinal cord injury. Based on these findings, Humanity and Inclusion recommended that as much as possible and as safety allows, health services for persons with disabilities should continue to operate and be adapted as the virus spreads. The study highlighted an urgent need for psychosocial support, and recommended action to address anxiety, to protect people from rumors of fake information, which could be contributing to increasing anxiety, stress and unnecessary of fear of COVID-19.

In Nepal, persons with disability are entitled to a disability card according to the severity of impairment.

Red = Complete impairment

Blue = Severe impairment

Yellow = Moderate impairment

White = Mild impairment

The UNDP rapid assessment of the impact of COVID-19 on the socio-economic development of Nepal (2020) also raised concerns about the barriers and discrimination persons with disabilities face in accessing basic services, information and health facilities. The study recommended Government to confront the prolonged fallout from the income and health shocks of COVID-19 by prioritising the needs of poor and marginalized populations.

The evidence to date from Nepal illustrates how the impact of COVID-19 on the lives of persons with disabilities is very severe, including exclusion from essential and specialized health services, access to information, hygiene, WASH facilities, basic needs, livelihood support and support services. There is a dire need of immediate psychosocial support to persons with disabilities. Underpinning this situation is a weak health system, a lack of knowledge among front line health providers on how to provide disability inclusive COVID-19 care, and the risk that persons with disabilities face discrimination in health settings as providers struggle to adjust to new COVID-19 protocols. There is a very real threat that people with disabilities will be left behind in the national COVID-19 response and recovery.

### 1.5 Intersectional vulnerability in Nepal: gender, caste and ethnicity

Gender inequality and social exclusion of people from historically disadvantaged caste and ethnic groups in Nepal, intersects with discrimination and neglect of people with disability. Caste and ethnic based social hierarchy are deeply rooted socio-cultural constructs of Nepalese society<sup>19</sup>. Progress to remove gender, caste and ethnic based discrimination is being made through education, law enforcement, globalization, and strengthening of democratic culture and human rights, but such inequality continues to be present in society. Directly and indirectly, gender, disability, caste and ethnic based discrimination and marginalization persist in different forms. In this context, where belonging to each of these groups

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<sup>18</sup> Nepal COVID-19 rapid need assessment report, Handicap International, April 2020.

<sup>19</sup> David N Gellner. Caste, Ethnicity and Inequality in Nepal,

[https://www.researchgate.net/publication/262127102\\_Caste\\_Ethnicity\\_and\\_Inequality\\_in\\_Nepal](https://www.researchgate.net/publication/262127102_Caste_Ethnicity_and_Inequality_in_Nepal)

amplifies vulnerability, it is important to be aware of the complexity of exclusion, and the social diversity of people with disability.

A 2015 study by CREHPA found that 57.7% of women with disabilities had ever experienced violence, including emotional violence (55.2%); physical violence (34%); and sexual violence (21.5%)<sup>20</sup>. Exclusion from access to sexual and reproductive health (SRH) issues is also well documented. A Marie Stopes Nepal study of the SRH needs of young people with disability showed 47% of currently sexually active young people not using any modern family planning, 54% perceived the nearest SRH related health facility not friendly to their disability and around one-fifth reported facing difficulty with service providers.<sup>21</sup>

In Nepal, Dalit women with disability are especially vulnerable to discrimination and social exclusion, and community reports suggest this has been further amplified by the pandemic<sup>22</sup>.

## 1.6 Rationale for the study

International and national evidence has highlighted the serious impact the pandemic has had on access to essential health services of persons with disabilities, including therapy, medicine, treatment, regular check-up, counseling, rehabilitation services, psychosocial counseling, medical equipment, hygiene related materials, assistive devices, and COVID-19 related information. While all these requirements are important, the level of individual need varies according to the severity and type of impairment they experience. Evidence of the specific needs of people with different types of disabilities is so far lacking in Nepal, and internationally<sup>23</sup>. This is an important evidence gap for disability inclusive policy and necessary to guide programming to respond to COVID-19.

Empirical observations in Nepal suggest that persons with hemophilia, spinal cord injury, psychosocial disability, intellectual disability and those living with multiple impairments are the most vulnerable, and suffer severe consequences from not having access to essential health services. The high dependency of persons with spinal cord injury on regular medical care and assistance, and their on-going need for special hygiene materials, and similarly, the imperative for essential medical care and psychosocial support for persons with serious mental health conditions, illustrate the critical role of the health system to meet the health needs of people with severe disabilities. The fragility of the health system, as illustrated by the lack of 'factor' available for persons with hemophilia, exposes people with severe disabilities to life-threatening and additional painful and debilitating conditions.

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<sup>20</sup> Puri M, Misra G, Hawkes S. Hidden voices: Prevalence and risk factors for violence against women with disabilities in Nepal. *BMC Public Health*. 2015;15:261. Accessed 27<sup>th</sup> Oct 2020 from file:///D:/1.%20Rajendra's%20Working%20Folder/Downloads/s12889-015-1610-z.pdf

<sup>21</sup> Integrating SRH needs of Young People with Disability within Youth Friendly SRH, accessed 27<sup>th</sup> Oct 2020 from <http://myhealthrightsfuture.com/assets/day-2%2C-msi--integrating-srh-needs-of-young-people-with-disability-within-youth-friendly-srh-service.pdf>

<sup>22</sup> [Krishna Gahatraj](#), from *Nepal's National Association of the Physical Disabled*, Dalits with disabilities hit hardest by lockdown in Nepal, [NEWS AND BLOGS](#) | 04 AUG 2020, accessed 27<sup>th</sup> Oct 2020 from <https://minorityrights.org/2020/08/04/nepal-lockdown/>

<sup>23</sup> Some reports refer to persons with spinal cord injury and psychosocial disability but without detail.

Given the exceptional vulnerability of persons with severe and complete disabilities, and the importance of reliable and specific information for policy, this case study explores the health needs, problems, barriers and challenges to accessing health services of these people. This case study is expected to inform the Federal Ministry of Health and Population of the health needs of persons with severe disabilities in the COVID-19 context, and enable the Ministry to provide a responsive and accessible COVID-19 service and policy response that protects the health and rights of persons with disabilities.

### 1.7 Objectives of the case study

The overarching objective of this case study is to document the situation and gaps in access to health services and care of people living with severe and complete disabilities during lockdown and the COVID-19 emergency, and make recommendations to strengthen service delivery in the future<sup>24</sup>. The Rights of Persons with Disability Act (2017) defines four levels of severity of disability (complete, severe, moderate and mild). The case study focuses on persons with severe and complete disability.

The specific objectives of the study are to:

- a) Assess the impact of the COVID-19 pandemic and lockdown on the life of people living with severe and complete disabilities;
- b) Identify the problems and barriers faced by people with severe and complete disabilities in the situation of COVID-19 and lockdown;
- c) Identify critical gaps in health services (both physical and mental health) delivered by the MoHP, gaps in coordination with other essential service providers, and areas of improvement;
- d) Generate facts for policy advocacy with the government and other stakeholders to make the emergency response disability inclusive; and
- e) Make recommendations for improving access to essential health services and care to people with severe disabilities during the pandemic/emergency situation and strengthening health systems.

### 1.8 Limitations of the case study

Given the emergency context and restrictions on movement, and the urgency to collect evidence and inform government provisions, the case study is primarily focused on access to essential health care with secondary and more limited attention to constraints in meeting broader financial, social and rehabilitation needs. Secondly, given the added vulnerability and needs of persons with severe disability, the study includes only persons with severe impairment or critical health issues such as spinal cord injury, intellectual disabilities, hemophilia, psychosocial disabilities and multiple disabilities. Thirdly, the geographical coverage of the study is limited to three provinces to enable the study to be completed in a timely way. Fourth, due to restrictions on movement and in order to reduce the risk of COVID-19 transmission, the study depended on virtual and telephone data collection with a limited number of in-person consultations.

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<sup>24</sup> Severe and complete disability are used in this report as these are terms used by Government in policies, laws and guidelines.

## Chapter 2 : Methodology

### 2.1 Ministry of Health and Population leadership

Population Management Division (PMD) in the Ministry of Health and Population provided leadership to the implementation of this study. The study was undertaken by NFDN with guidance from PMD, PPMD and EDCD and technical support from the UK-aid funded Nepal Health Sector Support Programme (NHSSP).

NFDN as the technical partner undertook the research design, prepared the data collection tools, collected data, compiled and analysed the data, and prepared this report. Several rounds of meetings were held with the MoHP (PMD, PPMD and EDCD) and NHSSP to decide on the scope of the study, the geographical focus and sample size. The Ministry of Health and Population and NHSSP reviewed and provided technical inputs to the research design and study report. The Ministry held weekly meetings with NFDN and NHSSP to review progress and facilitate the study including coordination with sub-national government authorities, and assisting NFDN arrange interviews with government stakeholders and health providers.

### 2.2 Case study approach

A qualitative case study methodology was agreed to be the most appropriate for this study given the objective of seeking depth of understanding of how COVID-19 has impacted the life of persons with severe disability, and to build on the rapid assessment studies undertaken in the very early phase of the pandemic that provided an immediate but less detailed assessment of the situation. The case study approach was also considered appropriate given the constraints of working in the COVID-19 emergency context, and the urgency to collect reliable data quickly to inform policy and service delivery.

The scope of the study was limited to primary data collection from persons with severe and complete disability, and related care givers in three provinces. This narrower geographical lens allowed the study to drill down to understand how COVID-19 was impacting persons with severe disability, rather than taking a geographically broader but more superficial exercise. The limited geographical scope also made the study manageable given the challenges of working in the COVID-19 context. In addition, interviews were held with a sample of health providers, municipalities, Provincial Ministry of Social Development and Provincial Health Directorate in the three focal provinces. National stakeholders were also consulted and are detailed in section 2.3.5 below.

#### 2.2.1 Sample selection

Province 1, 2, 5 and Kathmandu Metropolitan City were selected as the geographical area for primary data collection. Selection of the three provinces was based on the population size of each province, number of persons with disabilities in each, and respective number of COVID-19 cases per district. Kathmandu was selected because it is the site of the country's leading referral hospitals with specialists treating a range of impairments and complex conditions. Data on persons with disabilities was taken from the Census 2011. In addition, organizations working on psychosocial disability, spinal cord injury and hemophilia were consulted to assess the geographical distribution of persons with those impairments according to their records, and identify any areas with significant numbers of people with those conditions.

In the case of hemophilia, the client registration sheet of Nepal Hemophilia Society showed around 700 people with hemophilia spread across the country with a slightly higher number in Province 2 relative to the size of the provincial population. In the case of psychosocial and spinal cord injury, the number of people with disabilities was proportionate to provincial population of persons with disabilities. Data on COVID-19 cases was provided by the Ministry of Health and Population which showed Province 1, Province 2, Province 5 and Kathmandu as the highly affected geographical areas.

Given lockdowns and different forms of travel restriction across the country, it was not possible to travel to the field to meet respondents in person. Instead, data was collected via virtual interviews using online platforms such as zoom, MS teams, skype, and messenger. In case an online platform was not available to the respondent, interviews were held over telephone.

### 2.2.2 Sampling technique

Since this is a qualitative study and the target population of severe and completely disabled persons have highly diverse characteristics, purposive sampling was used. This enabled a sample of respondents to be selected that have a diverse range of impairments and needs. The purpose of this kind of sample design is to provide as much insight as possible into the event or phenomenon under examination, in this case the impact of COVID-19 on access to essential health services of persons with severe and complete disability.

*Table 1: Sample of persons with disability by geographical area*

Provinces	Intellectual Disability	Psychosocial Disability	Hemophilia	Spinal Cord Injury	Multiple Disability	Total
Province 1	3	3	3	4	2	15
Province 2	3	2	4	4	2	15
Province 5	3	2	3	4	3	15
Kathmandu	2	2	2	3	1	10
Total	11	9	12	15	8	55

*Table 2: Sample of care givers, helpers and personal attendants by geographical area*

Province	Care givers	Helpers	Personal Attendants	Total
Province 1	2	2	1	5
Province 2	2	2	1	5
Province 5	2	2	1	5
Kathmandu	1	1	1	3
Total	7	7	4	18

*Table 3: Consultations with representative organizations of persons with disabilities by geographical area*

Province	Intellectual Disability	Psychosocial Disability	Hemophilia	Spinal Cord Injury	All types of Disability	Total
Province 1	1	1	0	1	0	3
Province 2	1	1	1	0	0	3
Province 5	1	0	0	0	1	2

Kathmandu	0	1	1	1	0	3
Total	3	3	2	2	1	11

Table 4: Interviews of health providers by province and type of health facility

Province	Provincial Hospital	District Hospital	Local Health Centre	Total
Province 1	2	0	1	3
Province 2	0	2	0	2
Province 5	1	0	2	3
Total	3	2	3	8

Table 5: Interviews with Government authorities and stakeholders by geographical area

Province	Local Social Development Officer	Vice-Mayor	Provincial Social Development Ministry	Ministry of Health and Population	Municipality and Federation	Total
Province 1	0	0	2	0	0	2
Province 2	0	0	1	0	0	1
Province 5	1	1	1	0	0	3
Federal Institutions	0	0	0	5	1	6
Total	1	1	4	5	1	12

### 2.2.3 Primary respondents are persons with disabilities

The primary respondents of this case study are persons with disabilities who fall under the category of 'Severe' and 'Complete' disability according to the Act on the Rights of Persons with Disabilities 2074<sup>25</sup>. Altogether 55 persons with disabilities (15 from each targeted province and 10 from Kathmandu) were chosen as primary respondents. The sample size covers persons from the severe impairment groups of spinal cord injury, persons with hemophilia, intellectual disabilities, psychosocial disability and multiple disability.

### 2.2.4 Secondary respondents, care givers and parents

For the day-to-day health care, hygiene and other daily activities of persons with severe disabilities, the role of care givers, parents and personal attendant is crucial. For this particular sub-set, 18 respondents (5 from each province and 3 from Kathmandu) were selected. The 18 persons include care givers, parents or personal attendants of persons with disabilities. The main purpose of interviewing this respondent group is to explore their perspective and experiences of supporting the care and health of persons with disabilities.

<sup>25</sup> The Act Relating to Rights of Persons with Disabilities, 2074 (2017) Date of Publication in the Nepal Gazette 2074.6.29 (15 October 2017), accessed 27<sup>th</sup> Oct 2020 from <http://www.lawcommission.gov.np/en/wp-content/uploads/2019/07/The-Act-Relating-to-Rights-of-Persons-with-Disabilities-2074-2017.pdf>

### 2.2.5 Health service providers

Health service providers are key stakeholders to ensure that persons with disabilities have access to quality essential health services on an equal basis with others. They are equally responsible to provide special types of health services which are crucial for persons with disabilities due to their impairments. To explore the access of persons with disabilities to essential and special health services as per their need during the pandemic and lockdown, it was important to collect the experience and perspective of health service providers. Across three provinces, a total of 8 health providers were selected as respondents from provincial level hospital, district hospital and municipality level health centre.

### 2.2.6 National and other key informants

Representatives of Disabled Peoples Organisations and government authorities were also interviewed. See Annex 2 for details. This included representatives from 11 Disabled Peoples Organisations (DPO), and 12 respondents covering Federal Ministry of Health and Population, Federal Ministry of Women Children and Senior Citizen, Provincial Social Development Ministry, Provincial Health Directorate, municipalities, and Municipal Association of Nepal and Rural Municipalities of Nepal.

## 2.3 Data collection methods

### 2.3.1 Literature review

A review of evidence and reports on the health, social, economic and political impact of COVID-19 globally and in Nepal, was undertaken. The policy and legal frameworks underpinning the rights of persons with disability in Nepal were reviewed to assess the strength of the legal commitments in Nepal. Early rapid studies of the impact of the pandemic on persons with disability in Nepal were key background information and evidence on which this study builds. International evidence of the impact of COVID-19 on the lives of persons with disabilities were reviewed to explore the global trend of the impact, and to situate the Nepal experience in the larger global perspective. Health related disability specific policies and guidelines of the Government of Nepal, and the government COVID-19 protocol were reviewed alongside guidance issued by WHO. See Annex 1 for a list of the documents reviewed.

### 2.3.2 In-depth Interview

In-depth interviews were used to collect primary data using semi structured questionnaires to guide the interview. Different sets of questions were prepared for different respondent groups. Interviewers kept a written record of the key points from respondent responses. Due to travel restrictions, the interviews were conducted using a variety of online virtual platforms and telephone calls. In case respondents were unable to voice their opinions because of their impairments, a parent or close care taker was consulted to complete the questions on behalf of the person with disability.

### 2.3.3 Case stories and group consultations

Case stories were compiled to illustrate the individual experience of persons with disabilities as they cope with the impact of lockdown and the pandemic. Three small group consultations were also organized with persons with spinal cord injury, parents of persons with intellectual disabilities and persons with hemophilia.

#### 2.3.4 Informed consent

At the beginning of each interview, respondents were informed of the purpose and nature of the interview and asked for their consent to proceed. Consent to record the interview was also asked, and where provided, the interview was recorded to assist with data collection and analysis.

#### 2.4 Data validation and quality control

The lead researcher provided training and guidance to the data collectors and quality-controlled data collection and data capture. The lead researcher produced a written guideline to assist the data collectors. Five qualified and experienced interviewers were selected, all had significant experience of working with people with different types of severe impairment. The data collectors received orientation on the study objective, expected deliverables and data collection tools from the lead researcher through online virtual platform. All data collectors were regularly supervised and advised by the lead researcher who remained in close contact to trouble shoot problems. Each written record of the interview produced by the interviewer was verified by the lead researcher by cross-checking with the sound recorded version.

#### 2.5 Data presentation and analysis

The nature of data is qualitative. Data is presented in both tabulated and descriptive form. For analysis, descriptive and interpretive methods were used, and data was critically analyzed through comparison and triangulation among and between the responses of various types of respondents. The case stories are presented as examples of evidence to support the logic of analysis and conclusion.

## Chapter 3 : Review of Disability Policy in Nepal

### 3.1 Constitution of Nepal<sup>26</sup>

The Constitution of Nepal provides the right to equality of all citizens, and prohibits discrimination on the basis of disability. It provides the ground for special provisions by law for the protection, empowerment or development of marginalized community including persons with disabilities. The Constitution recognizes and promotes the rights of persons with disability in various areas:

- Right to education: the Constitution addresses the special needs of persons with disabilities and provides for sign language and braille.
- Rights of children: children with disabilities, are given the right to special protection and facilities from the State.
- Right to social justice: persons with disability have the right to participate in the state mechanism and decision-making process.
- Right to Health: the Constitution provides all citizens the right to free essential health care from the State, right to information about their medical treatment, equal access to health services and access to clean drinking waters.

### 3.2 Convention on the Rights of Persons with Disabilities

Nepal became the state party of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in 2010. CRPD considers disability an evolving concept which results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others. The convention defines persons with disabilities as having long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others<sup>27</sup>. CRPD recognizes that persons with disabilities have the right to the highest attainable standard of health and that the State must recognize that right without discrimination on the basis of disability. The right to health includes access to essential health services as well as specialized rehabilitation services, including residential care, community-based care and support services. Services should be provided on an individual or “person-centred” basis with due regard to the range of support services required (e.g., supportive devices, nursing, personal assistance, respite, rehabilitation, day activities and caring assistance).

### 3.3 Rights of Persons with Disabilities Act, 2017<sup>28</sup>

To align with Nepal’s signatory of CRPD, the government replaced the Disabled Protection and Welfare Act 1982 with the Rights of Persons with Disabilities Act, 2017 (RPD Act). The RPD Act incorporates many provisions ensured by CRPD and represents a shift from a welfare based to a rights-based approach. The

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<sup>26</sup> Constitution of Nepal 2015 article 18, Article 31, Article 39 and Article 35, Nepal Law Commission, <http://www.lawcommission.gov.np/np/archives/category/documents/prevailing-law/constitution/constitution-of-nepal>

<sup>27</sup> UNCRPD, 2006, Preamble (e) and Article 1

<sup>28</sup> Act on the Rights of persons with Disabilities 2017, Nepal Government, <http://www.lawcommission.gov.np/np/category>

RPD Act defines persons with disabilities as those who have barriers to participate in society in a full and effective way due to long term physical, mental and sensory impairment or functional limitation or existing barriers. The RPD Act classifies persons with disabilities into ten categories based on the unique nature of impairment:

1. **Physical disability:** includes those who have impairments in lower or upper limbs, muscles, spinal cord, bone, joints and have problems with mobility, working limbs and self-care. People of short height than average (less than 3 feet) are also considered in this category.
2. **Hearing disability:** includes profoundly deaf and hard of hearing.
3. **Visual disability :** includes three categories a) "fully blind" who cannot see at all and also cannot perceive light, b) 'blind' who cannot see at all but can perceive light and c) partially sighted.
4. **Voice and speech disability:** Those who have significant problems and barriers in speech and voice. For example, people with a stutter.
5. **Deaf-blindness:** Those who have both visual and hearing impairments.
6. **Hemophilia:** Those with the bleeding disorders called hemophilia.
7. **Autism:** Those who are living with Autism Spectrum Disorder (ASD).
8. **Intellectual disabilities:** Includes those who have downs' syndrome and other developmental delays.
9. **Psychosocial disability:** Those who are living with mental health issues and psychosocial problems.
10. **Multiple disability:** Those who are living with more than one form of the above mentioned impairments at once.

The Act further categorizes persons with disabilities into four different categories according to the severity of impairments, they are called complete, severe, moderate and mild. The Act includes the issuance of a Disability ID card which are colour coded for each level of severity of impairment: red (complete), blue (severe), yellow (moderate) and white (mild). The disability ID card is the main window to access the special privileges and services that the state has provided to persons with disabilities according to laws and policies. Each person with disability has a right to a disability ID card to access the disability specific entitlements provided by the state. Local municipality offices are responsible for providing disability ID cards to persons with disabilities residing in the municipality. In practice, many persons with disabilities report that they have not received a disability ID card<sup>29</sup>.

The RPD Act has ensured the rights of persons with disabilities and provisions, including:

- free health and education services
- reservation in employment
- accessibility in public place, transportation, information and communication service
- special discount on public transport
- community based rehabilitation services

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<sup>29</sup> Government of Nepal, Rights of Persons with Disabilities Act, 2017

- free assistive devices.

The Act has also provisioned the right to participation in decision making processes, protection from violence and abuse, and protects against discrimination on the basis of disability to all persons with disabilities, with some special provisions for women and children with disabilities.

### 3.3.1 Provisions for health, rehabilitation and social protection

In 2020, the Federal Government issued separate bylaws to implement the various structures, services, discounts and privileges related to the provisions of the RPD Act. The bylaws include the system and process to be put in place, and the details of services to be provided.

Provisions related to health, rehabilitation and social protection mentioned in RPD Act and its bylaws include:

- The cost of the treatment of heart disease, kidney disease, cancer and any other disease as decided by the government for persons with complete and severe disabilities shall be covered by the government.
- Government hospital shall provide psychosocial counseling to persons with psychosocial disability free of cost.
- Government shall provide required assistive devices to all persons with disabilities by ensuring all technical measurements prior to provision of assistive devices, free of cost.
- Government shall provide 'Anti Hemophilic Factor' to persons with hemophilia free of cost.
- Government shall take necessary action to remove all the physical barriers of hospitals and health institutions that hinder the access of persons with disabilities.
- Health workers of hospitals and health centres shall provide all necessary services to persons with disabilities with priority.
- All private and public hospitals and health institutions having 25 or more beds shall reserve at least 2 beds for persons with disabilities.
- Government hospitals shall provide various therapeutic services to persons with disabilities free of cost.
- Government shall provide required rehabilitation service to persons with complete and severe disability, intellectual disabilities, psychosocial disabilities and those who are poor and helpless.
- Personal attendant service shall be provided to persons with complete and severe disability through local municipality.
- Daily care service shall be provided to persons with severe and complete disability, intellectual disabilities, psychosocial disabilities, and autism through local municipality.
- Services such as clinical counseling, referral service, general counseling, peer counseling and parent counseling shall be provided to persons with disabilities at local level through rehabilitation centres.
- Persons with complete and severe disabilities shall be provided social security allowance as per the decision of the government.
- Persons with complete, severe and moderate disability shall be provided 50% discount on travel fare while travelling by any kind of public transport.

- Each type of public transport having 10 or more seat capacity shall allocate certain number of seats as reserved seats for persons with disabilities.
- Persons with severe or complete disability that want to make their private WASH facilities accessible, will receive financial and other support from government.
- Government shall conduct social protection programs for persons with disabilities with health insurance.

### 3.4 National Health Policy 2019<sup>30</sup>

The new National Health Policy, 2019 has respected the spirit of article 35 of the Constitution in its first objective, which is to create an opportunity for citizens to enjoy the rights to health ensured in the national Constitution. The Policy also includes the objective to strengthen social health protection and increase outreach of health services to the most marginalized populations. The policy does not include any specific strategies or special provisions to meet the needs of persons with disability, but takes a universal health care approach. Of particular relevance to persons with disabilities, it commits to:

- Universal Health Coverage of promotional, responsive, curative and rehabilitative services will be extended through an integrated approach.
- Easy access to specialized service will be ensured through health insurance.
- Emergency health service will be ensured to all people.

### 3.5 Disability Prevention and Rehabilitation Strategy 2016-2026<sup>31</sup>

The Ministry of Health and Population, Disability Prevention and Rehabilitation Strategy 2016-2-26 aims to prevent disability by addressing the causes of impairments, and to provide health related rehabilitation services to persons with disabilities in an effective and inclusive ways.

	Major focus
Prevention	<ul style="list-style-type: none"> <li>• maternity care</li> <li>• nutrition</li> <li>• early child care</li> <li>• safety measures at work</li> <li>• road and public places</li> <li>• treatment of diseases which cause disability</li> <li>• psychosocial counseling in district hospitals</li> <li>• corrective surgery</li> <li>• eyes and ear checking lab in district hospitals</li> <li>• genetic problems diagnostic lab in district hospitals</li> </ul>
Rehabilitation	<ul style="list-style-type: none"> <li>• availability of required medicines</li> <li>• medical rehabilitation services in district hospitals</li> <li>• mobilization of rehabilitation workers at municipality level</li> <li>• distribution of assistive devices through local unit of government</li> <li>• orthotics and prosthesis lab at provincial level</li> <li>• production and mobilization of therapists</li> </ul>

<sup>30</sup> Government of Nepal, Ministry of Health and Population, National Health Policy 2019.

<sup>31</sup> Government of Nepal, Ministry of Health and Population, Disability Prevention and Rehabilitation Strategy 2016-2026.

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|--|
| • early identification and interventions |
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### 3.6 National Guidelines for Disability Inclusive Health Services, 2019-2030<sup>32</sup>

Ministry of Health and Population has developed a National Guidelines for Disability Inclusive Health Services, 2019-2030. The overall objective of this guidelines is to support transition to disability inclusive health services. The specific objectives are:

- Enable health service providers to meet their statutory responsibilities related to the health rights of persons with disabilities.
- Provide practical information to health service providers on the delivery of respectful and dignified health care, and how they can reduce the attitudinal, communication and structural barriers that persons with disabilities face in accessing quality health services.
- Provide guidance to primary health care staff on their responsibility to integrate disability inclusion into the delivery of primary health care services and how.
- Provide guidance to secondary and tertiary hospitals on their responsibility to integrate disability inclusion into the delivery of hospital care and how to progressively realise disability inclusive medical services, disability-specific specialist services and health-related rehabilitation.
- Support education and training on disability inclusive health services, accessibility and client-oriented health care.
- Assist health management to organise and manage disability inclusive health services and leverage resources and partnerships to help meet the health needs of persons with disabilities.
- Raise awareness of persons with disabilities, including older people, of their sexual and reproductive health rights and availability of sexual and reproductive health services.

Implementation of the guideline covers three phases. The first phase runs from 2019 to 2022 and includes a focus on respectful communication, inclusive primary care, capacity building, evidence and accountability as its key working agendas. The second phase from 2023 to 2026 embraces inclusive secondary and tertiary care and disability specific specialist services. The final phase is to scale out.

The guideline includes a commitment to: provide disability inclusive primary health care services; delivery of wellness support and facilitation to persons with disabilities at hospitals; disability inclusive medical care, referral and follow up; rehabilitation services; disability inclusive sexual and reproductive health services; and disability inclusion in social health insurance.

### 3.7 Conclusion

The policy landscape for disability and disability inclusive health services has significantly improved since the Constitution was enacted, in 2015. This triggered the introduction of the Rights of the Persons with Disabilities Act, 2017 and stimulated the Ministry of Health and Population to update and align its

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<sup>32</sup> Government of Nepal, Ministry of Health and Population, National Guidelines for Disability Inclusive Health Service, 2019-2030.

disability strategies to adopt rights-based principles. The policy provisions and disability related health strategies and technical guidelines are an ambitious agenda which set out new service delivery commitments, with implications for resourcing and management. However, studies show that implementation of the raft of multisectoral policy responses to meet the needs and rights of persons with disabilities falls below expectations<sup>33</sup>. Weak policy implementation is one of the main barriers hindering the access of persons with disabilities to essential health services and rehabilitation<sup>34</sup>.

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<sup>33</sup> National Federation of the Disabled Nepal, 2019, National Report on Disability, unpublished.

<sup>34</sup> National Federation of the Disabled Nepal, 2019, National Report on Disability, unpublished.

## Chapter 4 :Key Findings

### 4.1 Demographic Characteristics of Primary Respondents.

Before discussing the experience of persons with disabilities during the COVID-19 outbreak, we first present the demographic characteristics of the primary respondents.

#### 4.1.1 4.1.1. Sex ratio of respondents

Out of total 55 respondents 45% are female and 55% are male; see Figure 1. Out of the female respondents, 24 were of reproductive age. For some impairment groups, such as hemophilia, all respondents were male. Hemophilia is a genetic bleeding disorder. Globally, one-third of hemophilia sufferers have no family history of the disorder, the majority have inherited the gene from the father or mother<sup>35</sup>. Women who carry the disorder tend to experience milder symptoms than men. Despite some effort, no LGBTQI or sexual and gender diverse respondents with disabilities were identified.

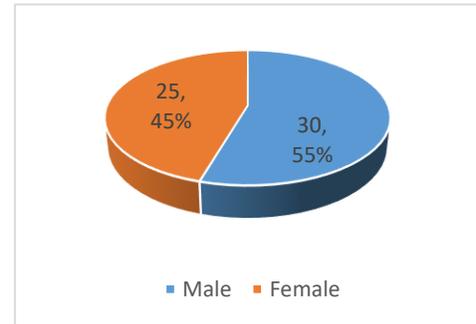


Figure 1: Number of respondents by sex

#### 4.1.2 Respondents by types of disabilities

Out of 55 respondents, the highest number were persons with spinal cord injury (15) followed by persons with hemophilia (12). The sample also included 11 persons with intellectual disabilities, 9 with psychosocial disabilities and 8 with multiple disabilities. See Figure 2 below.

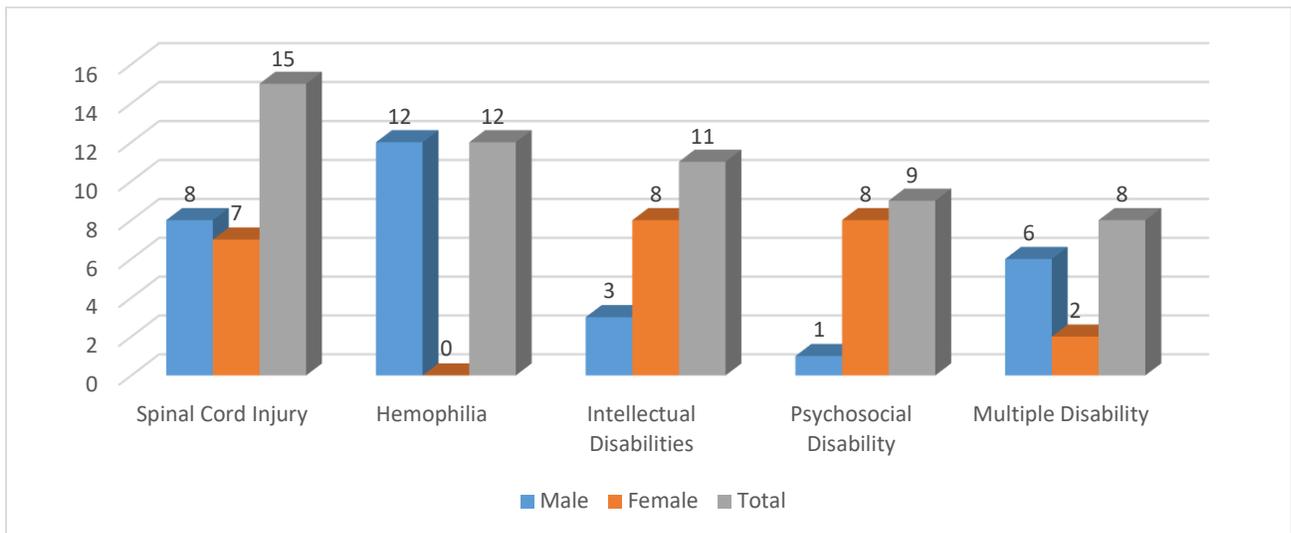


Figure 2: Number of respondents by type of disability and sex

<sup>35</sup> <https://www.cdc.gov/ncbddd/hemophilia/inheritance-pattern.html>

### 4.1.3 Caste and ethnicity of respondents

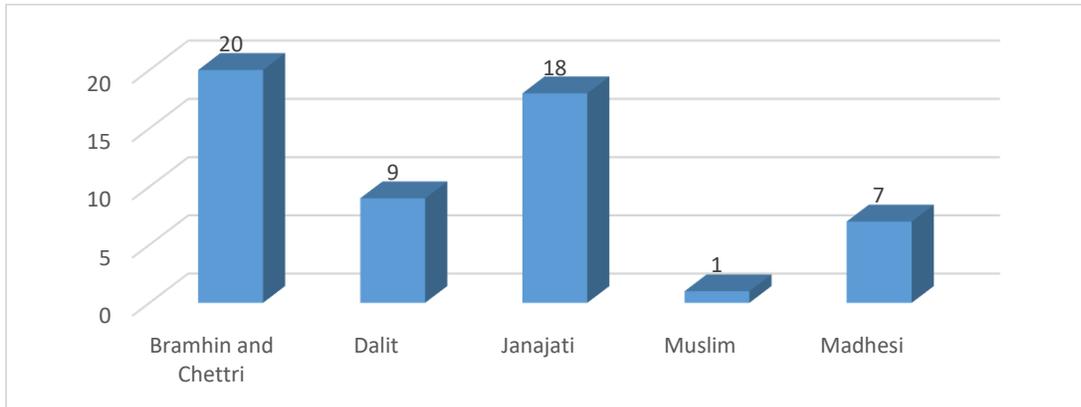


Figure 3: Number of respondents by caste and ethnicity/religion

While the researchers aimed to include respondents from each caste and ethnic group, time constraints and operational challenges of working in a pandemic meant that it was difficult to identify respondents from the Muslim community. In total, 20 (36%) respondents are from Brahmin/Chettri, 9 (16%) from Dalit, 18 (33%) are from Janajati, 7 (13%) are from Madhesi community and 1 person is from Muslim community. See Figure 3.

### 4.1.4 Access to disability ID card

Out of total 55 respondents, 41 (74.5%) reported having a disability ID card and 14 (25.5%) respondents not. Most respondents that had an ID card had either a red or blue card, 28 had a red (50.9%) and 9 had a blue (16.3%) ID card; this aligns with the focus of the study on persons with severe disability. See Figure 5.

Among the 14 respondents that reported to have no ID card, 8 respondents have psychosocial disabilities and 6 have hemophilia. Out of the 9 respondents interviewed having psychosocial disabilities only 1 person has a disability ID card. Similarly, among the 12 respondents with hemophilia interviewed, only 6 persons have a disability ID card.

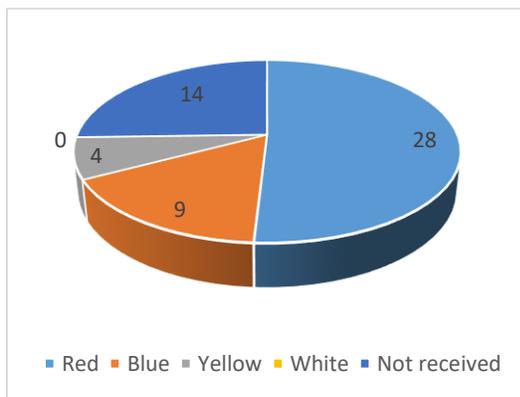


Figure 4: Number of respondents by colour of disability ID card

Red = complete impairment, blue= severe impairment, yellow = moderate impairment, white =mild impairment

During the consultations with representatives of DPOs, the gap in ID cards among people with psychosocial disabilities was discussed. It was reported that the deeply rooted stigma and discrimination towards persons with psychosocial disability meant that people with this condition do not want to expose their illness, and so do not claim a disability ID card. Psychosocial disability remains hidden in society. People with psychosocial disabilities are concerned that if they have an ID card their problem will be exposed, and the level of discrimination and stigma will increase. In the case of hemophilia, it was

felt that people with hemophilia miss out on ID cards due to the lack of technical capacity to identify hemophilia and its severity at municipality level.

#### 4.1.5 Occupation of respondents

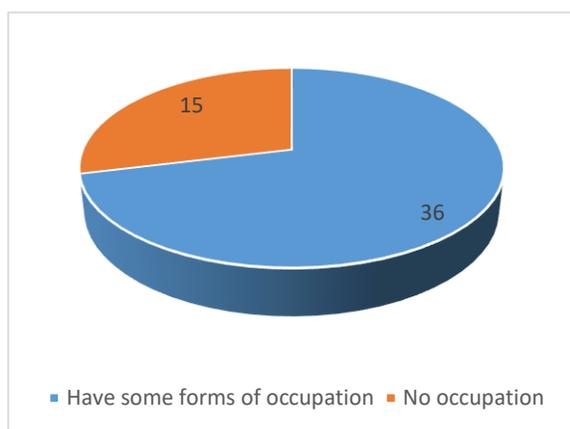


Figure 5: Number of respondents by occupation

Discrimination, stigma and infrastructural and transport barriers inhibit access to jobs and income opportunities of persons with disabilities; this is especially so for people with severe disability. Despite 51 out of 55 respondents being of working age, only 29% were engaged in some form of work; see Figure 5. The low incomes of those working however means they are partially dependent on their family. The remaining 71% of respondents were living without any source of income, and are completely dependent on their family or others.

## 4.2 Impact of COVID-19 on persons with severe and complete disabilities

Despite the diversity of respondents included in the study, both in terms of impairments and their social and geographical living situation, the study found a number of common experiences. The findings below are therefore separated into two main categories. Firstly, we present common experiences across the sample, and secondly, identify factors and experiences specific to people with different types of disabilities.

### 4.2.1 Common experiences of persons with severe and complete disabilities

#### *Impact of COVID-19 on daily living*

The majority of persons with severe disabilities included in this study are socially and economically dependent on their family. The study found that 82% of respondents need full time or part time support from others to meet their daily living needs such as food, clothing, toileting, bathing, mobility and participation in the community. The majority of respondents that need such assistance (91%) receive this care from family members. This high level of dependency on the family impacts the functioning of the entire family unit.<sup>36</sup>

#### *Family income:*

Two-thirds of respondents reported that the lockdown situation has affected their own or family income sources which has led to a financial crisis. Family members who are engaged in wage-based income, have their own business or private jobs have been severely affected. Small shops are closed, and agricultural products couldn't be sent to the market due to travel restrictions. Respondents noted how products were

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<sup>36</sup> In Nepal, professional personal attendants or care giver services to adults or children with disabilities are yet to be developed, though such services are starting to be provided in a very limited way by NGOs in Kathmandu.

damaged and jobs terminated. Those with family members working overseas noted how remittances have stopped as workers have either lost their job or been put on unpaid leave.

I am fully dependent to the support and income of my family. My family's income is based on the agriculture. Vegetable farming is main source of income, but due to the pandemic the market and transportation are closed. We could not send the product to the market for a long time. It gave a big loss to our family. All products are damaged. The suddenly imposed financial crisis has created problems also in my regular treatment.

*Experience of 46 years man living with hemophilia who belongs to Janajati community.*

**Mobility:** The majority of respondents reported that the COVID-19 pandemic has affected their daily mobility, and related support from helpers, caretakers, access to hygiene materials and food.

**Hygiene materials:** More than 15 respondents reported how the closure of markets and restrictions on public transportation is impacting their access to hygiene materials including menstrual pads. Some hygiene related materials are also not available in village markets.

**Diet:** More than 10 respondents noted how reduced family income and increased price of food has required the family to compromise on diet, and they are now consuming less nutritious food.

**Worry:** The fact that it is unclear how long the pandemic will last is fueling fears and anxiety. All respondents reported having a fear of COVID-19 infection, and most of them don't know what would happen if they get infected, and worry about how they will be treated at hospital. They don't know who will take care of them, and whether caretakers and helpers are allowed to accompany them in hospital. They are also worry about the accessibility condition of hospitals, beds and toilets.

I live in a remote place of Taplejung district. Due to the COVID-19 pandemic the public transportation service has been closed. I need to go to the hospital to see the doctor for my regular check-up but I cannot go there. In one hand I have a fear of infection, on the other hand I am also suffering with food crisis because I am fully depended to the earning of my son. Before COVID he used to go for daily wages work like collecting Cardamom and road construction and earned some money for family. But now there is no work for him and the earning of family has stopped.

*Experience of 51 years male living with Spinal Cord Injury from Taplejung District.*

I have severe physical problem. I need two persons for my daily care like bathing, cleaning, toileting and sleeping and my daily mobility. Due to the COVID-19 pandemic one helper cannot come to serve me from outside. I have only one helper and it is very much difficult to manage with one helper. My sons are in foreign employment. They sent me some money to me in regular basis but now they are also in financial problem due to the COVID-19 pandemic. Neither they can come here nor they send money to me. Even if they send some money, I cannot go outside to draw the money due to travel restriction and lockdown. I am also scared thinking that I might be infected.

*Experience of 50 years female living with Spinal Cord Injury from Janajati community in Sunsari District.*

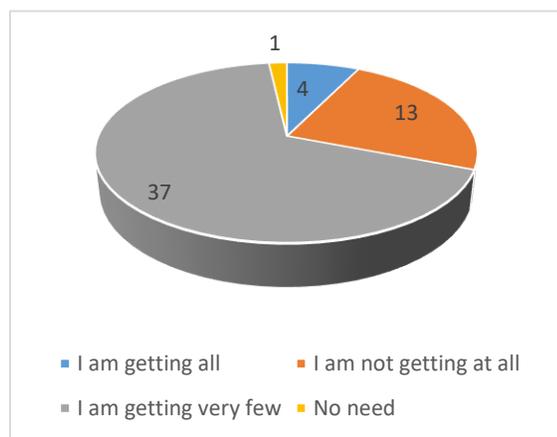
**Assistive devices:** 31 respondents use different types of assistive devices for their mobility and daily activities, and repair and replacement of these devices is critical for their mobility. Due to the lockdown and restrictions on movement imposed by the government, people with disabilities have not been able to get their assistive devices repaired or replaced as needed.

### *Impact of COVID-19 on access to health care*

The majority of persons with disabilities who have severe impairments need some form of regular health service. Out of the 55 study respondents, 71% said that they need some form of regular health service such as medical check-up, medicine and supplies, counselling, psychosocial therapy, and 27% said that they need such services sometimes. Before the COVID-19 pandemic, respondents were taking health services from a variety of institutions including local medical shop, private clinic, private hospital, government hospital, government health post and NGO. The cost of services varied according to the provider, with higher costs required to use private providers and medical shops. Bearing in mind the diversity of need and source of provider used, the average weekly expenses for health-related services was reported to cost between Rs. 500 to Rs. 4000 per person.

The choice of institution was reported to be based on the availability of services. The first choice was government hospitals or health posts given the lower cost. However, the lack of available services, poor quality care, waiting time and inadequacy of human resources at government facilities were reasons why respondents turned to private and non-governmental providers. Slightly more than 50% of the respondents reported taking their regular health services from private hospital, NGO operated rehabilitation centre, local private clinic and local medical shops, and the remainder from a mix of government and private institutions. A very common demand of all respondents is for the health services that they need on a regular or occasional basis, be treated as essential health care and made available from government hospitals and health posts free of cost.

*Figure 6: Number of Respondents by their Access to Health Services since COVID-19*



COVID-19 has had a major impact on access to health services of persons with severe impairments due to lockdown, travel restrictions and loss of income sources. Only 4 (7%) respondents confirmed that they are continuing to receive the regular and occasional services they were using pre-pandemic and continue to need; 37 (67%) said that very few services have continued; and 13 (24%) respondents claimed that their regular health services have been completely interrupted since COVID-19. See Figure 6.

The case study also found respondents were not provided with essential public health materials such as face masks, sanitizer, gloves and soap, or access to public health information on how to stay protected from the risk of infection. Out of 55 respondents, 87% said that they were not supported with personal protective hygiene materials and public health information.

The heightened vulnerability of persons living with severe disabilities to COVID-19 and the social and economic impact of the pandemic, means that meeting their health care needs and providing them with

essential hygiene supplies and public health information is of special importance, and a marker of the national response.

#### *Impact of COVID-19 on access to social assistance*

Among the respondents interviewed, 34 (61%) were receiving social assistance in the form of cash or goods or in-kind support from government, NGOs, private organizations and personal donors, before the COVID-19 pandemic. The pandemic has reduced this vital source of support, and this has been completely interrupted for 19 people or more than 50% of those who were previously benefitting.

#### 4.2.2 Experiences of people with specific disabilities

##### *Persons with spinal cord injury*

**Background:** Medically a spinal cord injury is defined as the damage to any part of the spinal cord or nerves at the end of the spinal canal which causes permanent changes in strength, sensation and other body functions below the site of the injury<sup>37</sup>. Nepal classifies spinal cord injury under physical disability<sup>38</sup>.

**Assistive devices:** Most persons living with spinal cord injury use assistive devices such as wheelchair, walker and crutches for mobility. Such assistive devices are provided by government institutions, non-government organizations or private charity organizations free of cost. During the COVID-19 pandemic, persons living with spinal cord injury reported that they were unable to get assistive devices repaired and this was a serious barrier to their functionality.

**Pressure sores** are a very common health related problem of persons with spinal cord injury, and regular care at a hospital or health clinic is needed to avoid the sores becoming severe and complicated. During a group consultation with persons with spinal cord injury, participants shared cases where people living in remote and rural areas have died due to lack of timely treatment of bed sores. Respondents shared that before COVID-19 they were managing to go to the hospital and health clinic for treatment of their bed sores, but since the pandemic it has not been possible. Six respondents expressed that the number of sores has increased and they are experiencing extreme pain. During the group consultation, some participants reported that they have to use strong pain killer or sleeping tablet to get relief from the pain, which they acknowledge is not good for their overall well-being.

**Medical supplies and hygiene materials:** Persons with spinal cord injury typically need a range of medical supplies and hygiene materials - such as catheter, urine bag, Clean Intermittent Catheterisation (CIC) pipe, jelly, diaper, sanitary and menstrual pads - to manage urine, menstruation, bed or pressure sore and defecation. Such basic items are needed to maintain personal hygiene, and by their nature have to be regularly replaced for hygiene and to avoid infection. In a normal situation, those residing in urban areas can access such items easily but this is more difficult for persons living in remote and rural areas as they are often not available locally. Access to these supplies has become very difficult since COVID-19 for all the respondents with spinal cord injury, even for those residing in urban areas because materials have

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<sup>37</sup> <https://www.mayoclinic.org/diseases-conditions/spinal-cord-injury/symptoms-causes/syc-20377890>

<sup>38</sup> Rights of Persons with Disabilities Act, 2017, Annex 1: Classification of Disability.

not been available in the local market. Living in such a desperate situation, respondents shared the additional health complications they are experiencing:

- Extreme pain in the body
- Worsened personal hygiene and sanitation
- Urine infection
- Problem of blood pressure, headache and stomach pain
- Anxiety and depression
- Constipation

I use CIC pipe to manage my urine. I cannot use one for a long time. I need to replace it but it is hard to get CIC pipe in my local area. Now I have only one. I have to go a bit far to bring this but there is lockdown and travel restrictions. I cannot go and I am also afraid of the infection of COVID 19. On the top of that after COVID pandemic I am also suffering with financial problems.

*Experience of 52 years male living with Spinal Cord Injury in Kathmandu District.*

Respondents shared how poor hygiene and sanitation and urine infection are some of the main causes of untimely death of people living with spinal cord injury.

Helper, personal attendant or care taker are critical for persons with spinal cord injury to assist with mobility, toileting, cleaning, bathing, sleeping, eating and to perform other daily activities. Family members generally provide this care in Nepal. With the pandemic this close physical interaction has been affected, respondents told how family members feel there is a risk of infection, and they try to maintain their physical distance to protect the person with disability. Similarly, due to the fear of COVID-19 infection, they cannot request the help of paid helpers from outside, and helpers are also reluctant to provide care because of the risks.

I live in a rehabilitation centre. Before COVID 19, I was enjoying adequate support from the helpers provided by the rehab centre in my daily activities such as toileting, bathing, cleaning and others. After COVID-19 pandemic the number of helper is not adequate and we are underserved. Sometime I am so panic for not having helper on time even to go to toilet. There is also problem in hygiene and sanitation. However, the organization has provided some hygiene materials but there is lack of nutritious food.

*Experience of 26 years female living with spinal cord injury in Kathmandu District.*

**Four personal attendants** were interviewed who were providing care and services to persons living with spinal cord injury. According to them, in normal times, unfriendly physical infrastructure and discrimination towards persons with disabilities were the main barriers to quality care. COVID-19 has impacted persons with disabilities, and their personal attendants significantly. Personal attendants shared how they have to travel by public transport to reach their workplace and every time have a chance of COVID-19 infection. During lockdown there were strict travel restrictions so they were not able to provide services to their clients, causing serious difficulties for them, and in some cases this led to bed sores and other problems because of lack of timely and proper care. Normally, personal attendants buy hygiene materials for clients from the market, but during the lockdown it was hard to find products in the market. Loss of income of persons with disabilities and their families due to COVID- 19 has also affected the income of their personal attendants who have to manage with lower income.

**Government provision:** Nepal government provides NRS 100,000/- as one-time support to persons with traumatic spinal cord injury for their treatment and rehabilitation in government hospitals. Persons with non-traumatic<sup>39</sup> injury are not covered by this provision. During a focused group discussion, participants

I am a personal attendant and serving to person with Spinal Cord Injury. COVID 19 pandemic has affected her and me badly. I cannot reach to her resident on time to provide service due to transportation problems. I have to help her for her daily activities such as cooking, eating, bathing, cleaning and mobility along with bring daily needs and food from the market. But due to the fear of COVID infection I am always worry. If I am infected she will have problems because in this situation it is hard to find other personal attendant. Due to the COVID pandemic there is problem to go to the hospital for regular check-up. For last few weeks she has fever but I am not able to take her hospital.

Experience of personal attendant serving to the female living with Spinal Cord Injury

gave thanks to the government for this provision, but at the same time they also said that one-time support is not enough for the health of people living with spinal cord injury. Since they have to live and participate in society with the injury, they requested the government to provide the health care and services they need on a daily basis.

**Observation of DPOs:** DPOs representing persons with spinal cord injury reiterated that the range of services needed by people with spinal cord injury have been severely interrupted by lockdown and the other restrictions introduced in response to the pandemic.

#### *Persons living with hemophilia*

**Background:** Hemophilia is a bleeding disorder caused by low clotting factors in the blood<sup>40</sup>. For people with hemophilia any internal or external bleeding such as that caused by cuts or injury, doesn't stop and can lead to serious health problems and sometimes death without timely treatment. In most cases, the anti-hemophilic factor is the main treatment to stop the bleeding, and this is provided through injection by a trained health professional. Clotting factor concentrates can be provided episodically to treat bleeding or prophylactically to prevent a bleeding episode.

**Supply of anti-hemophilic factor:** The Rights of Persons with Disabilities Act, 2017, ensured provision of anti-hemophilic factors to persons with hemophilia free of cost. Before COVID-19 the Ministry of Health and Population had not included the factor in the essential drugs list, secured supplies or allocated budget. Until 2020, government health institutions were not providing anti-hemophilic factors rather the NGO, Nepal Hemophilia Society was collecting a very limited number from international donors and providing it to persons in need.

With the introduction of lockdown, the stock of factor with Nepal Hemophilia Society was exhausted and fresh supplies could not be sourced because of the travel restrictions. Travel bans also meant that people suffering could not access hospital care for any form of temporary relief. This crisis situation was highlighted in the national and social media. Advocacy of DPOs and other stakeholders led to many

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<sup>39</sup> Traumatic spinal cord injury is caused by a sudden, traumatic blow to the spine that fractures, dislocates, crushes or compresses one or more vertebrae. <https://www.mayoclinic.org/diseases-conditions/spinal-cord-injury/symptoms-causes/syc-20377890>

<sup>40</sup> <https://www.cdc.gov/ncbddd/hemophilia/facts.html>

persons with hemophilia being seen on media platforms suffering with internal and external bleeding and pain.

In response to the provision of the RPD Act, and the crisis level shortages, the Federal Ministry of Health and Population, and some Provincial Ministries of Social Development (Province 1, Bagmati Province, Gandaki Province and Sudurpaschim Province) allocated budget for the supply of anti-hemophilic factor at provincial level across the country. MoHP allocated NRs 20.6 million for factor procurement for financial year 2020/21. During the time of lockdown, the Provincial Government of Province 1 bought an amount of anti-hemophilic factors using the fast track process, in coordination with National Federation of the Disabled Nepal and Nepal Hemophilia Society. According to Nepal Hemophilia Society, this urgent action taken by the government of Province 1 addressed the emergency situation created by the lockdown and helped to save the lives of people who were in a serious condition in Province 1. Despite budget allocations, other provinces have not yet used their allocations and procured anti-hemophilic factor and the supply problem remains.

*Complications faced by persons with hemophilia during the pandemic:* The shortages and lack of attention given to the supply of anti-hemophilic factor has left persons living with hemophilia facing serious complications, including:

- Extreme pain for a long time in joints.
- Damages in joints and additional physical limitations.
- Gradually they are compelled to use crutches and wheelchair to walk due to the damages in joints.
- The body cannot work due to the pain and regular bleeding.
- Use of strong pain killer and sleeping tablet to get relief.
- Problem of blood pressure and mental torture and stress.

#### **Some Personal Experiences**

My therapy has interrupted. I am having lots of problems and pain in joints. The joints are getting damaged. I live a bit far from the hospital. I don't know, for how long should I wait to open the public transport. In case of minor bleeding I try to manage it with help of ice but that is not a good solution.

*Experience of 20 years old male.*

I have regular pain for last few weeks. I am not able to go to see the doctor. There is problems to go outside to buy even a pain killer tablet. I need Factor but if get it, in my area, there are no any trained health worker who could support me to put the factor in my body.

*Experience of 18 years old male.*

There was an internal bleeding in my hands during lockdown. I could not go to see the doctor and therapist because of the travel restriction and I was also afraid of the risk of COVID infection. I used ice to relief from pain, put some bandage for one week. I went through an extreme pain and I had to use some strong medicine to get relief from the pain. Me and my family had to face a mental stress too.

*Experience of 27 years old male.*

**Observation of DPOs:** DPOs noted the reliable and affordable availability of anti-hemophilic factors is essential for the functionality and well-being of persons living with hemophilia. They reiterated that the amount that has been made available from international donors has only met life-saving needs rather

than enabling persons with hemophilia to lead a quality life. The COVID-19 pandemic situation has exacerbated the huge scarcity of anti-hemophilic factors in the country and left people facing serious and life-threatening conditions. DPOs felt that the government has heard the voice of persons with hemophilia and taken some initiative, such as provincial government budget allocations for factors, however, only in Province 1 have supplies been procured.

#### *Person living with psychosocial disability*

**Background:** Psychosocial disability is related to the mental health condition of a person and the social barriers and consequences. Persons with psychosocial disabilities may have to face challenges to set goals, make plans, engage in education, work and participate in social and cultural activities. Long-term psychosocial disorder includes schizoid disorder, anxiety disorders such as obsessive-compulsive disorder, post-traumatic stress disorder, agoraphobia and social phobia, mood disorders such as major and dysthymic depression and bipolar<sup>41</sup>.

The government of Nepal has classified psychosocial disability or mental health problems as a category of disability in the RPD Act. There is a lack of reliable and comprehensive data on persons living with psychosocial disability in Nepal. Nepal Health Research Council (NHRC) has estimated that 20-30% of the population are at risk of suffering from one or more mental health problems, and sporadic studies done in different parts of the country indicate an increasing prevalence<sup>42</sup>. A survey published by the NHRC in 2018, shows that the current prevalence of any form of mental disorder in Nepal is 12.9%<sup>43</sup>.

**Secondary data on access to health care:** Representatives of organizations working on psychosocial disabilities claim that the main health related issues of persons with psychosocial disability is lack of access to essential medicine, medical or psychiatric support and psychosocial counselling. Due to the deeply rooted discriminatory behavior of society and stigma towards persons with psychosocial disabilities, persons living with these conditions are deliberately hidden in the family. A person (or family) cannot easily accept or tell about his/her mental health problems in the community due to stigma and social discrimination, and this further increases their vulnerability<sup>44</sup>.

NHRC's 2018 mental health survey highlighted that among those with any form of mental health disorder, only 18.4% were able to receive treatment during the last 12 months. The major barriers in accessing and receiving care were related to knowledge and attitude barriers which fed into poor help seeking. For example, about 79.8% of the participants who did not receive treatment did so because they wanted to

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<sup>41</sup> What is Psychosocial Disability and how can the NDIS help ? <https://chessconnect.org.au/what-is-psychosocial-disability-and-how-can-the-ndis-help/>

<sup>42</sup> A Report on Pilot Study of National Mental Health Survey, Nepal. Government of Nepal, Nepal Health Research Council, 2018, [http://nhrc.gov.np/wp-content/uploads/2019/04/Pilot-national-mental-health.pdf?fbclid=IwAR0SgJpRCrXQmpHk5EkFAC3IqQhtqujAofUwHtJW00fIGlxGlyrqRFp2\\_5U](http://nhrc.gov.np/wp-content/uploads/2019/04/Pilot-national-mental-health.pdf?fbclid=IwAR0SgJpRCrXQmpHk5EkFAC3IqQhtqujAofUwHtJW00fIGlxGlyrqRFp2_5U)

<sup>43</sup> A Report on Pilot Study of National Mental Health Survey, Nepal. Government of Nepal, Nepal Health Research Council, 2018, [http://nhrc.gov.np/wp-content/uploads/2019/04/Pilot-national-mental-health.pdf?fbclid=IwAR0SgJpRCrXQmpHk5EkFAC3IqQhtqujAofUwHtJW00fIGlxGlyrqRFp2\\_5U](http://nhrc.gov.np/wp-content/uploads/2019/04/Pilot-national-mental-health.pdf?fbclid=IwAR0SgJpRCrXQmpHk5EkFAC3IqQhtqujAofUwHtJW00fIGlxGlyrqRFp2_5U)

<sup>44</sup> Based on the consultation with the representatives of KOSHIS, Organization working for the people with psychosocial disabilities.

solve their problem on their own, followed by the feeling that the problem would get better by itself. Similarly, about 63% thought that they did not have a problem.

**NHRC, 2018, A Report on Pilot Study of National Mental Health Survey, Nepal.**

"Among total 325 participants who had any form of mental disorders in past 12 months, 171 i.e. 52.6% talked about their problem with someone and only 69 (21.2%) searched for the treatment followed by only 58 (17.8%) who received complete treatment in last 12 months. Among those who talked with someone about their mental health problem, majority of them talked with husband/wife followed by friends and other family members, health workers, dharmi jhakri, and jyotist/priest. Among participants who took mental health services from different sources, all of them said that the service was helpful (NHRC. 2018. pg 14)."

**Impact of COVID-19 on access to health care:** In this case study, nine persons with psychosocial disabilities were interviewed. The respondents reported that they have very poor access to psychosocial care, services and support, and the social and financial cost of treatment is very high. All nine respondents said that they were taking the services they need from private health institutions, NGOs, and government hospitals in the past. COVID-19 has created more problems. Seven out of nine respondent reported that access to regular doctors, medicine, treatment, counseling and psychiatrists which they had been seeing before COVID-19 has been interrupted. Medicine is not available in the market, and travel restrictions and fear of COVID-19 infection has added more trouble. Respondents shared that they are not accessing any additional health service and hygiene related materials to cope with COVID-19 and since the pandemic they are experiencing additional health problems, including:

- Increased level of depression.
- Feeling pain in heart and something scary.
- Uneasy feeling and less sleep.
- Anxiety and stress have increased.
- No interest in food and less sleep.

Five out of nine respondents shared how the loss of their own or family's income source has increased their mental stress and they are living in the fear that there will be more problems in the future. Respondents have a fear of getting infected by COVID-19 any time, but they know very little about the disease, and don't know what to do to stay safe from infection, and how to be prepared to cope with the situation if they get infected.

This situation is panicking me. Every time I am scared of COVID infection. I am feeling that the level of depression has increased. I also have some other health problems which I need to check-up in regular basis. But I cannot go to see the doctor in this situation. My husband also has physical disability. He was engaged in tailoring before COVID and we had some income to run the family. After COVID he is not able to for work. My family is running out of income for a long time.

*Experience of 30 years female living with psychosocial disabilities who belongs to the Dalit community.*

Financially I am a poor person. I don't have any physical properties. On the top of that I have psychosocial problems. KOSHIS organization cared me by keeping in a transit home for sometime. Later on I thoughts to do something for me and my family. So, I took Rs. 50000 loan to do vegetable farming. But it is my misfortune that the COVID 19 pandemic started unexpectedly. There was lockdown for a long time. I could not send and sell my products in the market. I lost all products. Now I am not able to pay the installment of loan. I was mentally depressed again and attempted suicide but I again remembered my husband and stopped myself. Still I am not feeling good.

*Experience of 49 years female living with psychosocial disabilities.*

**DPO perspective on access to psychosocial health care:** A representative from KOSHIS, an organization working on mental health issues and psychosocial disability, says that financial problems are the main barrier to treatment of psychosocial conditions and medicines, and this is far from the capacity of those living in poverty or people of low economic status. It was noted that there are still cases in rural areas, where people with severe psychosocial problems are abandoned and homeless, and face violence, physical torture and other risks including gender based violence. The structure and availability of mental health services is also a major limiting factor. The institution and urban based nature of government's mental health services in Nepal, serve very few people. NGO services are limited to a few pocket areas.

KOSHIS has facilitated the formation of self-help groups among persons with psychosocial disabilities participating in its programs. The members of the self-help group meet each other on a regular basis and discuss about their day to day life. The main objective of the self-help group is to create a platform for sharing experiences and feelings. Members learn from each other about how to cope with situations, increase their sense of positivity, and gain personal strength to support their mental well-being. KOSHIS reported how COVID-19 has stopped the self-help group from meeting, which is negatively impacting members who had come to benefit from the group interaction.

I am one of the members of self-help group formed and facilitated by KOSHIS. We met sometime weekly and sometime fortnightly and shared our experience and feelings with our friends. We were happy and feeling very good doing that before COVID pandemic. After COVID it has stopped for a long time. But, KOSHIS is again trying to connect us virtually.

*Experience of female self-help group member.*

Representatives from KOSHIS and other DPOs believe that COVID-19 has increased mental health problems and further reduced access to psychiatric care, psychosocial counseling, rehabilitation services and medicine. There was the view that while Government has taken some good initiative to provide mental health services in some provincial level hospitals, at the local level, lack of trained human resources means a lack of psychosocial counselling and other services.

### *Persons living with intellectual disabilities*

**Background:** Intellectual disability involves problems that affect intellectual functioning such as learning, problem solving, judgment; and adaptive functioning such as daily living activities like communication, self-care and independent living<sup>45</sup>. This is also known as developmental delay or learning delay. Downs Syndrome is one sub-category of intellectual disability. The degree of severity of intellectual disability varies from mild to profound. People with intellectual disability often have challenges in usage of language and communication. They are not able to grasp abstract things of concept. They are comparatively less capable of understanding, comprehending, concentrating and memorizing things as other in the course of development<sup>46</sup>.

In Nepal, except for some residential facilities, most persons with intellectual disabilities live with their family under parental care. In the non-government sector, parents associations or groups are representing the voice and issues of persons with intellectual disabilities, and at national level there is one federation of parents associations representing the interests of students with intellectual disabilities.

**Health concerns and access to health services:** Parents of persons with intellectual disabilities provided information on behalf of their children for this study. During focus group discussion and interviews, parents shared the main health issues of their children with intellectual disabilities, noting that physical and intellectual conditions often went hand in hand:

- Epilepsy.
- Frequent shivering in the body.
- Heart problems and frequently suffering from cold and pneumonia.
- Being hyperactive and restless.
- Thyroid.
- Due to lack of physical work and mobility, persons gain weight which causes additional health problems.
- Cerebral Palsy which is a profound condition and needs very intensive care. Lack of proper care can lead to bed sore and pressure sore.
- Inability to express themselves even if something wrong is happening in their body.
- Unable to take care of themselves properly and maintain hygiene, and need other people's support for this.
- Need physiotherapy and other types of therapeutic services.

Parents reported a number of difficulties accessing care in health institutions. The lack of priority given to treating persons with intellectual disability means they struggle waiting in the queue for the doctor. Some parents reported how their children's challenging behavior led to abuse from health staff as they are not experienced or trained in how to provide health care to persons with intellectual disabilities. When patients cannot express themselves, it is difficult for doctors to diagnose and treat them, and this is further

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<sup>45</sup> <https://www.psychiatry.org/patients-families/intellectual-disability/what-is-intellectual-disability>

<sup>46</sup> Identifying Children with Intellectual Disability. <https://www.ejinsight.com/eji/article/id/1822005/20180420-identifying-children-with-intellectual-disability>

complicated because parents often felt that doctors are wary to accept parent's explanations. Parents in the group consultation shared that most of the time, doctors send the patient back with some medicine without a proper diagnosis of the problem. They collectively felt that persons with intellectual disabilities fail to receive quality clinical care from trained doctors who respect their dignity. The parents also shared that comparatively, private hospitals pay somewhat better attention because parents have paid high charges.

Some parents reported that medicines are essential on a regular basis to control epilepsy, shivering, stiffness of body, hyper activeness and heart related problems. But such medicines are costly, not available free of cost, and not affordable to the poor. Furthermore, parents felt that doctors did not inform them about the 72 types of medicine that are provided free of cost at government hospitals, and that this could save them some out of pocket spending.

Once my child was sick and I took her to the nearby hospital. After the general check-up the doctor wrote some medicine in the prescription but he did not say that he had prescribed some medicine which were available in the hospital at free of cost. I went outside and buy all medicine from the medical shop. But later on I knew from somebody that there were some medicine which I could have received from the hospital at free of cost.

Experience of parents taking part in the FGD.

Parents reported how their children cannot understand the risks and implications of COVID-19 and it is very hard to get them to physically distance, use face mask and sanitizer. One parent shared how it is hard to maintain physical distance with their child because they always want to come near to their dearest and touch and hug them. While some children don't want to use the face mask and sanitizer for others, they like and want to use it too much.

In my family, first I was infected with COVID. My son has intellectual disabilities who always live and sleep with me. Every time he wants me to care and love him. After COVID infection I tried my best to get him keep away from me but I could not do it. He was also infected from COVID. After this he mixed up with other family members and they were also infected. Now my whole family is infected with COVID.

Experience of parent with a child with intellectual disabilities taking part in FGD.

Due to lockdown and travel restrictions it is very hard to access hospital. Apart from travel, services at hospitals are difficult to access due to fear of COVID-19 at the hospital, and the requirement of a PCR test first, which is difficult to organize for persons with intellectual disabilities. In the current COVID-19 situation, hospitals are not paying proper attention to treatment of persons with intellectual disabilities. Pre-COVID-19, some parents reported how doctors, therapist or rehabilitation workers had delivered care to their child at home, but the option of home visit in the COVID-19 situation was not available.

**Observation of DPOs:** DPOs noted how COVID-19 related information is not accessible to persons with disabilities especially those with hearing impairment, visual impairment, autism and intellectual

disabilities and how they lack information on how to stay safe. The pandemic is panicking to the persons with intellectual disabilities and their parents in different ways. Their family income has reduced. They are not able to provide care to their children in this changed context. Regular health care to be received from hospital or health posts are interrupted. It is hard for them to teach their children about how to stay safe from COVID-19 infection.

#### *Persons living with multiple disabilities*

**Background:** Most cases of multiple disability are severe from the point of view of health and barriers the person faces in day to day life. Persons living with multiple disabilities need intensive care from parents, helpers or caretakers.

**Health needs:** Based on the discussion and in-depth interview with persons with multiple disabilities, mixed types of health-related needs and issues were reported:

- Assistive devices and regular health check-up.
- Medicine and health related counseling to stop or reduce additional health related problems.
- Physiotherapy, occupational therapy, speech therapy.
- Treatment of bed sore, pressure sore, body stiffness.
- Corrective surgery.
- Hygiene related materials and support.
- Providing caregivers or helpers to support their daily activities.
- Psychosocial counseling.

**Access to health services:** In normal situation services needed by people with multiple disabilities are only available in urban based hospitals. The RPD Act, disability policies and regulations have directed the government to provide such services free of cost and expand them to rural areas with adequate human resources. But respondents and DPOs reported how such provisions are yet to be put into practice on the ground. Those who are economically sound can take services from urban based hospitals or health institutions, but the poor and those living in rural areas lack access to services. This means that persons with multiple disabilities from rural areas face the extra burden of travel and accommodation cost, in addition to treatment cost. For services required on a regular basis, for instance, treatment of bed sore or pressure sore, therapy, psychosocial counseling, urine infection, the out of pocket and opportunity costs are very high.

COVID-19 has impacted persons with multiple disabilities in multiple ways. In this case study, eight persons with multiple disabilities were interviewed. Five out of eight have red disability ID card and three have blue. All are dependent on the income of their family, and depend on family members to support their daily activities. Respondents highlighted how COVID-19 has impacted the income of their family adversely and most of the health-related services they were taking before COVID-19 have been interrupted. The main reasons are similar to those reported for other groups, such as financial crisis in the family, lockdown, travel restriction, difficulties in accessing help from others, and fear of COVID-19 infection. Respondents also highlighted the increased market price of daily essentials as a major concern.

The reduced family income and increased market price of products has created a significant financial shock to the family.

I am fully dependent to the income of my family. My father was doing some wage-based work like putting color in houses before COVID. After the pandemic all works have stopped. There is no works for my father and we are out of income. It has also impacted in my health care and we cannot even buy our basic needs and hygiene materials as required.

*Experience of 22 years persons living with multiple disabilities.*

The fear of COVID-19 infection is high in each of the respondents participating in the study. The high dependency of persons with multiple disabilities and their need for intensive care and support if they are admitted to hospital raises concerns for how they would be cared for in the COVID-19 context. Normally, hospitals are unable to provide essential caregiver services to persons with disabilities at hospitals and patients are supported by the helpers they bring with them. But in the COVID-19 situation, hospitals may not provide permission to helpers due to the risk of infection. Their main concerns are:

- Is there provision for helper at hospital who could provide intensive care to severe and complete persons with disabilities, if they get infected?
- Are they allowed to bring their own helpers to the hospital and is the hospital ready to provide personal protective equipment to the helper.
- Do the health professionals know about the requirements of persons with disabilities?
- Will we receive care without any discrimination on the basis of our disabilities?

I know a little bit about how to be prepared to fight with COVID if I get infected but I really don't know about how the health worker will support me during the time of treatment if I am admitted at hospital for treatment. I don't know, whether I am allowed with my helper or not and I also don't have any information about how much the health workers know about needs of people like us.

*Experience of 22 years male living with multiple disabilities.*

*Access to social security:* Persons with red and blue disability ID cards are eligible to receive Rs. 3000 and Rs. 1600 respectively per month as social security allowance. This allowance is provided by federal government and distributed to individuals with disability ID cards provided by local municipalities. The lockdowns and restrictions have made it difficult for people to access their social security allowance.

We are two persons in our family, me and my mother. Financially we are surviving in Mother's pension and my social security allowance. But due to lockdown, travel restriction and fear of COVID infection mother cannot go outside to draw pension. I have same problems to go to bank to draw social security allowance. I have to hire vehicle for the security reason which is too much costly.

*Experience of 24 years female living with multiple disabilities*

#### 4.2.3 Experience of parents and family members

Parents and family members interviewed shared the challenge of balancing their responsibilities caring for those with disability and their other family responsibilities such as household work, income generation and social commitments.

**Care burden:** Based on interviews with 10 parents or family members (mainly mother or women), they spend between three to eight hours per day caring for the family member with disabilities. They noted that they frequently have to compromise on the quality of care they provide due to other family responsibilities and how this increases their stress and worry. Poor families who cannot afford to stay home are forced to leave the family member with disabilities at home alone. Parents worried about the risk of sexual violence, rape and abuse in such a situation.

In a case study recently carried out by NFDN on the situation of human rights for persons with disabilities from a remote village of Sudurpaschim Province, there are some evidences where persons with severe and complete disabilities are found to have been tied with rope or locked inside the room and left alone at home, and the parents gone outside for work<sup>1</sup>.

**Access to health care:** Respondents agreed that the quality and access to health related care for persons with complete and severe disabilities depend on the financial situation of the family. If the income of the family is good, and a member can provide the time to care for the person with disability, the quality of health care will be good, but for poor households it is challenging for the family to provide health care.

Respondents reported that the impact of COVID-19 on the care of persons with disabilities in the family is significant and especially for those facing financial pressures. They cannot take person with disabilities to hospital for regular health check-up, nor call the doctor at home for services. Due to travel restriction and fear of COVID-19 infection they rarely go to the market to buy food, other daily needs and medicine.

My son is living with hemophilia. During the time of lockdown suddenly there was internal bleeding in his gum. I could not take him to the hospital. I ask different place for anti-hemophilic factor but did not get positive response. He had extreme pain for a long time. I managed some medicine to relief from the pain but the bleeding remained for a long time. That time was really full of stress for me.

Experience of mother of persons with hemophilia

My wife has psychosocial problems. As she got this problem I had to leave my job to give time for her care. I should be near to her most of the time because nobody knows what happens in which time with her. Medicine is not working well. After COVID 19 the problem has increased. As she hears some news related to COVID or death from COVID she scares a lot. So, I do not turn on, facebook, youtube, TV and radio at home. Doctor has also increased the dosages of medicine. I had put some money at bank and the interest of the deposit was the main income source but due to the economic crisis appeared due to the COVID pandemic the interest rate of bank has also decreased significantly. It has created additional problems for me.

Experience of husband who is taking care of his wife living with psychosocial disabilities

In rural area, there is shortage of medicine. It is hard to maintain physical distancing in case of persons with intellectual disabilities, and to make them follow health behaviors to stay safe from COVID-19 infection. Parents think that their children with disabilities are weaker physically and mentally than children without disabilities and have high risk of COVID-19 infection; and this tends to make them protective.

#### 4.2.4 Reflections of health providers and government authorities on the impact of COVID-19 on people with disability

There is common agreement among all the health professionals and government authorities consulted for this study that persons with disabilities have faced significant challenges in accessing essential health care during the COVID-19 pandemic and lockdown. As reported earlier, travel restrictions contributed to the decline in use of health services of the general population and people with disabilities, and as hospital officials also noted, the decision to limit services to the provision of emergency services only in the early days of the pandemic, severely impacted clients in need of chronic care including hygiene supplies. In response, the Ministry of Social Development in Province 1 and 2 provided hygiene materials and medicines to some persons with disabilities as part of an initial relief package.

Province 1 supplied health and hygiene products to persons with spinal cord injury and distributed them in cooperation with NFDN and local DPOs. In addition, Province 1 procured and supplied anti-hemophilic factor to people with hemophilia.

Once the directive was given for hospitals to fully reopen, the full range of services have once again been made available, but as pointed out by the Ministry of Social Development in Province 2, the diversion of health workers to COVID-related services has led to staffing shortages and caused delays in services. Doctors interviewed from district and zonal hospitals in Provinces 1 and 2 noted that since COVID-19 there have been fewer patients with disabilities attending their hospitals.

Stakeholders noted the added risk of COVID-19 infection that people with complete and severe disability face given their specific health needs, and dependencies on others to support their care and well-being. Persons living with complete and severe disability are also at greater risk of experiencing a severe form of the disease given their pre-existing conditions. Despite the added vulnerabilities of people with disability, the response of the health service to prepare for COVID-19 cases among people with disability has been limited. In Province 2, ramps have been installed at a few isolation centres to improve accessibility, and attached toilet and bathroom provided for clients with accessibility needs. However, other critical preparations such as introduction of guidelines or training of staff on how to respond to the specific needs of people with disability in the event that they are admitted to a COVID-19 isolation centre, have not been introduced. No specific adjustments or preparations were reported from Province 1 or 5, although the authorities suggested that they are working closely with the provincial office of NFDN and would consult with NFDN or local DPOs if they faced specific challenges in caring for COVID-19 positive cases of persons with disabilities.

No instructions have been given to local health facilities to ensure they regularly contact persons with severe and complete disabilities by phone or in person given their vulnerability. No special efforts were made to check up on their health, to ensure they have sufficient supply of medicines, health and hygiene material, or respond to their fears and worries.

Municipal authorities interviewed were less aware of the impact of COVID-19 on the health of people with disability, and better informed about the problems they faced related to food, travel, and income.

#### 4.2.5 Government reflections on underlying gaps in provision of disability inclusive health services

**Federal Ministry of Health and Population:** Stakeholders consulted in the Federal MoHP acknowledged that the policy foundations that have been created to provide essential health care to persons with disabilities, including the National Guidelines on Disability Inclusive Health Services (2019-2030) are yet to be fully operationalised, and that significant gaps in services remain at all levels. Health workers and management are lacking training in disability inclusive health care, resources have not been provided to address accessibility barriers at facility level or provide special services to persons with severe and complete disabilities. The plan to establish at least one Spinal Injury and Disability Rehabilitation Centre in each province has not been implemented.

More positively, it was reported that progress is underway to expand mental health services at the provincial level including the provision of psychiatric care, and to train district and health centre staff to provide front-line mental health care. During the consultations, high-level stakeholders in Federal MoHP noted that COVID-19 has highlighted the serious health concerns of persons with severe and complete disabilities, and important lessons for the Ministry on how to secure the rights of these vulnerable people.

**Health providers** from health centres and hospitals identified a variety of reasons for the poor access to essential and specialized health services for people with disability even before COVID-19, this included:

- Physical infrastructure of health facilities is often not accessible to people with physical disabilities such as wheelchair users and visually impaired.
- Information services, signage and methods of communication in health facilities are not inclusive of persons with hearing impairment, visual impairment, intellectual disabilities, and autism. Hospitals don't have sign language interpreters.
- Health workers lack training or orientation related to disability and essential health services to be provided to people with disability at the local and district levels.
- Health centres and district hospitals are not equipped to provide assistive devices to persons with disabilities.
- Doctors and health staff in local and district facilities are not aware of the special health-related issues and needs of persons with disabilities such as spinal cord injury, hemophilia, intellectual disabilities, psychosocial disabilities, and other multiple impairments, and find it difficult to provide primary care to people with complete and severe disability.
- Specialized services are not available at the district or local level, forcing people to travel to specialist services which is often expensive and physically difficult.
  - For persons with hemophilia there is no diagnosis service at district or provincial hospitals. Without anti-hemophilic factor hospitals provide temporary solutions to sufferers, such as providing blood, but are unable to provide surgery.
  - Services for psychosocial disability are not available in most districts and there is a lack of psychiatric care at the district level.
  - In case of intellectual disabilities, health workers and doctors at district hospitals are not trained on how to serve them.

- Most district hospitals have no therapeutic services like physiotherapy, occupational therapy, and speech therapy.

One patient with spinal cord injury from Surkhet district came to see me for some advice, basic service, and counseling regarding some complaints he had due to the injury. He spent around Rs. 1000 for the services at the rehabilitation centre but spent more than Rs. 50000 in the travel with two helpers from Surkhet. If there were services available at least at the province level, he would not have to spend such a big amount.

We have to understand the treatment and rehabilitation of spinal cord injury in a cycle of services which includes primary support to reach out to the hospital, treatment of acute injury, rehabilitation service, returning back to the community, and provide regular basic health services and care in the community. All these services should be provided in a coordinated way. But in our country, the services are fragmented. I have observed many cases which don't come for rehabilitation after the first level of treatment because - first, there is no any rehabilitation service even at the province level, second they have to come to Kathmandu which may not be affordable for poor people, and third they may not have any information about rehabilitation services.

Spinal cord injury rehabilitation specialist from Spinal Injury Rehabilitation Centre, Kavre district.

**Provincial authorities** reported that despite the weaknesses in the system, persons with disability were given priority when they attended hospitals for general treatment. They also mentioned that some essential medicines for mental health conditions are on the essential drug list. The district hospital is primarily the point of referral up to specialist services although some very basic psycho-social counselling is available at some district hospitals. Basic care of persons with spinal cord injury is also provided at district hospital. Referral transport from district to provincial hospital for specialized services was reported to be provided by the hospital ambulance in some hospitals. It was noted that persons with disabilities are provided a discount in cost based on their disability ID card. Red cardholders are provided services free of cost whereas blue cardholders are provided a 75% discount in their general check-up, tests, diagnosis, and doctor's advice. The medicine which is on the list of essential drugs is provided free of cost.

## Chapter 5 : Recommendations

The perspectives and insight provided by each of the stakeholder groups included in this study, confirm the highly negative impact COVID-19 has had on access to essential health care and the daily living needs of persons with severe and complete disabilities. Building on the findings of the study, and the suggestions of each of the participant groups, two sets of recommendations are presented below. First are recommendations to immediately address the specific and additional challenges created by COVID-19 for the health of persons with severe and complete disability. Many of these recommendations will contribute to longer term institutional and systems changes, and will need to be sustained. Building on these immediate actions we present a second set of recommendations to support the longer term strengthening of the health system to provide disability inclusive health services. The second set of recommendations recognize that the primary health needs of people with disability need to be met on an equal basis to others, and in addition, the Government has a duty to progressively provide specialist services that are accessible and affordable to all persons with disabilities who need them.

### 5.1 Recommendations to reduce the immediate impact of COVID-19 on access to essential health care and daily living needs of persons with severe and complete disabilities

1. **Access to essential health care, public health information, medicines, assistive devices and health and hygiene related supplies:**
  - a. MoHP and Provincial Health Directorate to ensure adequate supplies of essential drugs for persons with severe and complete disability at hospitals and local health facilities.
  - b. MoHP in cooperation with Ministry of Federal Affairs and General Administration (MoFAGA) to develop and issue instructions to municipalities and local health facilities to provide persons with spinal cord injury, hemophilia, psychosocial disabilities, intellectual disabilities, and multiple impairments:
    - i. regular weekly health check-up service from local health workers either through in person visits or phone-based check-up.
    - ii. all essential medicines needed on a regular or occasional basis to manage their health needs, provided as required and free of cost.
    - iii. all health and hygiene materials as required including catheter, urine bag, Clean Intermittent Catheterisation (CIC) pipe, jelly, diaper, sanitary and menstrual pads be provided free of cost. The municipality health fund is one option to fund these inputs.
  - c. Hospitals to provide ambulance transport to persons with complete and severe disabilities that need to use hospital services, and free of cost.
  - d. Interrupted psychosocial counseling and psychiatric service at provincial and district hospitals to be restarted, and essential drugs for persons with psychosocial disabilities made available at provincial and district hospitals and local health facilities, once prescribed by an authorized prescriber (psychiatric doctor, medical officer and health assistant).
  - e. Local government to ensure that all persons with severe and complete disabilities have full access to public health materials to protect them from COVID-19 infection, including face

- mask, sanitizer, gloves, soap and COVID-19 related public information to stay safe from the infection. Distribution of materials may be in collaboration with DPOs and NGOs.
- f. Ministry of Women Children and Senior Citizen in cooperation with NDFN and other NGOs, map the need for assistive devices for spinal cord injury, multiple disabilities and other severe and complete disabilities, in each province. MoWCSC contract out the supply, repair and maintenance of assistive devices of people with complete and severe disabilities to local DPOs or NGOs.
  - g. COVID-19 related public information produced and disseminated by MoHP, provincial government and local municipalities to be made in accessible format such as easy-to-read, audio, pictorial, sign language, and local language.

**2. Disability inclusive COVID-19 testing and treatment:**

- a. Ministry of Health and Population in cooperation with the Ministry of Women Children and Senior Citizen, to develop interim guidelines on how COVID-19 testing and treatment services in each province are to respect the needs, and provide special care to persons with disability. This guideline will be targeted towards hospital management, doctors and health staff and accompanied by virtual or in-person orientation. It will allow persons with severe and complete disabilities to be accompanied by one helper/assistant when seeking diagnostic services or treatment for COVID-19. This helper/assistant will be supplied with personal protective equipment as per that provided to health workers in the hospital.
- b. Provincial government and local municipalities to ensure that isolation centres and quarantine facilities are accessible and safe for persons with profound and severe disabilities.

**3. Anti-hemophilic factors for persons with hemophilia:**

- a. Provincial Ministry of Social Development to assess the prevalence of hemophilia in each province and calculate the supplies required.
- b. MoHP to allocate conditional grant to each province, to be supplemented by provincial government as required, to procure sufficient supplies of anti-hemophilic factors for the province. Procurement to be expedited using the fast-track process. In financial year 2022/23, the Provincial Government to take full responsibility for funding anti-hemophilic factors.
- c. At least one provincial hospital in each province to be designated to provide services to persons with hemophilia.

**4. Information and social support to be provided to persons with disability and their families in each hospital:**

- a. Hospital based Social Service Units (SSU) to support persons with disabilities to access hospital care. MoHP to instruct SSUs on how to serve and support persons with disabilities and their parents, and the Provincial Ministry of Social Development, Health Directorate to monitor implementation.
- b. In hospitals without a SSU, MoHP and Provincial Ministry of Social Development to coordinate establishment of a disability focal desk in provincial and district hospitals as a contingency plan, and until a SSU is established.

## **5. Social protection of persons with severe and complete disability to offset the impact of the pandemic:**

- a. Public Health Service Act provision for the Ministry and Provincial Governments to establish an emergency health treatment fund to be activated to finance gaps in the care of people with complete and severe disabilities<sup>47</sup>.
- b. Ministry of Women Children and Senior Citizen in coordination with municipalities to develop and provide a new Livelihood Allowance for persons with complete and severe disabilities who are experiencing economic crisis due to COVID-19; to be distributed by municipalities.
- c. Local government to prepare a database of persons with severe and complete disabilities. Data to be disaggregated by gender, age, disability, government allowances and provisions currently received. This will provide evidence to inform local government relief and recovery plans and help ensure people with severe and complete disabilities are not left out.
- d. MoFAGA to facilitate local government's continued distribution of the disability ID card which has been interrupted by the COVID-19 situation.

## **5.2 Recommendations to support the Government's longer-term objective of providing disability inclusive health services**

### **1. Dissemination of federal policies and acts:**

- a. Ministry of Women Children and Senior Citizen to disseminate the Rights of the Persons with Disability Act, 2017 and related bylaws to provincial and local level authorities.
- b. Federal MoHP to disseminate disability specific health policies and plans to provincial and municipality stakeholders including Disability Prevention and Rehabilitation Strategy 2016-2026, and National Guideline on Disability Inclusive Health Services, 2019-2030.
- c. MoHP to socialize the National Guideline on Disability Inclusive Health Services to provincial, district and local level stakeholders so that they understand their responsibilities.
- d. Federal MoHP and Provincial Ministry of Social Development, Health Directorate to provide orientation to health facility managers, and hospital and health facility staff to support implementation of the National Guideline on Disability Inclusive Health Services, 2019-2030.

### **2. Federal level health systems strengthening to support disability inclusive health services:**

- a. Federal MoHP to define the location and responsibilities for providing essential and specialist health services to persons with severe and complete disabilities. Based on this commitment, MoHP to calculate the human resources needed to provide these services, and develop a medium term human resource development plan to meet these commitments.

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<sup>47</sup> Government of Nepal, Public Health Service Act, 2018, Section 33 states "The Ministry and Provincial Government shall set up an emergency health treatment fund to make arrangements for bearing the expenses of treatment of the poor and destitute, the person whose house and address is not traced, the family members of a martyr who sacrificed life in the course of popular movement, armed struggle and revolution, the family of the enforced disappeared person, the warrior of democracy, conflict victim and the displaced, the disabled, the wounded and the victim, in the case of not being able to bear the expenses incurred in treatment."

- b. In line with the Government of Nepal's (2013) national standards on accessibility of public physical infrastructure and communication services, the MoHP and MoWCSC plan and undertake regular Accessibility Audits of health-related infrastructures in collaboration and cooperation with local DPOs and accessibility experts. The reports from the Accessibility Audits to be submitted to the National Steering Committee chaired by the Minister of MoWCSC, and Disability Coordination Committees at Provincial and Municipality levels.
- c. Social health insurance to insure all persons with complete and severe disabilities into the scheme, and to raise awareness of this provision. The social health insurance package to cover the costs of providing essential and specialized health care to this target group. Until social health insurance is in a position to cover the costs of persons with severe and complete disability, free services at government facilities should be provided at the point of delivery with costs reimbursed to the facility by MoHP.

**3. Provincial level health system strengthening to support disability inclusive health services:**

- a. Provincial governments to establish a comprehensive rehabilitation centre and centre of excellence for spinal cord injury, intellectual disabilities, hemophilia, multiple disabilities, autism and other forms of impairment specific services. The centre of excellence to support capacity development of district and local level health workers on disability-related services provided at their level.
- b. Provincial government to ensure disability-related specialized services are provided at provincial hospitals. Provincial hospitals to be equipped and enhanced with additional facilities, special care units, and human resources to provide specialized services, treatment, and rehabilitation to persons with spinal cord injury, hemophilia, multiple impairments, intellectual disabilities, psychosocial disabilities, severe physical disabilities, and autism.
- c. Provincial government to ensure that all provincial health institutions are accessible to persons with disabilities and health workers are well trained to provide treatment, support, and special care to them as they come to take services.
- d. Provincial Government and Ministry of Social Development to allocate adequate budget for rehabilitation services, specialized services, and medicines for persons with disabilities.
- e. Provincial Government to provide capacity building to health workers at provincial, district and municipal level on disability issues, essential health services to be provided to spinal cord injury, psychosocial disability, intellectual disabilities, hemophilia, multiple disabilities and other disability category and the provision of respectful, empathetic and client-centred care to persons with disabilities.

**4. Strengthening the role of local governments to protect and meet the rights of people with severe and complete disability:**

- a. Local government to ensure that health institutions are accessible to persons with disabilities, and persons with severe and complete disabilities are prioritized in service delivery.
- b. Essential health care and primary treatment of persons with spinal cord injury, psychosocial disabilities, multiple impairments, and severe physical disabilities is available at local health

- facilities; with referral to higher level. Psychiatric services, counseling, therapeutic services, basic level rehabilitation services to be available at the district hospital.
- c. Municipalities to provide mental health and psychosocial disability awareness raising program at the community level on a regular basis.

## Annex 1: Documents Reviewed

Type of document	
Government of Nepal policies, laws and guidelines	<ul style="list-style-type: none"> <li>• Constitution of Nepal 2015 article 18, Article 31, Article 39 and Article 35, Nepal Law Commission, <a href="http://www.lawcommission.gov.np/np/archives/category/documents/prevaling-law/constitution/constitution-of-nepal">http://www.lawcommission.gov.np/np/archives/category/documents/prevaling-law/constitution/constitution-of-nepal</a></li> <li>• Rights of Persons with Disabilities Act, 2017 <a href="http://www.lawcommission.gov.np/np/category">http://www.lawcommission.gov.np/np/category</a></li> <li>• Bylaws on the Rights of Persons with Disabilities, 2020</li> <li>• Public Health Service Act, 2018</li> <li>• Ministry of Health and Population, National Health Policy 2019</li> <li>• Ministry of Health and Population, Disability Prevention and Rehabilitation Strategy 2016-2026</li> <li>• Ministry of Health and Population, National Guidelines for Disability Inclusive Health Services 2019-2030</li> <li>• Ministry of Women, Children and Senior Citizens, 2020, Guidelines for Stakeholders to work against COVID pandemic with special focus to the issues of persons with disabilities</li> <li>• Ministry of Health and Population, 2020, COVID related guidelines and updates. <a href="https://covid19.mohp.gov.np/">https://covid19.mohp.gov.np/</a></li> </ul>
International law	<ul style="list-style-type: none"> <li>• UN Convention on the Rights of Persons with Disabilities</li> </ul>
International evidence of the impact of COVID-19	<ul style="list-style-type: none"> <li>• WHO, 2020. <a href="https://www.who.int/emergencies/diseases/novel-coronavirus-2019/question-and-answers-hub/q-a-detail/q-a-coronaviruses">https://www.who.int/emergencies/diseases/novel-coronavirus-2019/question-and-answers-hub/q-a-detail/q-a-coronaviruses</a></li> <li>• <a href="https://www.worldometers.info/coronavirus/">https://www.worldometers.info/coronavirus/</a> retrieved on 19<sup>th</sup> October 2020.</li> <li>• UNDP, 2020, COVID 19, Socioeconomic Impact. <a href="https://www.undp.org/content/undp/en/home/coronavirus/socio-economic-impact-of-covid-19.html">https://www.undp.org/content/undp/en/home/coronavirus/socio-economic-impact-of-covid-19.html</a></li> <li>• World Bank, 2020, Global Economic Prospects. A World Bank Group, Flagship Report. <a href="https://www.worldbank.org/en/publication/global-economic-prospects">https://www.worldbank.org/en/publication/global-economic-prospects</a></li> <li>• How COVID impacts People with Disabilities, <a href="https://www.apa.org/topics/covid-19/research-disabilities">https://www.apa.org/topics/covid-19/research-disabilities</a></li> <li>• WHO, 2020, COVID 19 Disability Briefing. <a href="https://www.who.int/docs/default-source/documents/disability/covid-19-disability-briefing.pdf">https://www.who.int/docs/default-source/documents/disability/covid-19-disability-briefing.pdf</a></li> <li>• UNICEF, 2020, COVID 19 Response; Considerations for People with Disabilities. <a href="https://www.unicef.org/disabilities/files/COVID-19_response_considerations_for_people_with_disabilities_190320.pdf">https://www.unicef.org/disabilities/files/COVID-19_response_considerations_for_people_with_disabilities_190320.pdf</a></li> <li>• OHCHR. COVID-19 and the Rights of Persons with Disabilities. <a href="https://www.ohchr.org/Documents/Issues/Disability/COVID-19_and_The_Rights_of_Persons_with_Disabilities.pdf">https://www.ohchr.org/Documents/Issues/Disability/COVID-19_and_The_Rights_of_Persons_with_Disabilities.pdf</a></li> <li>• National Centre for Promotion of Employment for Disabled People (NCPEDP), 2020, LOCKED DOWN AND LEFT BEHIND (A Report on the Status of Persons with Disabilities in India During the COVID – 19 Crisis), accessed 27<sup>th</sup> Oct 2020. <a href="https://www.ncpedp.org/sites/all/themes/marinelli/documents/Report-locked_down_left_behind.pdf">https://www.ncpedp.org/sites/all/themes/marinelli/documents/Report-locked_down_left_behind.pdf</a></li> </ul>
Reports on the impact of COVID-19 in Nepal	<ul style="list-style-type: none"> <li>• UNDP, 2020, Rapid Assessment of Socio-Economic Impact of COVID-19 in Nepal</li> <li>• National Federation of the Disabled, 2020, Impact of COVID 19 Pandemic on Persons with Disabilities, A Rapid Assessment Report. <a href="https://nfdn.org.np/ne/impact-of-covid-19-pandemic-and-lockdown-on-persons-with-disabilities-a-rapid-assessment-report">https://nfdn.org.np/ne/impact-of-covid-19-pandemic-and-lockdown-on-persons-with-disabilities-a-rapid-assessment-report</a></li> <li>• Humanity and Inclusion, April 2020, Nepal COVID-19 rapid need assessment report.</li> <li>• <i>Krishna Gahatraj</i>, from <i>Nepal's National Association of the Physical Disabled</i>, Dalits with disabilities hit hardest by lockdown in Nepal, <a href="#">NEWS AND BLOGS</a>   04 AUG 2020, accessed 27<sup>th</sup> Oct 2020 from <a href="https://minorityrights.org/2020/08/04/nepal-lockdown/">https://minorityrights.org/2020/08/04/nepal-lockdown/</a></li> </ul>

Evidence on disability in Nepal	<ul style="list-style-type: none"> <li>• National Federation of the Disabled, 2019, Nepal National Report on Disability, unpublished.</li> <li>• A Report on Pilot Study of National Mental Health Survey, Nepal. Government of Nepal, Nepal Health Research Council, 2018, <a href="http://nhrc.gov.np/wp-content/uploads/2019/04/Pilot-national-mental-health.pdf?fbclid=IwAR0SgJpRCrXQmpHk5EkFAC3lqQhtqujAofUwHtJW00fGlXGlyrqRFp2_5U">http://nhrc.gov.np/wp-content/uploads/2019/04/Pilot-national-mental-health.pdf?fbclid=IwAR0SgJpRCrXQmpHk5EkFAC3lqQhtqujAofUwHtJW00fGlXGlyrqRFp2_5U</a></li> <li>• Puri M, Misra G, Hawkes S. Hidden voices: Prevalence and risk factors for violence against women with disabilities in Nepal. BMC Public Health. 2015;15:261. Accessed 27<sup>th</sup> Oct 2020 from file:///D:/1.%20Rajendra's%20Working%20Folder/Downloads/s12889-015-1610-z.pdf</li> <li>• Marie Stopes Nepal. Integrating SRH needs of Young People with Disability within Youth Friendly SRH, accessed 27<sup>th</sup> Oct 2020 from <a href="http://myhealthrightsfuture.com/assets/day-2%2C-msi--integrating-srh-needs-of-young-people-with-disability-within-youth-friendly-srh-service.pdf">http://myhealthrightsfuture.com/assets/day-2%2C-msi--integrating-srh-needs-of-young-people-with-disability-within-youth-friendly-srh-service.pdf</a></li> </ul>
Other research	<ul style="list-style-type: none"> <li>• David N Gellner. Caste, Ethnicity and Inequality in Nepal, <a href="https://www.researchgate.net/publication/262127102_Caste_Ethnicity_and_Inequality_in_Nepal">https://www.researchgate.net/publication/262127102_Caste_Ethnicity_and_Inequality_in_Nepal</a></li> </ul>
Sources of information on specific types of impairments	<ul style="list-style-type: none"> <li>• <a href="https://www.cdc.gov/ncbddd/hemophilia/inheritance-pattern.html">https://www.cdc.gov/ncbddd/hemophilia/inheritance-pattern.html</a></li> <li>• <a href="https://www.mayoclinic.org/diseases-conditions/spinal-cord-injury/symptoms-causes/syc-20377890">https://www.mayoclinic.org/diseases-conditions/spinal-cord-injury/symptoms-causes/syc-20377890</a></li> <li>• <a href="https://www.cdc.gov/ncbddd/hemophilia/facts.html">https://www.cdc.gov/ncbddd/hemophilia/facts.html</a></li> <li>• What is Psychosocial Disability and how can the NDIS help ? <a href="https://chessconnect.org.au/what-is-psychosocial-disability-and-how-can-the-ndis-help/">https://chessconnect.org.au/what-is-psychosocial-disability-and-how-can-the-ndis-help/</a></li> <li>• <a href="https://www.psychiatry.org/patients-families/intellectual-disability/what-is-intellectual-disability">https://www.psychiatry.org/patients-families/intellectual-disability/what-is-intellectual-disability</a></li> <li>• Identifying Children with Intellectual Disability <a href="https://www.ejinsight.com/eji/article/id/1822005/20180420-identifying-children-with-intellectual-disability">https://www.ejinsight.com/eji/article/id/1822005/20180420-identifying-children-with-intellectual-disability</a></li> </ul>

## Annex 2: Secondary Stakeholders Interviewed

Figure 4: List of health professionals interviewed

SN	Position	Sex	Health Facility	Province
1	Acting Chief Medical Superintendent	Male	Gaur District Hospital, Rautahat District.	Province 2
2	Medical Officer	Male	Jaleswor Hospital, Dhanusa District	Province 2
3	Senior Health Administrator	Male	Lumbini Province Hospital	Province 5
4	Health Assistant	Male	Kopawa Health Post	Province 5
5	Senior Medical Record Inspector and Information officer	Male	Mechi Zonal Hospital, Jhapa District	Province 1
6	Senior Hospital Nursing	Female	Koshi Zonal Hospitals, Morang District	Province 1
7	Spinal Cord Injury Specialist	Male	Spinal Cord Injury Rehabilitation Center, Kavre District	Bagmati Province
8	Chief of Health Section	Male	Banganga Municipalities	Province 5

Figure 5: List of Disabled Peoples Organisations interviewed

SN	Organization	Position	Sex	Province
1	Spinal Cord Injury Group	President	Male	Bagmati
2	Baradashi Disability Campaign	President	Male	Province 1
3	Bardiya Disability Rehabilitation Center	President	Male	Province 5
4	Parents Association of Intellectual Disabilities	President	Male	Province 1
5	Intellectual Disability Parents Association	President	Male	Province 2
6	Parents Association of Mentally Retarded	Presidents	Male	Province 5
7	Nepal Hemophilia Society	President	Male	Kathmandu
8	Hemophilia Society Nepal	President	Male	Province 2
9	National Federation of the Disabled Nepal	President	Male	Kathmandu
10	KOSHIS	Member	Male	Kathmandu
11	Province Branch of KOSHIS – Province 1	Member	Female	Province 1

Figure 6: List of government agencies interviewed

SN	Position	Government Agency	Level
1	Director	Ministry of Health and Population, Epidemiology and Disease Control Division, Teku	Federal Level
2	Section Chief	Ministry of Health and Population, Policy Section	Federal Level
3	Senior Health Administrator, Section Chief	Ministry of Health and Population, Leprosy Control and Disability Management Section	Federal Level
4	Division Chief	Ministry of Health and Population, Population Division	Federal Level
5	Section Chief	Ministry of Women Children and Senior Citizen, Disability Rights Promotion Section.	Federal Level
6	Executive Chief	Municipality Federation	Local Level
7	Director	Health Directorate Province 1	Province Level
8	Director	Health Directorate Province 5	Province Level

9	Division Chief	Social Development Ministry, Health Division Province 2	Province Level
10	Section Chief	Social Development Ministry, Disability and Senior Citizen Section, Province 1	Province 1
11	Section Chief	Women Children and Senior Citizen, Shivaraj Municipality	Local Level
12	Vice Mayor	Shivaraj Municipality	Local Level