

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





Objectives of the study

Assess the impact of the COVID-19 pandemic on the life of people living with severe and complete disabilities:

- Identify the problems and barriers faced in accessing essential health care
- Identify critical gaps in health services delivered by the MoHP, gaps in coordination with other essential service providers, and areas of improvement
- Generate facts for policy advocacy
- Make recommendations

Five target groups:

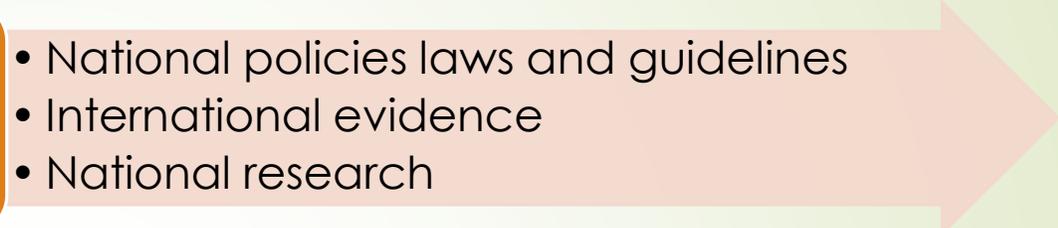
- people with spinal cord injury
- people with haemophilia
- people with psychosocial disabilities
- people with intellectual disabilities
- people with multiple disabilities

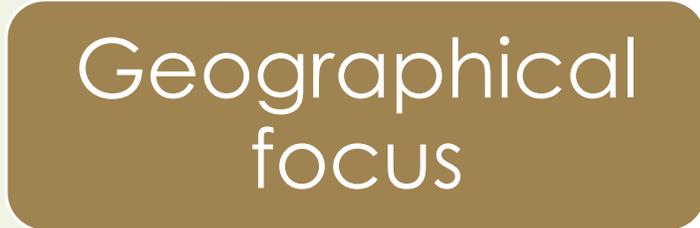


Methodology: Qualitative case study

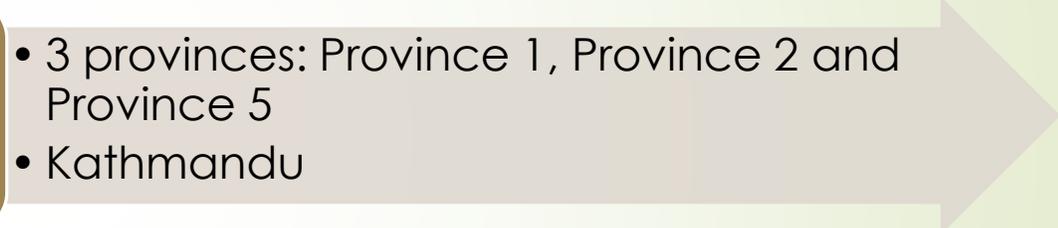


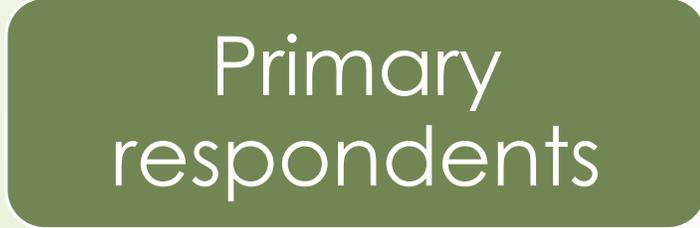
Literature review

- National policies laws and guidelines
 - International evidence
 - National research
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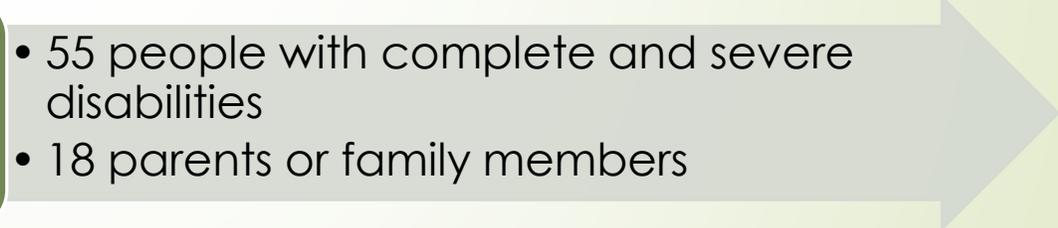


Geographical focus

- 3 provinces: Province 1, Province 2 and Province 5
 - Kathmandu
- 



Primary respondents

- 55 people with complete and severe disabilities
 - 18 parents or family members
- 



Secondary respondents

- 8 health providers
 - 12 government stakeholders
 - 11 Disabled Peoples Organisations
- 



Why people with disability are especially at risk of COVID-19

World Health Organization:

- ▶ 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.
- ▶ 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.



Policy context in Nepal

Constitution

Rights of Persons
with Disability Act,
2017

Health,
rehabilitation and
social protection
bylaws, 2020

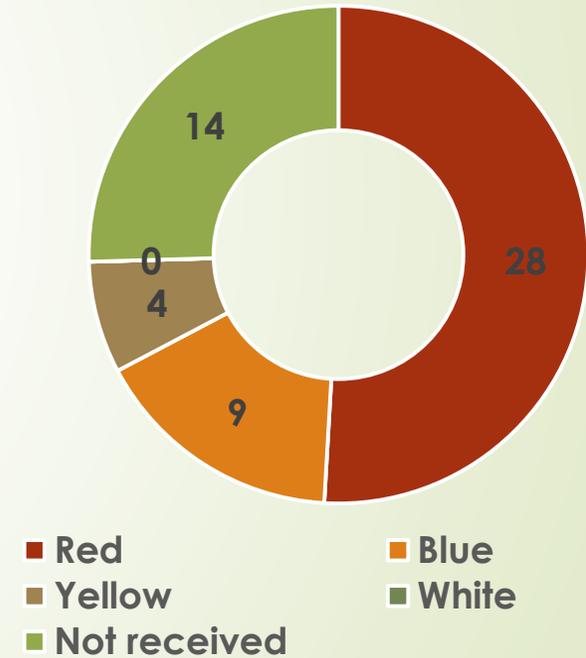
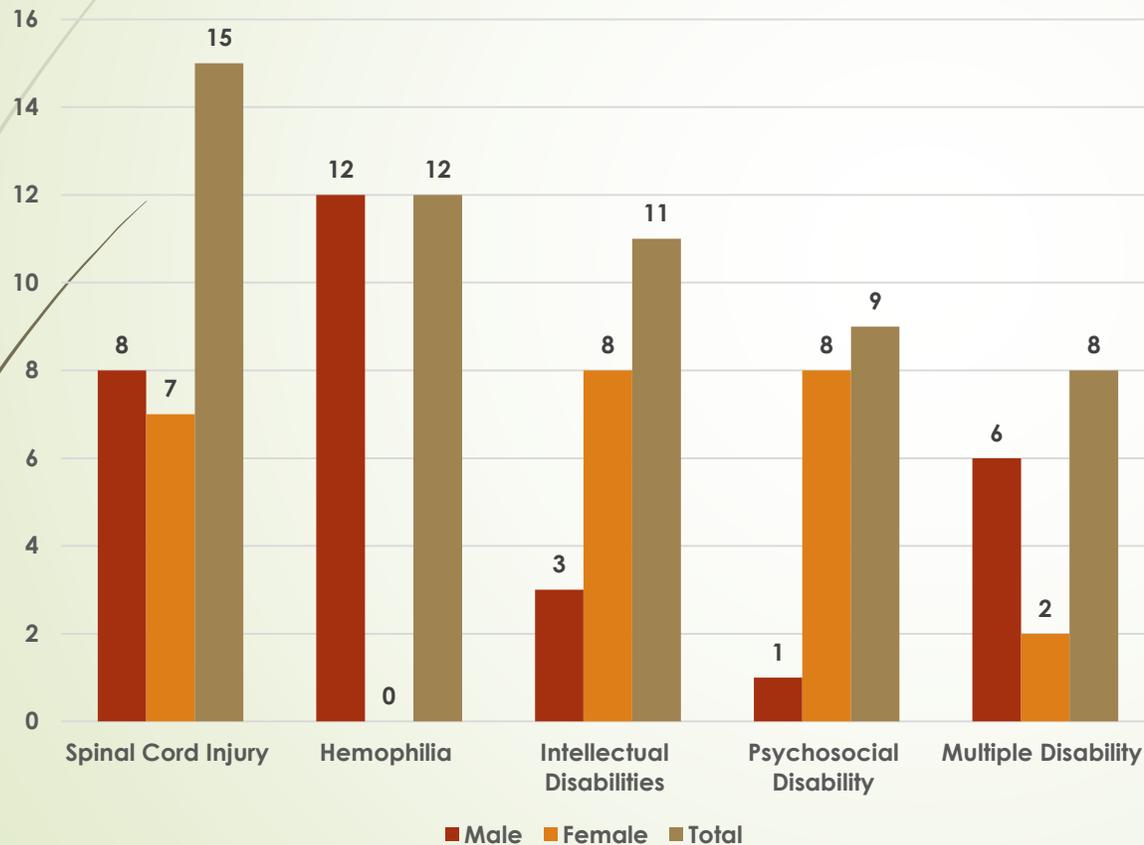
National Health
Policy, 2019

Disability Prevention
and Rehabilitation
Strategy 2016-2026

National Guidelines
for Disability
Inclusive Health
Services, 2019-2030

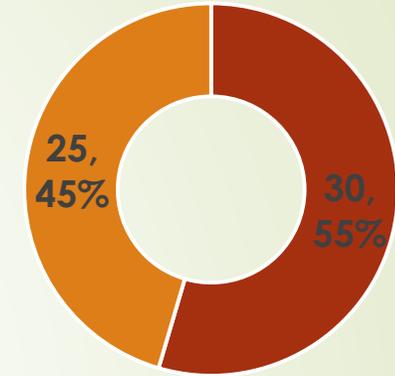
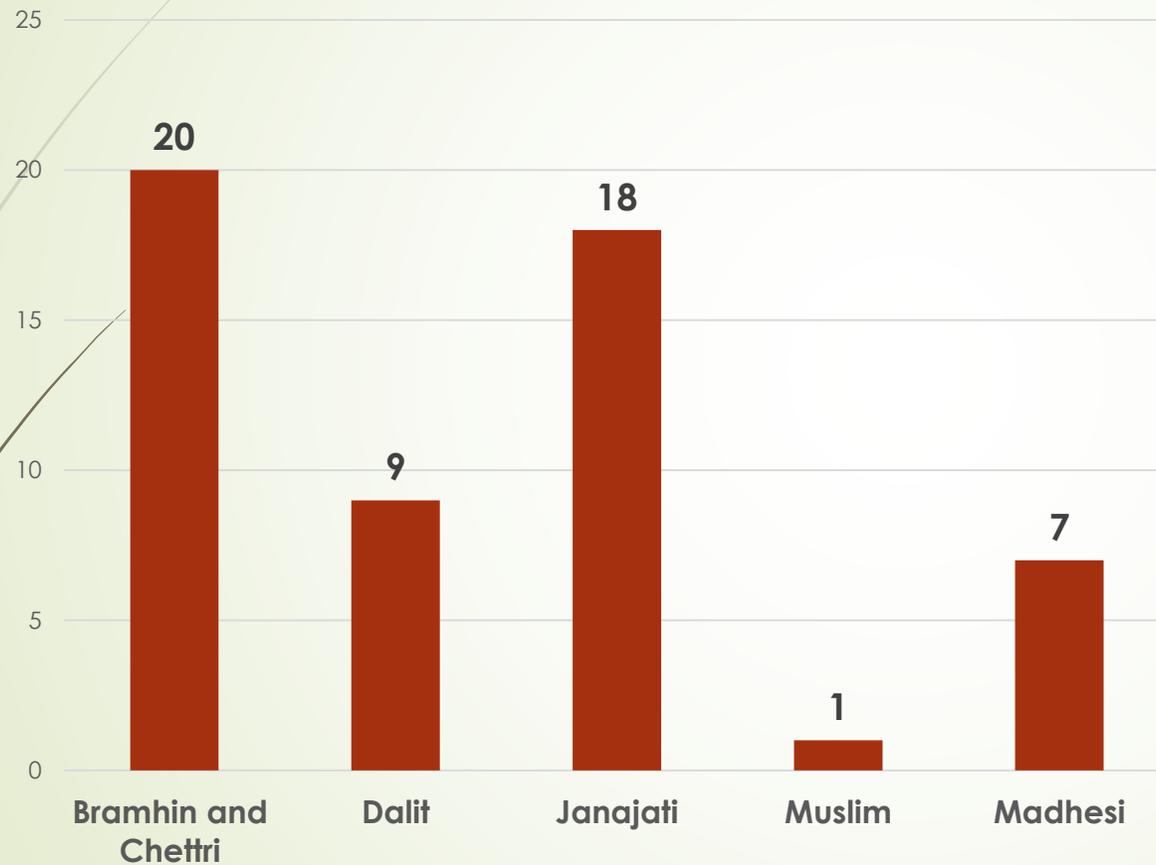
Strong policy base but weak implementation

Primary respondents by type of disability and ID card

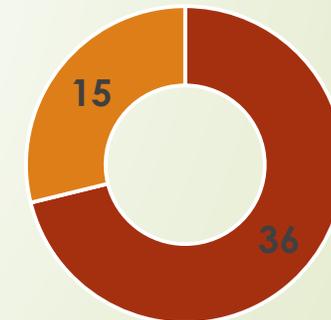


Red = Complete impairment
 Blue = Severe impairment
 Yellow = Moderate impairment
 White = Mild impairment

Respondents by social and economic background



■ Male ■ Female



■ Have some forms of occupation
■ No occupation

Evidence on the impact of COVID-19 in Nepal

Study	Findings
NFDN (2020), rapid assessment of impact of COVID-19 on PWD	<ul style="list-style-type: none">• 41% little awareness and 6% completely unaware of COVID-19• 42% little knowledge and 7% complete lack of knowledge on how to stay safe from infection• 45% had regular health services or medicines interrupted• 45% in urgent need of hygiene materials• Greater severity of impairment the greater the barriers to access information
Humanity and Inclusion (2020), COVID-19 rapid need assessment	<ul style="list-style-type: none">• 36% of PWD facing barriers to access COVID-19 related information• 40% of PWD reported dire need of sanitary and hygiene materials such as sanitary pads, catheter, adult diapers• health services for PWD should continue to operate• need for psychosocial support



Key findings of the case study



Common experiences

Background context:

- ▶ High dependency: 82% depend on their family for food, clothing, toileting, bathing, mobility and participation in the community.
- ▶ 71% need regular health service - medical check-up, medicine and supplies, counselling, psychosocial therapy.
- ▶ 27% need health services sometimes.

Pandemic has resulted in:

- ▶ Two-thirds in financial crisis.
- ▶ 13 (24%) regular health services completely interrupted.
- ▶ 37 (67%) very few health services continued.
- ▶ 87% no personal protective hygiene materials such as face masks, and no access to public health information on how to stay protected.
- ▶ 15 no access to hygiene materials
- ▶ 31 depend on assistive devices but have no access to repairs or replacements.
- ▶ 19 out of 34 no longer receiving social assistance

Persons with spinal cord injury

- ▶ Lack of access to health and hygiene materials to manage urine, menstruation, pressure sores and defecation.
 - ▶ Lack of access to health providers to manage pressure sores.
- Additional health complications:
- ▶ Increased beds sores.
 - ▶ Extreme pain.
 - ▶ Urine infection
 - ▶ Anxiety and depression

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

- ▶ Rights of Persons with Disabilities Act, 2017 provides for free anti-hemophilic factor.
- ▶ Not on essential drug list.
- ▶ Donations from Nepal Hemophilia Society.
- ▶ Stocks exhausted and not replenished.
- ▶ MoHP budget allocation NRs 20.6 million for FY 2020/21.
- ▶ Province 1, Bagmati Province, Gandaki Province and Sudurpaschim Province budget allocation.
- ▶ Province 1 procurement but no other.
- ▶ Supply problem persists.
- ▶ Shortages of factor is inflicting additional complications: extreme pain, damage to joints, lost physical mobility

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

- ▶ Stigma and discrimination.
- ▶ Hidden from society.
- ▶ 7 out of 9 can no longer access regular doctors, medicine, treatment, counseling and psychiatrists.
- ▶ Medicine is not available in the market, and travel restrictions and fear of COVID-19 has added to their troubles.
- ▶ Pandemic has increased depression, anxiety and stress

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

- ▶ Do not understand risks and implications of COVID-19
- ▶ Challenging to physically distance, wear mask and sanitizer
- ▶ Difficult to organize PCR test
- ▶ No home based care
- ▶ Poor quality care: doctors dispense medicine without a diagnosis; staff not trained.

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.

Persons with multiple disabilities

- ▶ Only urban hospitals.
- ▶ High out of pocket costs for people from rural areas.
- ▶ Services interrupted by COVID-19
- ▶ Uncertainty on procedures if person infected and has to be admitted to hospital:
 - ▶ Can caretaker attend
 - ▶ Will they receive PPE
 - ▶ Are health staff trained to care for a person with multiple disabilities
 - ▶ Will they receive care free of discrimination

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.



Reflections of health providers and government authorities

- ▶ Limited response from health service.
- ▶ No guidelines or training of staff on care of COVID-19 +ve persons with disability.
- ▶ Piecemeal response from provincial and municipal governments.
- ▶ No instructions to local health facilities to regularly check up on persons with severe and complete disabilities; provide medicines and hygiene material.
- ▶ Significant gaps in services at all levels; policy not operationalized.



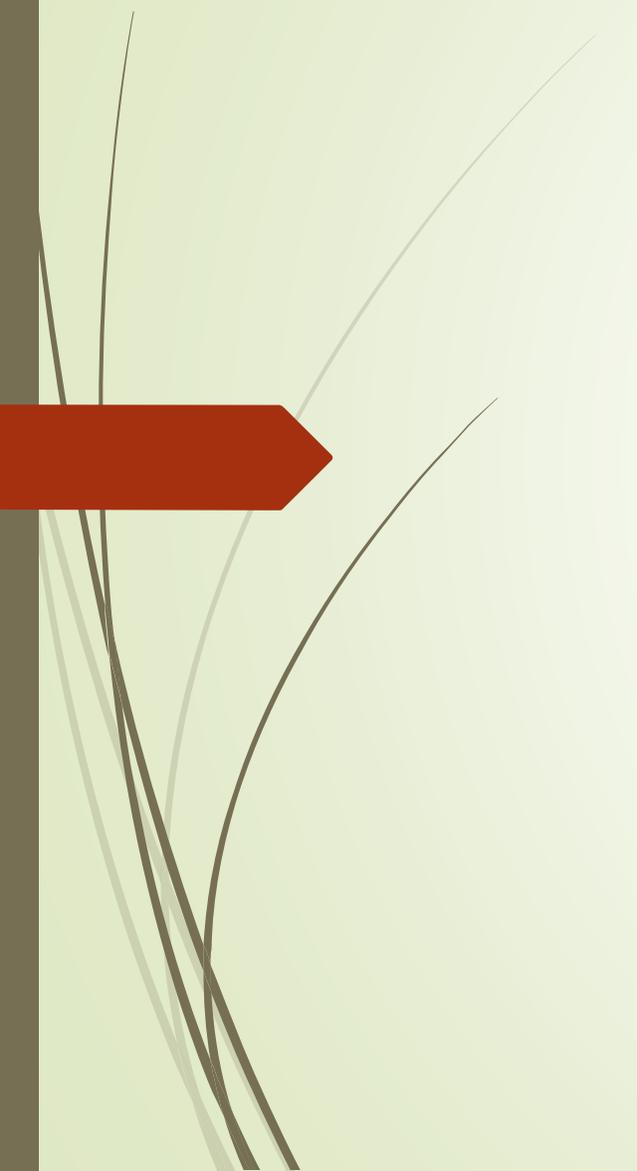
Recommendations for immediate action

1. Access to essential health care, public health information, medicines, assistive devices and health and hygiene related supplies.
2. Disability inclusive COVID-19 testing and treatment.
3. Anti-hemophilic factors for persons with hemophilia.
4. Information and social support to be provided to persons with disability and their families in each hospital.
5. Social protection of persons with severe and complete disability to offset the impact of the pandemic.



Recommendations to strengthen the health system and deliver policy provisions

1. Dissemination of federal policies and acts.
2. Federal level health systems strengthening to support disability inclusive health services.
3. Provincial level health system strengthening to support disability inclusive health services.
4. Strengthen the role of local governments to protect and meet the rights of people with severe and complete disability.



Thank you