



Nepal Health Sector Support Programme III (NHSSP – III)

Policy Brief Impact of COVID-19 on People with Complete and Severe Disabilities



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Impact of COVID-19 on People with Complete and Severe Disabilities

the pandemic is hurting the poorest, the least empowered and most vulnerable the hardest

Background

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.

The study

Led by Ministry of Health and Population, undertaken by National Federation of the Disabled Nepal, and technically supported by UK-aid funded Nepal Health Sector Support Programme. The study

- documents the impact of the pandemic on access to essential health services and care of people with severe and complete disabilities
- 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.
- presents recommendations to address the gaps.

Policy context

Strong policy provisions, disability related health strategies and technical guidelines have been introduced. Implementation is below expectation and hindering access to essential health services and rehabilitation.

Common experiences

The majority of persons with severe and complete disabilities depend on their families for 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.

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

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, 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 need a range of medical supplies and hygiene materials 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 need regular care at a hospital or health facility. Since COVID-19, respondents have not been able to access treatment of their bed sores, leading to increased sores and extreme pain.

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 for example, urine infection, extreme pain, 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: The Rights of Persons with Disabilities Act, 2017, provides 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 and the only source was from the NGO, Nepal Hemophilia Society, which was collecting a very limited number from international donors.

With lockdown, the stock of factor 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 anti-hemophilic factors using the fast track process. Other provinces have not yet used their budget allocations and the supply problem remains.

Additional health complications: The shortages of factor have left persons living with hemophilia facing serious complications, including regular bleeding, extreme pain and damages to joints and loss of 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 multiple disabilities

Access to health services: Services needed by people with multiple disabilities are only available in urban areas. The out of pocket and opportunity costs are very high especially for those from rural areas. Most of the health-related services taken 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, leaving patients doubly impacted.

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 professionals and government authorities

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.

The policy provisions for people with disabilities are yet to be fully operationalized 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.

What needs to be done now

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.
- 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.

What needs to be done to strengthen the health system and deliver on policy provisions

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 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.