

Issue paper on participation of persons with disabilities in the provision of inclusive healthcare COVID-19 processes in Lesotho

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Abstract

The Lesotho National Federation of Organizations of the Disabled (LNFOD) is the umbrella body of organizations of persons with disabilities in Lesotho. Its mission is to advocate for, promote, protect and defend the rights of persons with disabilities and their families through training, emotional support and by representing their interests to government, private sector, development partners and the wider community. LNFOD is a leading umbrella DPO working to promote the rights of persons with disabilities including the right to inclusive healthcare services for persons with disabilities for more than two decades. From the foregoing, LNFOD has been supported by the United Nations resident Coordinator's office to develop an issue paper on the need for participation of persons with disabilities in inclusive healthcare COVID-19 processes in Lesotho.

In this issue paper on promotion and participation of persons with disabilities in inclusive healthcare services for all, LNFOD argues that the COVID-19 has exacerbated the pre-existing social, economic and political barriers which have been hindering full participation and inclusion of persons with disabilities in the health sector in Lesotho. The paper argues that COVID-19 has compounded the situation of persons with disabilities in terms of access to healthcare due to health restrictions imposed to save lives and lack of access to information and communication relating to health, which persons with disabilities could have used to save lives, and protect themselves from contracting coronavirus. Although COVID-19 has disrupted our health system and created uncertainty in the provision of quality health care services for the citizens of Lesotho, LNFOD argues that full participation and inclusion of persons with disabilities in the COVID-19 and health sector decision-making processes, can help Lesotho to build back better leaving no one behind in the fight against COVID-19 pandemic. Finally, the issue paper outlines the actions and recommendations that must be implemented in order to mitigate the negative effects of COVID-19 on the healthcare, life and safety for persons with disabilities.

Introduction

On 30 January 2020, WHO declared the COVID-19 outbreak a public health emergency of international concern.¹In response, Lesotho has developed an Integrated National COVID-19 Plan and the National Preparedness and Response Plan for COVID-19.²Under the leadership and coordination of the United Nations Resident Coordinator and in line with principles of 'Delivering as One', the UN Lesotho has established a response team, that is aligned to the United Nations Development Assistance Framework (UNDAF) pillars, to support the national response to COVID-19.³By adopting the "One Health Approach" and "Whole-of-Society Approach", the UN support focuses on strengthening national coordination and leadership, national emergency response and health systems to ensure inclusive and equitable access to facilities by all, particularly vulnerable segment of society.

Interaction with organizations of persons with disabilities reveal that limited disability awareness and capacity among COVID19 coordinating and decision-making bodies and the society at large has excluded

1 World Health organisations 'declaration of the outbreak as a public concern and a pandemic'
<https://www.who.int/emergencies/diseases/novel-coronavirus-2019/events-as-they-happen> (accessed 22 April 2021).

2 UNDP terms of reference for the development of disability issue papers and communication materials in accessible formats.

3 UNDP terms of reference for the development of disability issue papers and communication materials in accessible formats.

persons with disabilities from participating and benefiting from COVID-19 preventive and recovery processes on an equal basis with others.⁴

It is against this background that the United Nations Resident Coordinator's office supported LNFOD to develop disability issue papers and accessible communication materials for promotion of inclusion of persons with disabilities in COVID-19 processes in Lesotho.

The purpose of this issue paper therefore is to promote participation and inclusion of persons with disabilities in the inclusive healthcare and COVID-19 processes.

The objective is to prepare the issue paper on participation and inclusion of persons with disabilities in inclusive healthcare and COVID-19 process to support policy actors and programmers in the health sector to include persons with disabilities in the COVID-19 interventions.

This issue paper is divided in five sections, the first section deals with the summary; the second section focuses on the introduction, the third section deals with the context; the fourth section elaborates on the impact of COVID-19 on the healthcare services for persons with disabilities; and the fifth section concludes the paper with actions and recommendations which may be taken to mitigate the effects of COVID-19 on health of persons with disabilities and promotion of the inclusion of persons with disabilities in the health sector of Lesotho.

Context

The research shows that, even under ordinary circumstances, persons with disabilities are less likely to access healthcare, education, employment, and to participate in the community.⁵ They are more likely to live in poverty, experience high rates of violence, neglect, abuse, and are usually the most marginalized in the crisis-affected communities.⁶

COVID-19 has compounded this situation, disproportionately affecting persons with disabilities directly and indirectly.⁷

The key barriers which Basotho with disabilities encounter when seeking inclusive healthcare services from the health facilities include inaccessible physical infrastructure that hinders their access; lack of accessible information and communication public health materials, which usually promote public health illiteracy among women and girls with disabilities about their sexual and reproductive health services; and negative attitudes from the health workers which prevent persons with disabilities from accessing health services on an equal basis with others.⁸

4 As above.

5 C Johnstone 'Ministry of Social Development situational analysis report on persons with disabilities' (2019) at 20.

6 C Johnstone 'Ministry of Social Development situational analysis report on persons with disabilities' (2019) at 25.

7 Interview with the DPOS (30 April 2021).

8 C Johnstone 'Ministry of Social Development situational analysis report on persons with disabilities' (2019) at 35.

According to the (2016) census report, Basotho with disabilities who are in need of public health services are estimated at 2.5% of the total population of Lesotho.⁹ This is a significant number of the citizens of Lesotho which the health services should effectively respond to their health needs.

Lesotho has 16 hospitals and 276 health facilities that provide healthcare services to all people living across the ten districts of Lesotho.¹⁰

It is difficult and challenging for persons with disabilities to access healthcare services provided by the said hospitals and health centres due to the attitudinal and environmental barriers facing persons with disabilities, thereby leading to poor health outcomes for persons with disabilities.¹¹

The right to health was internationally recognized for the first time in 1948 under the Universal Declaration of Human Rights, which advocates for equitable access to healthcare services.¹² This right is now enshrined under a number of international human rights to which Lesotho is a state party. As a human right, the right to health is universal, indispensable and interconnected to other human rights. How this right applies to people with disabilities and states' responsibilities in this regard are clearly articulated under the United Nations Convention on the Rights of People with Disabilities (CRPD).¹³ CRPD states as follows:

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure equal access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation.

Issue: How Has COVID-19 Impacted Access To Healthcare Services By People With Disabilities In Lesotho?

This issue paper argues that COVID-19 has disproportionately affected persons with disabilities in terms of access to healthcare and life saving information.

Lack of public health information and communication materials in accessible formats for persons with disabilities: following the declaration of a national emergency in March 2020, the Government of Lesotho established the National Covid-19 Secretariat (NACOSEC), which works with the Ministry of Health to coordinate COVID-19 related interventions in Lesotho.¹⁴ One of NACOSEC's key roles is to educate the public about COVID-19 measures so that the public may protect themselves from contracting this deadly disease.¹⁵ Nevertheless, the Ministry of Health and NACOSEC did not produce information and

9 Bureau of Statistics population housing census report (2016).

10 UNDP 'public health sector expenditure review' (2017)

11 Sintef 'Living conditions among persons with disabilities' (2011) at 40.

12 UDHR 1948 Art 25

13 UNCRPD Art 25

14 www.nacosec.org.ls.

15 Rabasotho Moeletsi 'LNFOD lobbying meeting with NACOSEC on inclusion of persons with disabilities in COVID-19 interventions' (http://www.infod.org.ls/uploads/1/2/2/5/12251792/disability_lesotho_august_2020.pdf) accessed 25 April 2020).

communication materials in accessible formats for persons with disabilities, which could equally help persons with disabilities to access information in a timely manner.¹⁶

Persons with disabilities further report that it is difficult, if not impossible, for the visually impaired, the deafblind, and for persons with intellectual disabilities to access health information from the communication channels of the NACOSEC because their website is not accessible to the screen readers, and all the information posted on their communication channels is produced in colours and pictures, which makes it hard for persons with visual disabilities to follow what is being reported.¹⁷

This oversight compounded the situation for persons with disabilities, especially those who need information in accessible formats, to be more exposed to COVID-19 due to a lack of COVID-19 preventative health information. Many persons with disabilities could not benefit from NACOSEC, the Ministry of Health and development partners' efforts to educate the public on how to remain safe during the pandemic. In addition, the exclusion of persons with disabilities in the production of accessible communication materials was compounded by the lack of equitable representation of persons with disabilities in the Ministry of Health and NACOSEC management teams responsible for public health awareness.¹⁸

It is important to note that persons with disabilities, through their representative organisations, did not participate in the Ministry of Health and NACOSEC decision making processes, which decided upon appropriate interventions to protect lives and ensure the safety of the nation, despite the several attempts initiated by their organisations.¹⁹

This simply means that lack of participation of persons with disabilities in the above-mentioned decision-making processes in relation to health denied Lesotho an opportunity to design and implement disability inclusive COVID-19 interventions, which could have reached all, including persons with disabilities.²⁰

Public health COVID-19 regulations

Ever since the enactment of the Public health COVID-19 regulations that sought to curb the spread of COVID-19 in March 2020, persons with disabilities were presented with new barriers that negatively affected the health, social, economic and political life of persons with disabilities.²¹

16 Rabasotho Moeletsi 'LNFOD lobbying meeting with NACOSEC on inclusion of persons with disabilities in COVID-19 interventions' http://www.infod.org.ls/uploads/1/2/2/5/12251792/disability_lesotho_august_2020.pdf)accessed 25 April 2020).

17 Interview with the DPOS 30 April 2021.

18 Interview with the DPOS (30 April 2021).

19 Rabasotho Moeletsi 'LNFOD lobbying meeting with NACOSEC on inclusion of persons with disabilities in COVID-19 interventions' http://www.infod.org.ls/uploads/1/2/2/5/12251792/disability_lesotho_august_2020.pdf)accessed 25 April 2020).

20 Rabasotho Moeletsi 'LNFOD lobbying meeting with NACOSEC on inclusion of persons with disabilities in COVID-19 interventions' http://www.infod.org.ls/uploads/1/2/2/5/12251792/disability_lesotho_august_2020.pdf)accessed 25 April 2020).

21 Interview with the DPOS 30 April 2021.

Persons with disabilities said that regulations that require physical distancing threatens their personal assistance service, which they need when interacting with the society, as their personal assistants were not recognized by the regulations.²²

It was difficult for some persons with disabilities to wear face masks due to health risks from underlying conditions.²³

In addition, the deaf community report that the wearing of face masks makes it quite difficult for them to access health, social and other services since they cannot properly communicate, and lip read what is being said by the service provider. ²⁴The requirement to wear masks hindered them from communicating and interacting with the healthcare service providers thereby increasing their chances of being excluded from accessing health services on an equal basis with others.

Pursuant to these regulations, new rules were informally promulgated by different healthcare centers to avoid and minimize the spread of the disease. For example, most health care centers restricted the number of patients who can access services on daily basis. Patients were then required to queue outside the health center's yard where their body temperatures are measured after which they will be allowed to enter the premises strictly individually. These new regulations were not effectively communicated with actual and potential patients as one would only know about them upon their arrival at the health center.

People with disabilities cry that new health regulations newly imposed as a result of COVID-19 significantly restricted their access to health centers. They report that due to disability related hardships they usually cannot arrive at the health centers very early. They reported that even assistance or support they used to enjoy from their loved ones' decrease because of the fear and stigma attached to the disease. (Although few did report that they received necessary support from their family members and friends who woke up early to stand in the queues on their behalf).

Visually impaired people and those with speech and hearing disabilities have also reported that they are usually humiliated at the health centers by the security officers as well as the health personnel who vehemently demand them to maintain physical distancing with their assistants, which is impossible without the health center providing the alternative support.

Access to COVID-19 treatment

As a National Response and Preparedness Strategy to COVID-19, The Ministry of Health identified isolation centers where COVID-19 patients could be safely treated without spreading the disease. These centers fall short of accessibility standards. That is, they are not physically accessible to people with some forms of disabilities such as visual and physical disability. Moreover, the health personnel in these centers are not disability oriented thus lack the requisite capacity to adapt necessary modifications in order to

22 Interview with the DPOS 30 April 2021.

23 Rabasotho Moeletsi 'LNFOD lobbying meeting with NACOSEC on inclusion of persons with disabilities in COVID-19 interventions' http://www.infod.org.ls/uploads/1/2/2/5/12251792/disability_lesotho_august_2020.pdf (accessed 25 April 2020).

24 Interview with NADL 30 April 2021.

effectively interact with people with disabilities. This means that where a person with disability is a COVID-19 patient, it is unlikely that they will get equal medical treatment.

Access to COVID-19 vaccine

In terms of access to COVID-19 vaccines, persons with disabilities report that it is going to be difficult for them to access vaccines on an equal basis with others because they have not been prioritized by the vaccine plans as people who should get the vaccine in the first groups of persons.²⁵ Persons with disabilities report that they have not received public health education about the COVID-19 vaccine so that they can make informed decisions and consent to vaccination should they get such an opportunity.

In conclusion, most of the barriers which persons with disabilities faced in terms of access to health services during COVID-19 point to the fact that the participation of persons with disabilities is crucial in the decision-making processes undertaken by the coordinating bodies.

If persons with disabilities, through their representative organisations, were given the opportunity to contribute towards how the health sector can be disability inclusive during COVID-19, many barriers could have been avoided and COVID-19 may not have compounded the situation of persons with disabilities in terms of access to health the way it did. LNFOD therefore appeals to the coordinating bodies, particularly the Ministry of Health, to promote good health and well-being of all persons by seeking participation of persons with disabilities in the provision of inclusive quality healthcare.

Recommendations

In order to minimize and eventually end health disparities by people with disabilities in access to healthcare services in Lesotho, during and post COVID-19 this paper proposes the following long-term and short-term solutions:

- 1. With the participation of people with disabilities in the decision-making and implementation processes, the health sector response to COVID-19 must adhere to universal design.** Universal Design is a principle first established under UNCRPD which suggests a proactive as opposed to reactive approach in design and provision of services. In terms of this principle, people with disabilities should be an integral part of the design of the healthcare service. In relation to this, healthcare entities should consult people with disabilities and or their representative organizations in order to identify which structural, environmental, financial and attitudinal adaptations should be made in order to effectively mainstream people with disabilities as equal consumers of health care services, whose health care needs should equally be met. When doing this, a blanket approach which treats people with disabilities as a homogeneous group should be avoided. Both women and girls with disabilities should be meaningfully consulted. In addition to this, universal guidelines on inaccessibility is a resourceful document. Data collection on who accesses services on a daily basis should be disaggregated with disability in order to track and or monitor as to whether people with disabilities (both men and women) are equally accessing healthcare services, and to support appropriate design. In line with the provisions of Persons with

²⁵ Interview with the DPOS 30 April 2021.

Disabilities Equity Act No24 of 2021, make action plans through which healthcare providers will include and mainstream people with disabilities within their services as well as a clear Monitoring and Evaluation tool that contains clear indicators on men and women with disabilities.

- 2. In terms of enacting disability inclusive public health COVID-19 regulations, it is proposed that the Ministry of Health and NACOSEC should employ draftsmen conversant with disability rights and involve persons with disabilities in the drafting process so that they can better advise how the regulations should be disability inclusive.** The regulations will now have either a section of disability in which the law will clearly outline how persons with disabilities should be protected by the regulations. This will reduce the inequalities suffered by people with disabilities when interacting with the service providers since the regulations will have provided guidance in terms of how persons with disabilities should be protected. Participation of persons with disabilities, through their representative organizations, should be ensured in the COVID-19 decision-making processes so that the issues pertaining to persons with disabilities in terms of health are addressed and included from the planning stage up to the final stages. This may help in preventing barriers which may emanate from the implementation of the health interventions for persons with disabilities. The provision of personal assistance service should be ensured to those participating in the decision-making bodies to enable persons with disabilities to participate without any disadvantage caused by impairments.
- 3. Information and communication about COVID-19 should be availed in accessible formats to people with diverse disabilities.** In Braille, large print, audio, sign language interpretation as well as in a local language (e.g., Sesotho or Sephuthi), as most people with disabilities do not have a good command of English. Information can also be availed in simplified messages for persons with intellectual and psychosocial disabilities. Knowledge is power, and therefore persons with disabilities will be equally empowered and feel accepted and respected by the Ministry of Health if the information is accessible for all including people with disabilities. Cooperation with disability representative organization is very important here.
- 4. It is also recommended that both quarantine and isolation centers be moved to disability friendly facilities or be modified in line with guidelines on accessibility. Health personnel within these facilities should be sensitized and capacitated on how to handle people with disability.** This will enhance access to COVID-19 related health care services for persons with disabilities. Provision of reasonable accommodations for people with disabilities within the health care centers is the easiest, fastest and the most affordable measure to include people with disabilities. Reasonable accommodation in this regard means measures which may be put in place to adjust and modify services provided in order to ensure that persons with disabilities equally get the service in question. It is recommended those in charge of the health facilities first build the capacity of health personnel on disability issues and how to meet the needs of patients with disabilities on a daily basis. Alternatively, in order to effectively provide disability related accommodations, it is recommended that the health personnel consult representatives of people with disabilities beforehand and or enquire from the disabled patients on how they can reasonably accommodate them in order to meet their health needs. Reasonable accommodation

simply requires modifications of normal modes of service delivery to meet the needs of individuals. This may include but not limited to allowing people with disabilities and their personal assistants to exceptionally be allowed to keep physical contact

5. It is recommended that health personnel identify and allow people with disabilities to jump long queues in order to make sure that they access health care services during COVID-19.
6. It is recommended that health personnel should adopt alternative forms of communication including a sign language interpretation and/or specialized writing for some patients with speech and hearing disabilities.
7. It is recommended that where health care facilities are not physically accessible, health personnel should consider moving consultation rooms and dispensaries to accessible rooms or giving healthcare services to a patient with disabilities at a more convenient place in a given time
8. It is further recommended that health care providers communicate with the representative of people with disabilities before making changes and communicating the changes and adaptations with potential clients' community councils and/or other effective means.

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