

# Lest We Forget | COVID-19, Persons with Disabilities and an (Un)Inclusive Healthcare System

**V I D H |** Centre for  
Legal Policy





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Any errors are the authors' alone.

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# I. Introduction

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## A. Background and Context

According to the World Health Organisation ('WHO'), over 1 billion people are estimated to experience disability.<sup>1</sup> In recent times, the number of people experiencing disability on the global level is on the rise due to an increase in the incidence of chronic health problems as well as population ageing<sup>2</sup>—an estimated 46% of older people aged 60 years and above have disabilities,<sup>3</sup> 1 in every 5 women is likely to experience disability during her lifetime, and 1 in every 10 children is a child with a disability.<sup>4</sup> When it comes to India, 2.2% of the population is estimated to live with some form of disability, according to the census conducted in 2011.<sup>5</sup>

Of the world's population that is estimated to experience disability, 3.8% require healthcare services.<sup>6</sup> While persons with disabilities are a heterogeneous group, with diverse needs and concerns, they tend to have additional healthcare needs when compared with persons without disabilities. This includes both routine requirements, and requirements uniquely linked to their specific impairment.<sup>7</sup>

Despite this, persons with disabilities have not been recognized as a population group which specifically requires the attention of public healthcare services, and healthcare services tend to be inaccessible to them.<sup>8</sup> For example, adults with disabilities are more likely to skip or delay seeking services for their healthcare needs because of the high associated costs, and women with disabilities, specifically women with mobility impairments, are less likely to receive reproductive healthcare services.<sup>9</sup>

Although India has a law on the rights of persons with disabilities, which includes barrier-free access to healthcare services, in the form of the Rights of Persons with Disabilities Act, 2016 ('RPwD Act'),<sup>10</sup> such barriers continue to persist. Further, the pre-existing challenges to

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<sup>1</sup> 'Disability and Health' (World Health Organisation, 24 November 2021) <<https://www.who.int/news-room/fact-sheets/detail/disability-and-health>> accessed 23 June 2022.

<sup>2</sup> *ibid.*

<sup>3</sup> 'Disability and Ageing' (United Nations Department of Economic and Social Affairs) <<https://www.un.org/development/desa/disabilities/disability-and-ageing.html>> accessed 23 June 2022.

<sup>4</sup> World Health Organisation and World Bank, 'World Report on Disability' (December 2011) <<https://www.who.int/publications/i/item/9789241564182>> accessed 23 June 2022; UNICEF, 'The State of the World's Children 2013: Children with Disabilities' (November 2013) <<https://www.unicef.org/reports/state-worlds-children-2013>> accessed 23 June 2022.

<sup>5</sup> National Statistical Office, 'Persons with Disabilities (Divyangjan) in India - A Statistical Profile: 2021' (31 March 2021), p. 28 <[http://www.nhfdc.nic.in/upload/nhfdc/Persons\\_Disabilities\\_31mar21.pdf](http://www.nhfdc.nic.in/upload/nhfdc/Persons_Disabilities_31mar21.pdf)> accessed 23 June 2022.

<sup>6</sup> *supra* note 1.

<sup>7</sup> 'COVID-19 Outbreak and Persons with Disabilities' (United Nations Department of Economic and Social Affairs) <<https://www.un.org/development/desa/disabilities/covid-19.html>> accessed 23 June 2022.

<sup>8</sup> Gloria L Krahn, Deborah Klein Walker and Rosaly Correa De Araujo, 'Persons with Disabilities as an Unrecognized Health Disparity Population' (2015) 105(2) American Journal of Public Health <<https://ajph.aphapublications.org/doi/full/10.2105/AJPH.2014.302182>> accessed 23 June 2022.

<sup>9</sup> US Department of Health and Human Services, 'Disability and Health in the United States 2001-2005' (July 2008) <<https://www.cdc.gov/nchs/data/misc/disability2001-2005.pdf>> accessed 23 June 2022.

<sup>10</sup> Rights of Persons with Disabilities Act 2016, s 25.

accessible healthcare have been exacerbated due to COVID-19 as well as by the measures adopted to contain it. This has been discussed in more detail below.

## B. Impact of COVID-19 on Persons with Disabilities

While the pandemic disrupted almost every aspect of life, it has been well-established that it has had a disproportionate impact on persons with disabilities.<sup>11</sup> The pandemic has impacted persons with disabilities on a fundamental level and on multiple fronts—the ability to conduct activities of daily living such as maintaining personal hygiene, dressing and eating; increased social alienation; difficulty in detecting and communicating the symptoms of COVID-19; and restricted or delayed access to essential public health information and critical healthcare.<sup>12</sup> Some of these challenges were further compounded for persons who had the complications of existing comorbidities, such as heart disease, asthma, etc., due to their disabilities.<sup>13</sup>

It has been widely reported that the needs of persons with disabilities were not adequately accounted for in the implementation of COVID-19 containment measures.<sup>14</sup> Most primary of these is the lockdown, which itself diminished the access of persons with disabilities to healthcare services—for example,<sup>15</sup> lack of accessibility to testing facilities as home-collection was halted; access to essential medical aids and medicines such as diapers, catheters, disposable sheets, antibiotics, etc. were limited due to either discontinued home delivery services, or the unavailability of these items; lack of public transportation facilities led to difficulty in receiving treatment for certain conditions, such as epilepsy, which require outpatient care, clinical observations, physiotherapy, etc. Further, persons with disabilities were left isolated and socially alienated, given that they are dependent on social and peer support groups and systems such as reading rooms, listening circles, cafes, and friendship groups.<sup>16</sup>

In addition, persons with disabilities have had to face discrimination and prejudice in healthcare settings, given that healthcare workers are not trained and sensitised appropriately for working with persons with disabilities. Such a lack of awareness combined with the high burden

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<sup>11</sup> 'COVID-19 and persons with disabilities' (*Office of the High Commissioner for Human Rights*) <<https://www.ohchr.org/en/covid-19-and-persons-disabilities>> accessed 23 June 2022.

<sup>12</sup> Observations based on the grievances of persons with disabilities received through the National Helpline for Persons with Disabilities of the National Centre for Promotion of Employment for Disabled People

<sup>13</sup> E Umucu and B Lee, 'Examining the impact of COVID-19 on stress and coping strategies in individuals with disabilities and chronic conditions' (2020) 65(3) *Rehabilitation Psychology* <<https://psycnet.apa.org/fulltext/2020-32861-001.html>> accessed 23 June 2022.

<sup>14</sup> Divya Goyal, 'People with disabilities during the COVID-19 pandemic in India' (*Observer Research Foundation*, 28 November 2020) <<https://www.orfonline.org/expert-speak/people-disabilities-covid19-pandemic-india/>> accessed 23 June 2022.

<sup>15</sup> National Centre for Promotion of Employment for Disabled People, 'Locked Down and Left Behind: A Report on the Status of Persons with Disabilities during the Covid-19 pandemic' (2020) <[https://ncpedp.org/reports/Report-locked\\_down\\_left\\_behind.pdf](https://ncpedp.org/reports/Report-locked_down_left_behind.pdf)> accessed 23 June 2022.

<sup>16</sup> *ibid.*



placed on the healthcare system has contributed to discriminatory attitudes towards them,<sup>17</sup> well as a lack of prioritisation for their healthcare needs and medical rationing.<sup>18</sup> Information on protocols to be followed to stay protected from COVID-19, its risks, treatment, etc., was also often not available in an accessible format for persons with disabilities.<sup>19</sup>

Such policy measures also led to challenges for persons with disabilities which were unique to their pre-existing disabilities. Some examples of this are as follows:

- Persons with Down Syndrome, immune dysregulation and increased cytokine production faced heightened risks from COVID-19, given that these conditions increase vulnerability to infections. This is especially pertinent as mortality is mainly related to cytokine release syndrome, which is an associated risk of COVID-19.<sup>20</sup>
- Persons with blindness and deaf blindness faced communication challenges in medical settings, as they could not communicate with healthcare professionals in the absence of an interpreter. Following measures like social distancing was also not feasible for persons with deaf blindness as they rely on the assistance of other people to carry out their daily activities.<sup>21</sup>
- Persons with intellectual and developmental disabilities faced the risk of being unable to identify or report symptoms of infection,<sup>22</sup> as well as adjustment-related problems due to abrupt disruptions in their routines and support systems given the lockdowns.<sup>23</sup>

## C. Legal Framework for the Right to Health of Persons with Disabilities

A brief overview of the legal framework underlying the right to health of persons with disabilities is provided here. The right to health to persons with disabilities is operationalised through the RPwD Act, which is based on certain international obligations. Further, the COVID-19 guidelines issued by the central government in respect of persons with disabilities are discussed briefly, and an overview is provided of the judicial engagement in this respect.

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<sup>17</sup> *ibid.*

<sup>18</sup> EE Andrews and others, 'No body is expendable: Medical rationing and disability justice during the COVID-19 pandemic' (2020) 76(3) *American Psychologist* <<https://psycnet.apa.org/record/2020-54103-001>> accessed 23 June 2022.

<sup>19</sup> Manoj Sharma, 'People with disabilities suffer as Covid limits access to care' (*Hindustan Times*, 31 May 2021) <<https://www.hindustantimes.com/cities/others/people-with-disabilities-suffer-as-covid-limits-access-to-care-101622397701857.html>> accessed 23 June 2022.

<sup>20</sup> H De Cauwer and A Spaepen, 'Are patients with Down syndrome vulnerable to life-threatening COVID-19?' (2021) 121(3) *Acta Neurologica Belgica* <<https://pubmed.ncbi.nlm.nih.gov/32444942/>> accessed 23 June 2022.

<sup>21</sup> Gus Alexiou, 'Blind People's Social Distancing Nightmare to Intensify as Lockdowns Ease' (*Forbes*, 7 June 2020) <<https://www.forbes.com/sites/gusalexiou/2020/06/07/new-normal-of-social-distancing-could-become-a-new-nightmare-for-blind-people/?sh=57f36f9eac0f>> accessed 23 June 2022.

<sup>22</sup> R Alexander and others, 'Guidance for the Treatment and Management of COVID-19 Among People with Intellectual Disabilities' (2020) *Journal of Policy Practice in Intellectual Disabilities* <<https://pubmed.ncbi.nlm.nih.gov/32837529/>> accessed 23 June 2022.

<sup>23</sup> K Courtenay, 'COVID-19: challenges for people with intellectual disability' (2020) 369 *The BMJ* <<https://www.bmj.com/content/369/bmj.m1609>> accessed 23 June 2022.

## International Human Rights Treaties

At the outset, it must be acknowledged that India is a dualist state, and accordingly, obligations under international treaties are not binding, until Parliament enacts a domestic law to operationalize them. That said, Article 51 (c) of the Constitution of India obligates the government to ‘foster respect for international law and treaty obligations in the dealings of organised peoples with one another’. Indian courts have also striven to develop domestic rights and constitutional jurisprudence ‘in lockstep with international law’.<sup>24</sup> For instance, the Supreme Court, in holding that transgenders constituted the third gender, *inter alia*, drew support from the Yogyakarta principles.<sup>25</sup> Further, the Supreme Court has held that customary international law which is not contrary to Indian domestic law shall stand incorporated in India’s domestic law.<sup>26</sup>

The RPwD Act has been enacted to give effect to the United Nations Convention on the Rights of Persons with Disabilities (**‘UNCRPD’**). The UNCRPD is an international human rights treaty by the United Nations (**‘UN’**) for persons with disabilities. It is the first international human rights instrument for persons with disabilities and imposes obligations on national governments to ensure the fulfilment of the rights of persons with disabilities. These obligations are applicable to the Government of India, as India is a signatory to the UNCRPD.

The UNCRPD is also relevant to the public response to the COVID-19 pandemic as regards persons with disabilities. In this respect, provided below is a brief snapshot of the key rights contained in the UNCRPD and some of their implications on what would constitute an appropriate pandemic response that would be compliant with the UNCRPD.

S. No.	The right at issue	Implications for the COVID-19 response <sup>27</sup>
1.	Involvement of persons with disabilities in decision-making processes  [Articles 4.3 and 33.3]	Persons with disabilities, through their representative organisations, should be widely consulted in: (a) The planning and execution of containment and emergency measures (b) Crisis response and impact assessment.
2.	Equality and non-discrimination  [Articles 5, 8, 10 and 28 ]	The government must ensure that: (a) Persons with disabilities can equally benefit from general or individual “protection measures, health services, including life-saving measures, social protection, quarantine facilities and

<sup>24</sup> Lavanya Rajamani, International Law and the Constitutional Schema in Sujit Choudhry, Madhav Khosla, and Pratap Bhanu Mehta (ed), *The Oxford Handbook of the Indian Constitution* (Oxford University Press 2016) 143, 156.

<sup>25</sup> National Legal Services Authority v. Union of India, (2014) 5 SCC 438.

<sup>26</sup> Vellore Citizens Welfare Forum v. union of India, 1996 5 SCR 241.

<sup>27</sup> Police and Human Rights Resources, ‘Internal HRTB Toolkit of Treaty Law Perspectives and Jurisprudence in the Context of Covid-19’ (February 2021) <<https://policehumanrightsresources.org/internal-hrtb-toolkit-of-treaty-law-perspectives-and-jurisprudence-in-the-context-of-covid-19>> accessed 23 June 2022.

		provisions, and the distribution of essential supplies in the context of the COVID-19 crisis.” (b) Awareness-raising measures on issues that can detrimentally impact persons with disabilities.
3.	Physical and informational accessibility  [Article 9 and 25]	In the context of COVID-19, this means access to information on: (a) Public health management; (b) Specific COVID-19 prevention and containment measures; (c) Information on essential supplies and services; (d) Accessibility of health platforms, including hotlines, websites, radio, video, and leaflets; (e) Accessibility of remote consultancy services and quarantine facilities; and (f) Use of text messages; captioning, sign language interpretation, and Easy Read.
4.	Freedom from exploitation, violence, and abuse  [Article 16]	In this context, it means paying particular attention to the unique vulnerability of persons with disabilities to domestic violence.
5.	Right to independent living and involvement with community  [Articles 14 and 19]	This includes personal assistance, in-home support, supply of essential services, and monitoring of the impact of the pandemic on the disabled who are institutionalised.
6.	Right to health  [Articles 10 and 25]	Access to the “same range, quality and standard of health care as provided to other persons” and preventing discriminatory denial of healthcare services based on disability.

*Table 1: Key rights under the UNCRPD and their implications for an appropriate COVID-19 response*

In addition to the UNCRPD, different UN agencies have also issued guidance specifically concerning the COVID-19 pandemic. In March 2020, when the WHO announced the outbreak of the COVID-19 virus, it also released brief guidelines, ‘Disability Considerations during the Covid-19 Outbreak’ which provided for certain considerations for persons with disabilities.<sup>28</sup> The guidelines highlighted the barriers that they may face while accessing required services and explained the need for additional considerations for persons with disabilities. In relation to the public response to the pandemic, the guidelines recommended that the following actions should be taken as part of the response plan: (a) Ensuring that information and communications

<sup>28</sup> World Health Organisation, ‘Disability considerations during the COVID-19 outbreak’ (March 2020) <<https://www.who.int/docs/default-source/documents/disability/covid-19-disability-briefing.pdf>> accessed 23 June 2022.

on the pandemic and public health are accessible (for example, by using accessibility practices to draft such documents and disseminating such communications widely to persons with disabilities); (b) Taking targeted measures for persons with disabilities and their support networks (for example, by providing financial assistance to caregivers of persons with disabilities); and (c) Taking targeted measures for disability service providers (for example, by prioritising organisations providing disability services in relation to providing protective equipment such as masks, sanitisers, etc).<sup>29</sup>

Further, the UN came out with a policy brief which highlighted the impact of COVID-19 on persons with disabilities.<sup>30</sup> Stressing the concept of ‘Build Back Better’, the policy brief outlined key actions and recommendations to both make the response and recovery systems inclusive for persons with disabilities and to build a disability-inclusive COVID-19 response plan. It identified the following key actions that must be taken across sectors: (a) Persons with disabilities must be mainstreamed in all aspects of the COVID-19 response plan; (b) Ensure that information, facilities and services relevant to COVID-19 are accessible to persons with disabilities; (c) Persons with disabilities should actively participate and be consulted in all aspects of the COVID-19 response plan; (d) Accountability mechanisms must be established for the inclusion of persons with disabilities in the COVID-19 response plan.<sup>31</sup>

## ***Rights of Persons with Disabilities Act, 2016***

The RPwD Act is the primary disability rights legislation in India and was enacted in 2016 to fulfil India’s obligation under the UNCRPD.<sup>32</sup> Based on the spirit of equality, non-discrimination, and respect for the dignity of persons with disabilities, it puts in place a legal framework to ensure accessibility for persons with disabilities and to provide them with reasonable accommodations where necessary.

As regards healthcare, the RPwD Act places an obligation on the Central and State Governments and local authorities to take appropriate measures to ensure barrier-free access to persons with disabilities in all parts of government and private hospitals and other healthcare institutions and centres.<sup>33</sup> These authorities are also obligated to take steps to provide persons with disabilities priority in attendance and treatment.<sup>34</sup> It further obligates such authorities to provide healthcare to persons with disabilities during natural disasters and other ‘situations of risk’,<sup>35</sup> and guarantees them “equal protection and safety.”<sup>36</sup>

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<sup>29</sup> *ibid* p. 5.

<sup>30</sup> UN Sustainable Development Group, ‘Policy Brief: A Disability-Inclusive Response to COVID-19’ (May 2020) <<https://unsdg.un.org/resources/policy-brief-disability-inclusive-response-covid-19>> accessed 23 June 2022.

<sup>31</sup> *ibid* p. 2-3.

<sup>32</sup> Rights of Persons with Disabilities Act, 2016.

<sup>33</sup> *ibid*, s 25(1)(b).

<sup>34</sup> *ibid*, s 25(1)(c).

<sup>35</sup> *ibid*, s 25(2)(i).

<sup>36</sup> *ibid*, s 8.

## ***COVID-19 Guidelines for persons with disabilities***

Various government agencies have laid down guidelines for ensuring inclusion and support to persons with disabilities during COVID-19. During the start of the pandemic, the Department of Empowerment of Persons with Disabilities under the Ministry of Social Justice & Empowerment (**'DEPwD'**) recognised persons with disabilities as an especially vulnerable population group that must be provided with protection and safety. In view of this, the DEPwD formulated the Comprehensive Disability Inclusive Guidelines for Protection and Safety of Persons with Disabilities during COVID-the 19 (**'Comprehensive Guidelines'**).<sup>37</sup> The Comprehensive Guidelines provide for general action points for various state and district authorities that would place focused attention on the protection and safety of persons with disabilities. Among other things, they provide for the following:

1. Ensuring information accessibility to persons with disabilities.
2. Exempting caregivers of persons with disabilities from lockdown restrictions.
3. Exempting employees with disabilities from essential services work.
4. Providing training to emergency service providers for treating and working with persons with disabilities.
5. Providing essential support to quarantined persons with disabilities.
6. Mechanisms to address disability-specific issues by the State Commissioner for Persons with Disabilities and the Nodal Officers for Persons with Disabilities.

In addition to the general action points provided through the Comprehensive Guidelines, the DEPwD formulated a list of basic accessibility features that should be present in COVID-19 testing facilities, quarantine centres, and hospitals and health centres.<sup>38</sup> Some of these accessibility features include:

1. Self-operated devices (e.g., sanitiser dispensers, soaps, etc.) placed within the reach of persons with disabilities.
2. Simple and prominent signs placed in accordance with standard requirements of colour and contrast.
3. Provision of at least one low-height counter at the reception areas, pharmacies and testing areas.
4. Ramps with railings should be provided.

Further, guidelines have also been issued in relation to vaccinations for persons with disabilities. After the commencement of the vaccination drive in India, guidelines were issued to make the process of vaccination more accessible to persons with disabilities in May 2021. Given that the process of getting vaccinated at far-off or inaccessible centres was challenging for persons with disabilities, the Ministry of Health and Family Welfare (**'MoHFW'**) issued guidelines for near-to-home COVID-19 vaccination centres for senior citizens and persons with disabilities.<sup>39</sup> Near-to-home vaccination took a community-based approach wherein

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<sup>37</sup> Department of Empowerment of Persons with Disabilities, 'Communication relating to the comprehensive guidelines for the welfare of persons with disabilities during COVID-19' (D.O. No. 4-12/2020-AIC, 24 April 2020) <<https://disabilityaffairs.gov.in/content/GuidelinesforwelfareofPersonswithDisabilities.pdf>> accessed 23 June 2022.

<sup>38</sup> *ibid.*

<sup>39</sup> Ministry of Health and Family Welfare, 'Guidance Note: Near to Home COVID Vaccination Centres (NHCVC) for Elderly and Differently Abled Citizens' (27 May 2021)

vaccines were intended to be administered in non-health facilities, such as school buildings, community centres, etc. Among other things, these guidelines provided for facilitating the travel of beneficiaries and ensuring that the vaccine centres would be accessible to persons with disabilities and senior citizens.

However, while the near-to-home vaccine facilities brought some respite to persons with disabilities, the issues with inaccessibility continued to persist for those who were bedridden and in home care. In this respect, MoHFW came up with door-to-door vaccinations in September 2021 for persons with disabilities, senior citizens, and those with restricted or limited mobility.<sup>40</sup> In this regard, the MoHFW announced that “any person willing to get vaccinated and who cannot travel to the vaccination centre, the arrangement of at-home vaccines have been made”.<sup>41</sup> Guidelines do not seem to be available in the public domain on door-to-door vaccination.

## ***Judicial Engagement***

During the period of the pandemic, the judiciary issued directions to various government bodies to address the difficulties being faced by persons with disabilities. In this respect, a brief overview of some noteworthy cases is provided below.

### **I. Interventions by the Supreme Court**

In 2021, as India was gripped by the second wave of the pandemic, the Supreme Court initiated *suoto motu* proceedings to monitor the government’s response to the pandemic, and took up, among other things, the issue of inaccessibility of the CoWIN platform for the visually challenged.<sup>42</sup> It noted specific issues with the CoWIN platform, which, among others, included: (a) unavailability of audio or text captcha; (b) unavailability of keyboard support for navigating the website; (c) adequate time not given to schedule appointments before a user is automatically logged off; and (d) persons with disabilities not being able to find out the days on which vaccine slots are available. The Court directed the government to respond to all the issues that it flagged. There is no publicly available information on the progress of the case on this count.

Further, Evara Foundation, a disability rights non-governmental organisation, filed a case in the Supreme Court, seeking improvement of the support facilities to ensure access to vaccinations for persons with disabilities.<sup>43</sup> In this relation, the Supreme Court directed the DEPwD to invite suggestions from all stakeholders and domain experts in disability for their input on upgrading

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<<https://www.mohfw.gov.in/pdf/GuidanceNearToHomeCovidVaccinationCentresforElderlyandDifferentlyAbledCitizens.pdf>> accessed 23 June 2022.

<sup>40</sup> Rhythma Kaul, ‘People with disability can get Covid vaccines at home’ (*Hindustan Times*, 24 September 2021) <<https://www.hindustantimes.com/india-news/people-with-disability-can-get-covid-vaccines-at-home-101632423306719.html>> accessed 23 June 2022.

<sup>41</sup> Sushmi Dey, ‘At home vaccine for disabled, people with special needs gets government nod’ (*Times of India*, 24 September 2021) <<https://timesofindia.indiatimes.com/india/at-home-vaccine-for-disabled-people-with-special-needs-gets-government-nod/articleshow/86468181.cms>> accessed 23 June 2022.

<sup>42</sup> *Suo Motu Writ Petition (Civil) No. 3 of 2021 in Re: Distribution of Essential Supplies and Services During Pandemic* (Supreme Court of India).

<sup>43</sup> *Evara Foundation vs Union of India*, Writ Petition Civil No. 580/2021 (Supreme Court of India).



the existing framework of vaccination for persons with disabilities. The DEPwD was directed to subsequently present comprehensive proposals to the MoHFW, which was mandated to review the proposals and assess the requirement for modifications to make the existing framework of vaccination for persons with disabilities more effective. However, this matter has not yet been decided by the court.

## II. Interventions by High Courts

Various High Courts have also provided directions to State Governments in relation to persons with disabilities. For instance, in *Meenakshi Balasubramanian v. Union of India and Others*, the Madras High Court emphasised the importance of prioritising persons with disabilities in vaccine administration, stating, “Accordingly, the statement of the State is recorded that all Government vaccination centers will have a separate counter throughout the day when vaccination is undertaken at such centers exclusively for persons with disabilities. At any rate, persons with disabilities should be given priority in being vaccinated even if the numbers do not warrant an exclusive counter...”<sup>44</sup>

Further, disability rights organisations filed legal proceedings in the High Courts of Karnataka, Madras, Jharkhand, Calcutta, Patna, Jammu and Kashmir, Delhi, Orissa, and Uttarakhand “seeking priority for persons with disabilities in attendance and treatment of COVID-19”.<sup>45</sup>

These interventions generally were well received. For example, courts provided for the following measures:

- In Tamil Nadu, setting up a separate counter at government-run vaccination centres to address the vaccination needs of persons with disabilities.<sup>46</sup>
- In Uttarakhand, the setting up of door-to-door and community vaccination centres and vaccination sites.<sup>47</sup>

## D. Project Overview

As of November 2021, India’s COVID-19 vaccination drive had administered over 100 crore doses in a record time of 9 months.<sup>48</sup> However, when it came to persons with disabilities, data cited by the MoHFW during Parliament’s Winter Session indicated that only 8,390 persons with disabilities had received the first dose of vaccination and 4,018 persons with disabilities

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<sup>44</sup> *Meenakshi Balasubramanian vs Union of India*, Writ Petition Civil No. 2951/2021 (High Court of Madras).

<sup>45</sup> ESCR-Net et al, ‘To Mr. Gerard Quinn United Nations Special Rapporteur on the Rights of Persons with Disabilities, Request for communications to United Nations member States providing further guidance on the rights of persons with disabilities and redress for violations in the context of the COVID-19 pandemic’ (2022) <<https://www.escr-net.org/news/2022/civil-society-groups-submit-report-covid-impacts-un-special-rapporteur-rights-persons>> accessed 25 June 2022, 2.

<sup>46</sup> *ibid.*

<sup>47</sup> Affidavit of the Health Secretary of Uttarakhand before the Court of Uttarakhand, in Writ Petition No. 71 (High Court of Uttarakhand).

<sup>48</sup> Ministry of Health and Family Welfare, ‘India’s Cumulative COVID-19 Vaccination Coverage exceeds 106.31 Cr’ (1 November 2021) <<https://pib.gov.in/PressReleasePage.aspx?PRID=1768308>> accessed 23 June 2022.

had received both the doses.<sup>49</sup> With 2.68 crore persons with disabilities in India as of 2011, this amounts to less than 1% of the population of persons with disabilities in India.<sup>50</sup>

The reported numbers may be affected by inaccurate data collection, especially as it relates to disability, but it raises significant questions on the status of healthcare facilities for persons with disabilities. It is evident that persons with disabilities were initially excluded and not prioritised in the vaccination drive.<sup>51</sup> Further, the measures taken to contain the pandemic, such as lockdowns, were challenging for persons with disabilities, leading to communication difficulties, violence, lack of access to routine healthcare, and increased social alienation.<sup>52</sup>

In this context, this project aimed to: (a) conduct data-based research to generate evidence on the accessibility of healthcare and COVID-19 vaccinations for persons with disabilities; and (b) advocate for the upgradation of the healthcare system for persons with disabilities and present policy recommendations. The details of the components and initiatives taken as part of this project are as follows:

1. A study on the accessibility of healthcare and COVID-19 vaccinations, conducted in collaboration with the National Centre for Promotion of Employment for Disabled People ('NCPEDP'). The remainder of the report is focused on this study.
2. In an existing case before the Supreme court,<sup>53</sup> Vidhi Centre for Legal Policy ('Vidhi') filed an intervention and suggested several measures that should be implemented to improve the accessibility of healthcare measures for persons with disabilities. The intervention application is available [here](#). The matter was last listed on 12 May 2022, but it has not been taken up on or since that date.
3. The DEPwD had put out a notice soliciting comments from the public on improving existing vaccination facilities for persons with disabilities.<sup>54</sup> Vidhi submitted comments in response to this notice, which is available [here](#).
4. Vidhi submitted a representation to Mr. Gerard Quin, UN Special Rapporteur on the Rights of Persons with Disabilities, in collaboration with the Disability Law Unit of the Human Rights Law Network, ESCR.Net and other organisations working on persons with disabilities rights. The representation is available [here](#).

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<sup>49</sup> Bindu Shajan Perappadan, 'COVID-19 | Only 4,018 people with disabilities got both doses of vaccine till November-end' (*The Hindu*, 7 December 2021) <<https://www.thehindu.com/news/national/only-4018-people-with-disabilities-got-both-doses-of-covid-19-vaccine-till-november-end/article37880304.ece>> accessed 23 June 2022.

<sup>50</sup> National Statistical Office, 'Persons with Disabilities (Divyangjan) in India - A Statistical Profile: 2021' (31 March 2021), p. 30-31 <[http://www.nhfdc.nic.in/upload/nhfdc/Persons\\_Disabilities\\_31mar21.pdf](http://www.nhfdc.nic.in/upload/nhfdc/Persons_Disabilities_31mar21.pdf)> accessed 23 June 2022.

<sup>51</sup> Debabrata Patra, 'How Covid-19 Vaccine Drive Left Out Persons with Disabilities' (*Outlook India*, 18 August 2021) <<https://www.outlookindia.com/website/story/opinion-how-covid-19-vaccine-drive-left-out-persons-with-disabilities/389325>> accessed 23 June 2022.

<sup>52</sup> Jayashree Narayanan, 'Pandemic and a lockdown: Persons with disabilities grapple with more challenges' (*The Indian Express*, 22 September 2020) <<https://indianexpress.com/article/lifestyle/life-style/persons-with-disabilities-day-to-day-challenges-coronavirus-covid-19-lockdown-pandemic-handwashing-social-isolation-distancing-6383363/>> accessed 23 June 2022; Indian Institute of Public Health Hyderabad, 'A Strategic Analysis of Impact of COVID-19 on Persons with Disabilities in India' (2020) [https://phfi.org/wp-content/uploads/2020/12/COVID-impact-final-report-IIPH-to-CBM-HI\\_02122020.pdf](https://phfi.org/wp-content/uploads/2020/12/COVID-impact-final-report-IIPH-to-CBM-HI_02122020.pdf) accessed 23 June 2022.

<sup>53</sup> *supra* note 43.

<sup>54</sup> Department of Empowerment of Persons with Disabilities, 'Public Notice' (2 February 2022) <[https://disabilityaffairs.gov.in/upload/uploadfiles/files/Public%20Notice\(1\)\(1\).pdf](https://disabilityaffairs.gov.in/upload/uploadfiles/files/Public%20Notice(1)(1).pdf)> accessed 23 June 2022.



5. Vidhi is currently in the process of submitting suggestions to the MoHFW for the formulation of standards for a disability-friendly healthcare system.

## II. Methodology of the Study

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The current research study followed a mixed-methods approach, where a combination of quantitative and qualitative data was collected and analysed to understand the experiences of persons with disabilities in accessing routine healthcare services, vaccines and healthcare related to COVID-19, and information about COVID-19, during the period of the pandemic.

### ***Sampling Method***

Survey data was collected between November 2021 and January 2022, from a sample of 239 persons with disabilities, across states in India. The sample consisted predominantly of persons with disabilities residing in urban regions within these states.

The study was designed as a rapid assessment, intended to capture the varied experiences of persons with disabilities with different types of disabilities in their access to healthcare services and information related to the COVID-19 pandemic. The study thus aims to highlight how existing laws/guidelines that mandate inclusive practices for ensuring access to healthcare and healthcare information for persons with disabilities (and especially in times of crises), were not implemented during the pandemic.

The sample of 239 persons with disabilities was selected through convenience sampling from within the existing network of partner organisations - NCPEDP, and their partner organisations - Swabhiman, Odisha; Shishu Sarothi, Assam; Arushi, Madhya Pradesh; Association of People with Disabilities, Karnataka; Sense International India, Gujarat; Viklang Adhikar Manch, Bihar; and Viklang Sahara Samiti, Delhi-NCR. These organisations were selected to facilitate sampling and data collection for this project due to their vast network of beneficiaries across states in the country, which includes persons with disabilities across types of disabilities, socioeconomic statuses and geographies.

Partner organisations were provided with the following criteria for the selection of respondents for this study – (a) persons who had any form of disability; and (b) persons who were at least 18 years old at the time of the survey. It is important to note here that the decision to sample only adult persons with disabilities above the age of 18 years, was guided by the fact that at the time of the study being conducted the provision of vaccination was only for adults.

### ***Data Collection and Analysis***

Surveys were designed by the research team, with inputs from NCPEDP and other partner organisations (please see Annexure I for the draft questionnaire). The survey was made available in English and Hindi.

Surveys were self-administered by respondents, through Google Forms, which were shared with respondents through partner organisations.

While it was expected that most respondents would be able to fill in the survey by themselves, ‘coordinators’ from partner organisations were made available in the case that respondents needed any form of assistance – such as for translation of the tool to local languages (apart

from Hindi or English), navigating the interface, using devices, etc. For this purpose, the research team organised a training session with the coordinators from partner organisations to familiarise them with the survey tool. Despite this, as all questions of the survey were not made mandatory for respondents to answer, we find some attrition on key questions of the survey. The percentages reported below account for this.

Respondents were asked questions about their healthcare needs and access to healthcare services both, before and during the COVID-19 pandemic; their ability to access information related to COVID-19 such as safety protocols, symptoms, details about vaccines, etc., which included questions about whether platforms/ government advisories or notices hosting such information were made accessible for persons with disabilities with specific disabilities, such as visual disabilities; their access to health care services in the case that they contracted COVID-19; and their ability to access vaccines, including their ability to navigate the CoWIN mobile application independently.

In addition, they were asked questions specifically about their experience of the pandemic as a person with a disability such as whether they were aware of, and were able to use any services provided by the State targeting persons with disabilities - such as a helpline, priority vaccination drives for persons with disabilities, etc.

Finally, respondents were asked about their age, gender, social and economic background, and the nature of their disability. While this information was captured, the scope of this study was limited to understanding how persons with disabilities navigated health care and information access on the basis of their disabilities. As such, we do not delve into how intersectional disadvantages of class, caste, rurality or gender might interact with one's disability in determining such access. This is potentially an area of research that can add further depth to the preliminary evidence presented here. This assumes significance in light of the research evidence that indicates that intersectional factors such as education and rural status impact the ability of persons with disabilities to access healthcare. To illustrate, a study in Sri Lanka indicates, in the context of women with disabilities: "the combination of COVID-19 related stresses with their gender, rurality and ethnicity disproportionately entrenches them within systems of exclusion and marginalization."<sup>55</sup>

The survey included a combination of objective questions and open-ended questions to capture respondents' experiences in greater depth on key questions. Quantitative data collected on objective questions are presented as descriptive statistics, while open-ended questions were analysed thematically, and used to supplement quantitative results.

## ***Sample Description***

A total of 239 respondents participated in the questionnaire. Respondents included persons with disabilities across types of disability - including locomotor disability, visual impairment, hearing impairment, speech and language disability, intellectual disability, multiple sclerosis, and multiple disabilities.

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<sup>55</sup> Niro Kandasamy, Binendri Perera and Karen Soldatic, 'COVID-19 from the Margins: Gendered-Disability Experiences in Sri Lanka' (2021) 8(1) *Disability and the Global South* <[https://disabilityglobalsouth.files.wordpress.com/2021/01/dgs08\\_01\\_04.pdf](https://disabilityglobalsouth.files.wordpress.com/2021/01/dgs08_01_04.pdf)> accessed 25 June 2022.

The sample group was diverse in its demographic features, comprising an approximately equal share of male and female persons, residing in both urban and local settings, from across major states of India, such as Assam, Karnataka, Bihar, Madhya Pradesh, etc. Sample characteristics are provided below, which have been supplemented with national averages from the Census of India 2011 ('Census 2011').

## I. Gender and Age

Respondents belonged to the age bracket of 18 to 65 years, with 50.6% women and 49.4% men. A majority of the sample, i.e., 45.6%, fell in the 18-25 age group; 37.2% of the sample fell in the 26-35 age group; 14.2% of the sample fell in the 36-45 age group; 2.5% of the sample fell in the 46-55 age group; 0.4% of the sample fell in the 55-65 age group. The division of persons with disabilities by gender is largely similar to the national average - where, according to the Census 2011, 56% of persons with disabilities were men and 44% were women. However, Census 2011 reports that the age bracket of 10-19 years had the highest incidence of disability (17%) followed by the age bracket of 20-29 years (16%).<sup>56</sup> Compared to this, our sample is largely skewed to a younger age group of 18-25 years and does not include persons with disabilities below the age of 18 years.

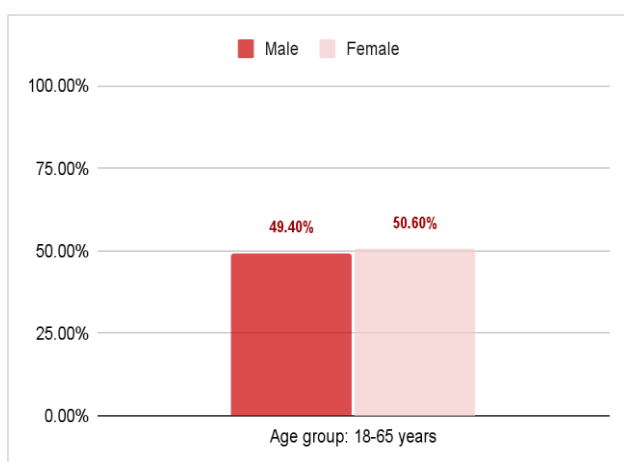


Fig. 1: Gender Distribution of the Sample

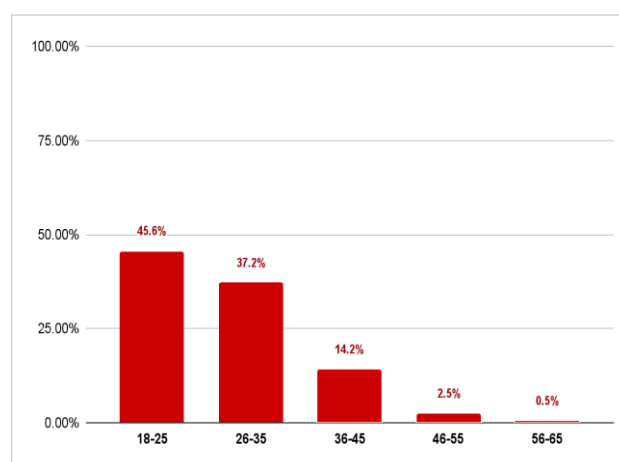


Fig. 2: Age Distribution of the Sample

## II. Urban-Rural Residence

34.5% of the respondents in our sample belonged to a rural background, and 65.5% of the respondents belonged to an urban background. This is substantially different from national averages where 69% of persons with disabilities reside in rural areas, with the incidence of disability significantly overlapping with rurality.<sup>57</sup> One explanation for this in the sample could be that persons with disabilities in urban areas were more easily accessible to the partner organisations, more willing to participate, and more able to self-administer the survey.

<sup>56</sup> supra note 50, p. 34.

<sup>57</sup> ibid, p. 28.

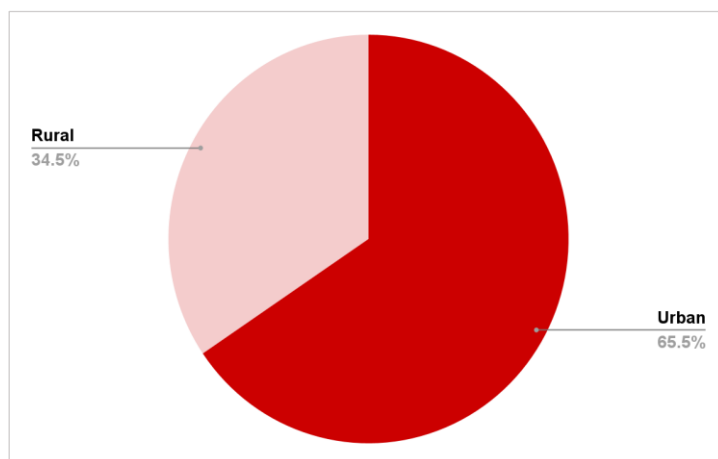


Fig. 3: Urban-Rural Residence of the Sample

### III. Educational Qualifications

A majority of respondents in our sample, i.e. 46% had received education beyond grade 12 (undergraduate and postgraduate education); followed by 35.1% who had received schooling till grade 12; followed by 8.4% who had received no formal schooling; followed by 6.7% who had received schooling till grade 8; followed by 3.8% who had received schooling till Grade 5 and below.

This is substantially different from national averages, where 45% of persons with disabilities had received no formal schooling. 11% had received schooling till below the primary level; 13% had received schooling till the primary level but below the middle school level; 9% had received schooling till the middle school level; 13% had received schooling till the secondary level; and 5% had received schooling till the higher secondary level and above.<sup>58</sup>

Level of highest educational qualification	Number of respondents	Percentage of respondents (%)
No formal schooling	20*	8.4*
Grade 5 and below	9	3.8
Grade 6-8	16	6.7
Grade 9-12	84	35.1
Above Grade 12	110	46

\*This includes 2 respondents who had received vocational training.

<sup>58</sup> Ibid, p. 33.

Table 2: Educational Qualifications of the Sample

#### IV. Employment Status

Employment status was captured as a binary variable with 75.7% of respondents reporting they were unemployed at the time of the survey. According to the Census 2011, 36% of persons with disabilities were employed and 64% were unemployed.<sup>59</sup>

This is significant to note as even though the sample is comparatively more advantaged on the basis of education levels and rurality, they include a higher percentage who are unemployed, higher than the national average for persons with disabilities.

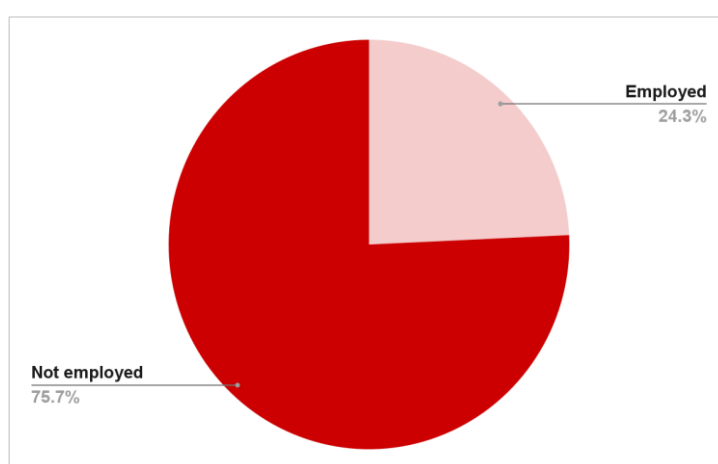


Fig. 4: Employment Status of the Sample

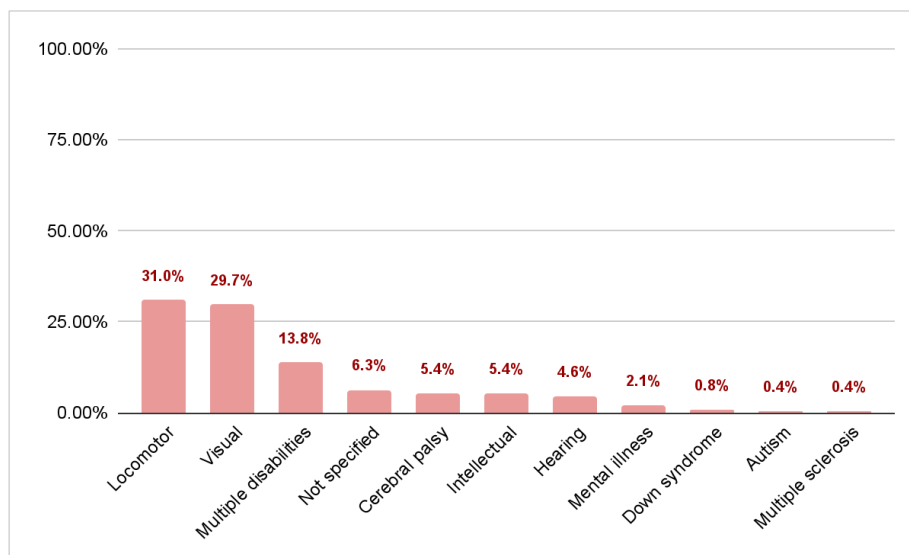
#### V. Nature of Disability

In the sample, a majority of the sample, i.e., 31% had locomotor impairment; 29.7% had visual impairment; 13.8% had multiple disabilities; 6.4% had not specified the nature of their disability; 5.4% had cerebral palsy; 5.4% had intellectual disability; 4.6% had hearing impairment; 2.1% had mental illness; 0.8% had Down syndrome; 0.4% had multiple sclerosis; and 0.4% had autism.

According to the Census 2011, 20% of persons with disabilities had locomotor impairment; 19% had visual impairment; 8% had multiple disabilities; 18% had other (unspecified) disabilities; 6% had intellectual disability; 19% had hearing impairment; 7% had speech impairment; 3% had mental illness.<sup>60</sup>

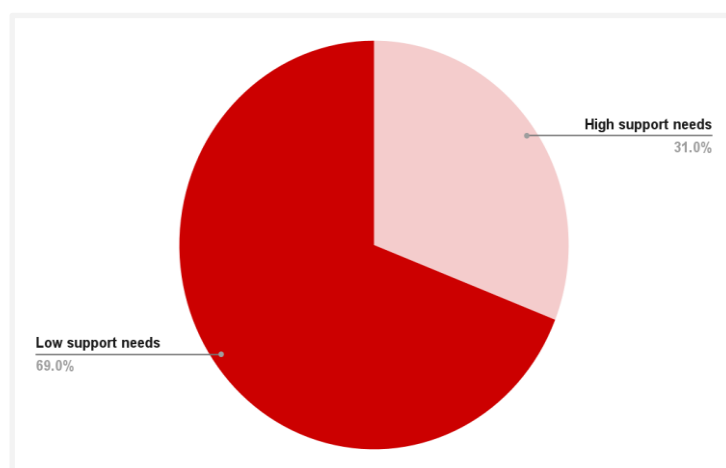
<sup>59</sup> *ibid*, p. 34.

<sup>60</sup> *ibid* p. 29.



*Fig. 5: Nature of Disability of the Sample*

The sample was also asked about the nature of their support needs, which refers to the manner and intensity of the assistance required by persons with disabilities to be able to carry out activities in their daily lives. This has an impact on the capacity of persons with disabilities to access healthcare services, and especially on the degree of independence one can exercise with everyday activities. Support needs would be higher for those persons with severe disabilities who would require higher levels of care and assistance. In this sample, 69% reported having low support needs and 31% reported having high support needs.



*Fig. 6: Nature of Support Needs of the Sample*

## III. Findings of the Study

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This chapter presents the detailed findings of the survey, across the four parameters mentioned earlier. As the last section shows, the sample of this study is considerably more advantaged on the basis of education levels and rurality, compared to the national average for persons with disabilities in India. Specifically, both education levels and the region of residence - urban or rural - are likely to have a direct and indirect impact on access to healthcare services and information. As such, the difficulties faced by this sample in accessing healthcare during the pandemic, are very likely an underestimation of the difficulties faced by their more socio-economically vulnerable counterparts across the country. On the other hand, we see that almost 75% of our sample were unemployed at the time of the survey, while 31% reported having high support needs. This might potentially have an adverse effect on their ability to access healthcare services and information.

### A. Access to healthcare services before and after the outbreak of the COVID-19 pandemic

As healthcare systems in India were not completely accessible to persons with disabilities even prior to the COVID-19 pandemic, this study sought to understand how persons with disabilities experienced healthcare facilities pre-COVID-19, and to compare these experiences during the COVID-19 period. Accordingly, access to the following has been assessed: (a) routine healthcare services; and (b) healthcare services specific to COVID-19.

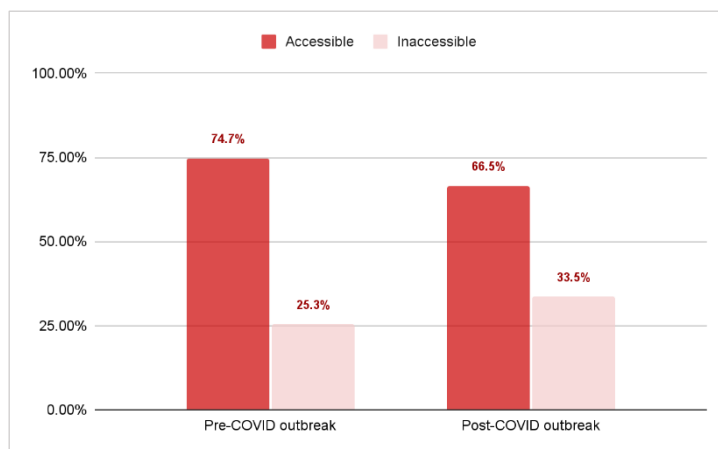
For this, respondents were asked whether they faced difficulty in accessing healthcare services before the outbreak of COVID-19, for example, in visiting hospitals for routine check-ups, getting priority treatment in hospitals, accessing medications, accessing emergency care, etc. Out of the 123 respondents who responded to this question, 25.3% stated that they had found healthcare facilities inaccessible even before the COVID-19 outbreak. Some reasons reported for this were - long waiting times at medical centres due to the lack of priority of services for persons with disabilities, financial difficulties, lack of access to medicines, and lack of adequate transportation services for persons with disabilities.

To enable a comparison between the accessibility of healthcare before and after the outbreak of the pandemic, respondents were asked if they faced difficulty in accessing the same healthcare services they required earlier, during the pandemic.

Out of 146 respondents who responded to this question (which includes 114 of the 123 respondents who had answered the question on the accessibility of healthcare services before the outbreak of the pandemic), 33.5% stated that they found healthcare services inaccessible due to the pandemic. This includes 61.3% of the respondents who stated that they found healthcare inaccessible before the pandemic as well and continued to find such services



inaccessible after the pandemic and 18.4% of respondents who stated that they found services accessible before the pandemic but found them inaccessible after the pandemic.



*Fig. 7: % of respondents that found healthcare services accessible before and after the outbreak of the pandemic*

Some of the reasons cited for the lack of accessibility after the pandemic were the lack of adequate transportation services, closed hospitals, unavailability of medical staff, waiting times, and financial constraints. It should be noted that the reasons that have been cited for lack of accessibility before and after the pandemic are systemic and similar—for example, financial constraints, waiting times and lack of priority treatment, etc. Accordingly, it is likely that the reasons for inaccessibility before the pandemic remained operational, and might have been further exacerbated due to the pandemic.

In relation to healthcare services required due to the pandemic, a majority of the respondents, i.e., 96.2%, reported that they did not contract COVID-19, which eliminated the need for such services. Of the 3.8% (i.e., 9 respondents) who reported contracting COVID-19, 77.8% (i.e., 7 respondents) stated that they received appropriate and timely treatment on time and 22.2% (i.e., 2 respondents) reported not receiving such treatment.

Respondents were also asked about the kinds of reasonable accommodations that could have been provided to them, which would have improved their access to healthcare during the pandemic. Some of the suggestions that were received mentioned the unavailability of trained healthcare providers (e.g., training in sign language, availability of information in braille), the proximity of healthcare centres to their homes, wheelchair accessibility in hospitals, telephonic consultation with doctors or home visits by doctors, provision for home delivery of medicines, and separate provisions for persons with disabilities (e.g., wards).

## B. Access to COVID-19 vaccines and the CoWIN platform

As one of the major goals of the study was to examine accessibility to vaccines for persons with disabilities, it aimed to examine this question both in relation to the CoWIN platform and in relation to the vaccination centres.

### *CoWIN Platform*

69.5% of the total 239 respondents stated that they were able to register themselves on the CoWIN platform. Those who could not register themselves reported that the platform was inaccessible for persons with visual impairment, the platform would reload automatically and not provide sufficient time to successfully register, the requirement of submitting an OTP, among others. Even among those who could register themselves, 66.9% reported needing external support to register on the platform, such as with assistance from family members.

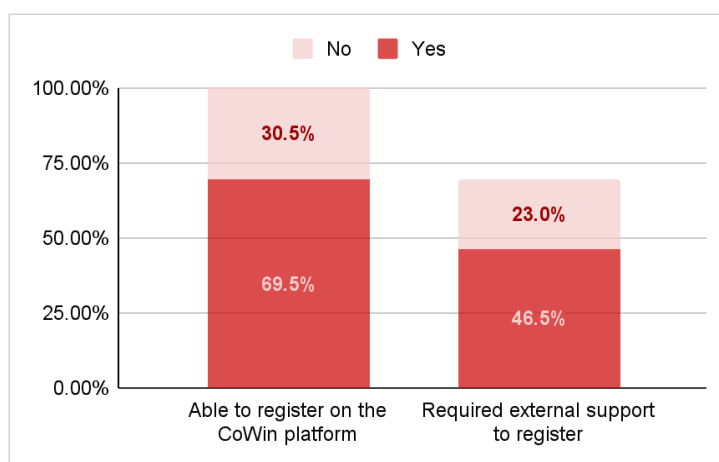


Fig. 8: % of respondents that could register on the CoWIN platform and % of respondents that required external support

### *Vaccinations*

Of the total 239 respondents, 89.5% had received the vaccination, and of those who received the vaccination, 84.6% had received both doses. It is notable that at the time of the study, which concluded on 3 January 2022 (i.e., a year since the vaccine rollout), 10.5% of the sample had not received a single dose of the vaccine. This is despite the fact that the sample was relatively more socioeconomically advantaged than the general population of persons with disabilities in India. In contrast, 7% of the Indian population had not received any dose of the vaccination as of 16 January 2022.<sup>61</sup> Further, 28.5% of the respondents who received the vaccination stated that they had to make multiple attempts to get the vaccination.

<sup>61</sup> 'India marks one year of COVID vaccination' (World Health Organisation, 17 January 2022) <<https://www.who.int/india/news/feature-stories/detail/india-marks-one-year-of-covid-vaccination>> accessed 16 September 2022.

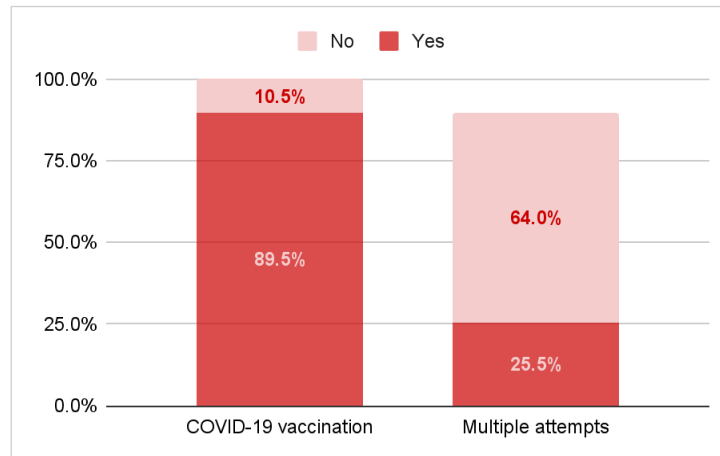


Fig. 9: % of respondents that received the COVID-19 vaccination and % that had to make multiple attempts for the vaccination

### ***Measures for persons with disabilities: Priority in vaccination and door-to-door vaccination***

Out of the total number of persons who could get vaccinations, only 52.8% were able to avail of the vaccination on a priority basis. Furthermore, 46.2% of the respondents who could avail of priority vaccination reported that the facilities they visited were not accessible, given inaccessibility to wheelchairs, overcrowding and long queues at the centres, and large distance from home.

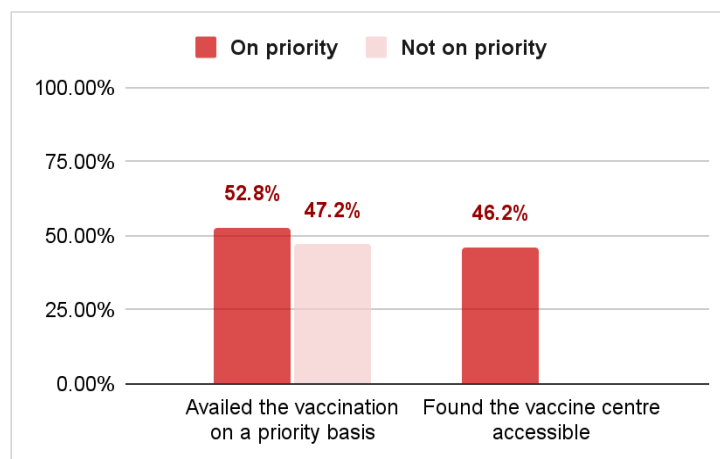


Fig. 10: % of respondents that received the COVID-19 vaccination on a priority basis and % of respondents that found the vaccination centre accessible

Moreover, 87.7% of the respondents stated that they did not have the opportunity to access door-to-door vaccination.

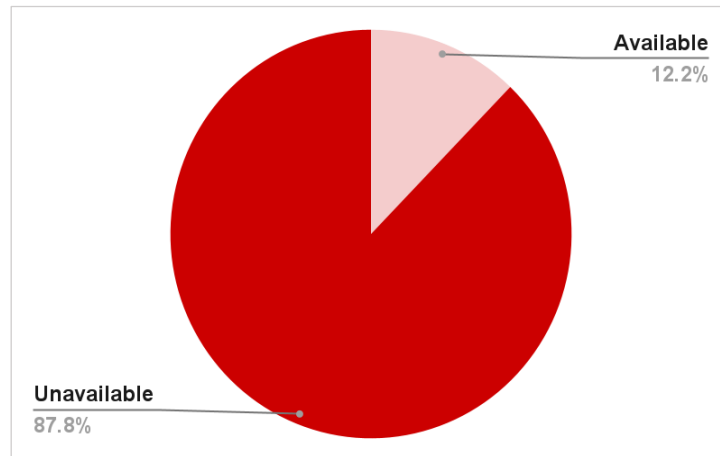


Fig. 11: % of respondents that had the opportunity to avail door-to-door vaccination

## C. Access to information on COVID-19

During the pandemic, the Central Government and the State Governments issued several guidelines and advisories for the public, such as protecting oneself from COVID-19, precautions to be taken while travelling, and quarantine protocol. This study aimed to assess the extent to which such information was disseminated keeping the needs of persons with disabilities into account. This refers to the provision of such information in an accessible format and the efficacy of dissemination methods for persons with disabilities.

A majority of the respondents stated that information on COVID-19 was not available in an accessible format. In relation to general information, such as on safety precautions, 61.1% stated that they could not find such information in an accessible format. Further, 57.7% of the respondents stated that information on vaccinations was not available in an accessible format.

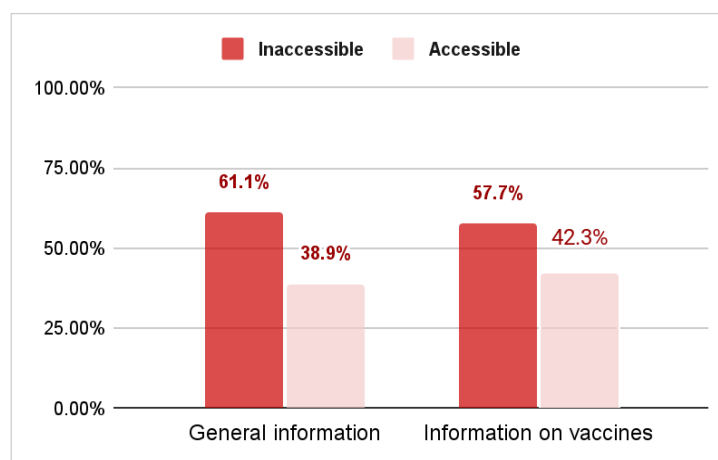
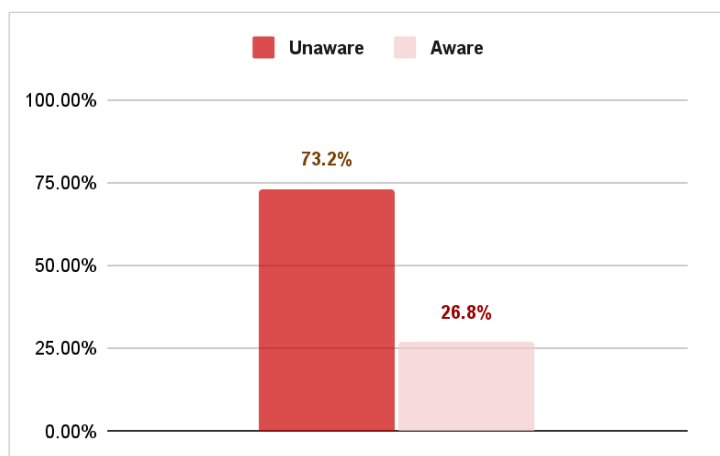


Fig. 12: % of respondents that found general information on COVID-19 and information on vaccines accessible

Respondents were also asked if they were aware of any helpline set up to support persons with disabilities, and 73.2% stated that they were not aware of such a helpline.



*Fig. 13: % of respondents that were aware of the helpline set up to provide support to persons with disabilities*

## IV. Policy Recommendations

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Through the present study, an evidence-based assessment of the challenges faced by persons with disabilities in India in accessing healthcare services during the pandemic has been conducted. This chapter outlines recommendations, which may assist in building an informed policy response to public health emergencies as well as creating a disabled-friendly health system.

Accordingly, the recommendations can be grouped into two categories: (a) recommendations that specifically relate to the current pandemic; and (b) recommendations for creating a disabled-friendly health system more generally.

The recommendations provided below flow from the requirement of providing reasonable accommodation to persons with disabilities under the RPwD Act, international obligations under the UNCRPD, judgments and directions of the Supreme Court, as well as guidelines issued by the government on addressing the concerns of persons with disabilities during the pandemic. The recommendations have also been formulated in view of the findings of our survey, as discussed in chapter 3. These recommendations have also been shared as part of the intervention application filed before the Supreme Court and the comments submitted to the DEPwD.

### *Policy recommendations specific to the COVID-19 pandemic*

1. Appointment for vaccinations: As the study found, 30.5% of respondents were unable to register on the CoWIN platform, and 23% of respondents required external support for the same. In this regard, the following measures should be implemented to ensure that persons with disabilities are able to register for vaccination appointments in an easy and hassle-free manner.
  - a. Measures should be taken to enable persons with disabilities to register for vaccinations and book their appointments telephonically. This would be consistent with the right to equality and non-discrimination embodied in the UNCRPD, which implies that persons with disabilities should be able to equally benefit from health services. Accordingly, an additional and disabled-friendly mode for booking vaccine appointments, which would enable access to vaccinations, will be consistent with this provision of the UNCRPD.
  - b. An accessibility audit of the CoWIN platform should be conducted, and steps should be taken to address the features identified as inaccessible to persons with disabilities. The Supreme Court has already directed the Central Government to conduct such an audit for CoWIN and Arogya Setu in May 2021.<sup>62</sup> Therefore, this measure is long overdue and should be implemented on priority.

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<sup>62</sup> *Suo Motu Writ Petition (Civil) No. 3 of 2021 in Re: Distribution of Essential Supplies and Services During Pandemic* (Supreme Court of India).

- c. Steps should be taken to strengthen and operationalise measures for the provision of vaccinations to persons with disabilities i.e., priority vaccination, door-to-door vaccination, and near-to-home vaccination. This would be pursuant to the obligation cast on the government to ensure priority in attendance and treatment for persons with disabilities, in the context of healthcare, as embodied in the RPwD Act.
2. Accessible and disabled-friendly vaccination centres: While a majority of the sample had received at least one dose of the vaccination, it was reported that vaccination facilities were not accessible, given inaccessibility to wheelchairs, overcrowding and long queues at the centres, and large distance from home. To address this, the following measures should be implemented:
  - a. Pursuant to the obligation placed on the government to ensure barrier-free access to persons with disabilities under the RPwD Act, vaccination centres should be made physically accessible. This can be done through the availability of ramps, parking spots for wheelchairs, signage with appropriate contrast and colour, etc.
  - b. In line with the requirement to provide reasonable accommodations to persons with disabilities, vaccination centres should have appropriately trained and sensitised resource persons who will be responsible for providing support to persons with disabilities. This includes: (a) the availability of support staff to assist persons with disabilities navigate the vaccination centre with ease; (b) technically competent persons, such as sign language interpreters, who can communicate with persons with disabilities; and (c) a designated point of contact to whom persons with disabilities may reach out to address any questions or concerns. This would be consistent with the emphasis provided on training emergency service providers in the Comprehensive Guidelines published by the DEPwD.
  - c. A question should be added to vaccine registration forms, to bring into play the support system generated for persons with disabilities in the vaccination process and to collect data on the vaccination of persons with disabilities.
3. Informational accessibility and accountability: In the present study, it was found that 61.1% of the respondents were unable to access information pertaining to the pandemic, and 57.7% were unable to access information relating to vaccinations. To address this, and in line with the emphasis on information accessibility embodied in the UNCRPD as well as in the Comprehensive Guidelines by the DEPwD, the following measures should be taken:
  - a. COVID-19 helplines should be available to meet the needs of persons with disabilities during the pandemic. For this, the staff manning such helplines must be provided sensitization training to equip them to address the needs of citizens with disabilities.
  - b. A simple and comprehensible document on FAQs should be drafted for persons with disabilities.

- c. Dissemination activities should take place to ensure awareness of such measures among persons with disabilities.

## ***Policy recommendations for building a disabled-friendly healthcare system***

India's experience with the COVID-19 pandemic offers stakeholders an opportunity to spell out the obligations of the government as they relate to meaningful access to healthcare for persons with disabilities. To this end, we have outlined some benchmarks for ensuring end-to-end comprehensive and holistic accessibility of healthcare facilities for persons with disabilities. This guidance can become a template for ensuring that healthcare programmes in future are disabled-friendly. They are as follows:

1. Digital accessibility of healthcare platforms must be ensured. Any such platform must undergo an accessibility audit prior to its release, and it must be ensured that all issues flowing from the audit are remedied prior to the public release of the platform.
2. Audits must be conducted of the full panoply of services to be provided from the standpoint of disability inclusion, including: (a) accessibility of paperwork and prescriptions; (b) whether reasonable accommodations are being provided; (c) whether the physical infrastructure is disabled-friendly. Consistent with the principle of providing reasonable accommodation to persons with disabilities and the obligation of the government to ensure barrier-free access to healthcare facilities to such persons, as embodied in the RPwD Act, this will help in ensuring the accessibility of healthcare services.
3. A network of technical persons, such as sign language interpreters, special educators and other disability professionals, should be built on the district-level, and connected to healthcare facilities. Having such a network in place would help build resource capacity and enable healthcare facilities to draw on the support of such professionals when necessary. Further, disability sensitization training should be provided to healthcare workers who are tasked with administering any healthcare programme or providing related services. This will help in operationalising the guarantee of reasonable accommodation for persons with disabilities as embodied in the RPwD Act.
4. An accountability and monitoring mechanism should be developed, which would ensure continued compliance with accessibility norms, spelt out in the RPwD Act, 2016. In addition, a grievance redressal mechanism to ensure prompt resolution of complaints should be created. For instance, the DEPwD had designated the State Commissioners for Persons with Disabilities and Nodal Officers for Persons with Disabilities, in the Comprehensive Guidelines, to deal with any disability-related issues. A grievance redressal mechanism must be developed on similar lines, which can assist persons with disabilities in navigating the healthcare system as well as serve as an accountability check on the appropriate authorities.



# Annexure I

## Draft Questionnaire on the Effect of COVID-19 on Access to Healthcare for Persons with Disabilities

### *I. Demographic information*

1. Name
2. Age
3. Gender
4. Place of residence
5. Urban or Rural
6. Educational qualifications
7. Employment status
8. Self-employed

### *II. Disability-specific information*

9. Disability Certificate
10. UDID Card
11. Are you a person with disability?
12. If yes, what is your disability?
13. Are you a person with disability having high support needs?
14. If yes, do you have anybody to support you?
15. How does your disability impact your everyday life?
16. Do you have existing comorbidities (Sickle Cell Disease/Bone marrow failure/Thalassemia Major/Persons with intellectual disabilities/Muscular Dystrophy/Acid attack with the involvement of the respiratory system/persons with disabilities having high support needs/multiple disabilities including deaf-blindness/congenital heart disease/diabetes etc.)?

### *III. Access to healthcare services before the outbreak of the COVID-19 pandemic*

17. Before COVID-19 did you have difficulty in accessing healthcare services ( visiting hospitals for routine check-ups, getting priority treatment in hospitals, accessing medication, emergency care etc.)?

### *IV. Access to healthcare services after the outbreak of the COVID-19 pandemic*

18. Did you face any difficulty in accessing the same healthcare services during the COVID-19 pandemic? If yes, what?
19. Did you test COVID-19 positive?
20. If yes, did you receive appropriate treatment on time?

21. Were you hospitalized or home quarantined?
22. If hospitalized, was the quarantine centre/hospital service accessible?
23. What parts of it were accessible, and what parts were inaccessible?
24. What reasonable accommodations do you think would have improved your access to healthcare during this period?

#### *V. Access to COVID-19 vaccines and the CoWIN platform*

25. Were you able to register yourself on the CoWIN platform?
26. If yes, independently or with support?
27. What difficulties did you face in using the platform?
28. Have you received the COVID-19 vaccination?
29. If yes, partially or fully?
30. Have you received the certificate post-vaccination?
31. Did you receive the vaccination on a priority basis as per the notification by the Ministry of Social Justice & Empowerment, Government of India dated 07.07.21 regarding 'Priority in COVID Vaccination to persons with disabilities as well as their caregivers'?
32. If yes, was it accessible?
33. If no, what challenges did you face?
34. Did you have to make multiple attempts to get the vaccine?
35. How did you reach the vaccination centre from your house?
36. Did you have the opportunity to obtain door-to-door vaccination? Would you have benefited from it?

#### *V. Access to information on COVID-19*

37. Was information about COVID-19 available in an accessible format?
38. Was information about COVID-19 vaccination available in an accessible format?
39. Were you aware of any dedicated helpline that was set up to support persons with disabilities?

#### *VI. Additional information*

40. What is your general perception of the COVID-19 pandemic?
41. Any other information that you would like to share with us?



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