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# **The global COVID-19 Disability Rights Monitor: implementation, findings, disability studies response**

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The global COVID-19 Disability Rights Monitor (COVID-19 DRM, <https://www.covid-drm.org/data>) has been a milestone in the struggle for disabled people's lives and rights during the COVID-19 pandemic. The COVID-19 DRM report (Brennan et al., 2020), published in October 2020, revealed major injustices suffered by disabled people during the first stage of the pandemic. In this paper, we present and discuss the implementation and findings of the COVID-19 DRM, emphasising the centrality of disabled people's voices in this initiative and endorsing the report's recommendations. We also offer a disability studies response by making recourse to the social model of disability, independent living philosophy, and analyses of biopolitics. We argue that the COVID-19 DRM illuminates injustices that predate the pandemic and whose critique needs to guide post-pandemic reconstruction.

## **COVID-19 DRM: implementation**

The COVID-19 DRM resulted from a concerted effort of seven disability rights organisations: Validity Foundation; European Network on Independent Living; International Disability Alliance; Disability Rights International; Disability Rights Unit at the Centre for Human Rights, University of Pretoria; International Disability and Development Consortium; and Disability

Rights Fund / Disability Rights Advocacy Fund. This coordinating group has been actively supported by local groups and organisations of disabled people from around the world. The initiative aimed to assess the impact of the national governments' responses to the pandemic on disabled people. Data collection took place between 20 April and 8 August 2020, when a survey was distributed in 25 languages and in three versions – for disabled people, for relatives and disability organisations, and for government representatives and human rights authorities – via internet and on paper through the implementing organisations' networks.

The survey consisted of 40 closed and open-ended questions formulated in consultations among the implementing organisations and grounded in a human rights-based approach to disability. It received 2,152 responses from 134 countries, including responses from disabled people (n=863), disability organisations (n=525), family members (n=448), governments (n=26), human rights authorities (n=12), and other stakeholders. Most of the respondents self-identified as female (n=1,325), with a much smaller number self-identifying as male (n=695). The majority self-identified as persons with physical disabilities (n=943), followed by persons with intellectual (n=524) and psychosocial disabilities (n=447). To analyse the qualitative data, non-English responses were translated into English by using Google Translate.

The COVID-19 DRM arguably created 'the largest internationally comparable data set on the experiences of persons with disabilities during the COVID-19 pandemic' (Brennan et al., 2020: 19) at the time of the report's publication. The voices of disabled people clearly dominated the responses to the survey, which included many written testimonies that brought the quantitative findings to life and helped reveal the personal implications of COVID-19 policies (see <https://www.covid-drm.org/voices>). Disabled people experiencing intersecting injustices such as disabled women, as well as people routinely excluded from data collection initiatives such

as those with intellectual and psychosocial impairments, were strongly represented in the survey responses.

The COVID-19 DRM was an emergency piece of research and its quick turnaround conditioned several limitations. The survey was not made available in easy-read and sign language formats – however, one of the implementing organisations, the International Disability Alliance, conducted a separate COVID-19 survey targeted exclusively at disabled people and available in ‘plain language’ and International Sign (<https://www.internationaldisabilityalliance.org/covid19-survey>). The COVID-19 DRM had an unequal geographical coverage, with most responses coming from Europe (n=1143, led by Germany), followed by Africa (n=397, led by South Africa), the Americas (n=388, led by the United States), and Asia (n=185, led by India). Underrepresented regions included Northern and Central Africa, Western, Eastern and Central Asia, the Caribbean, and Oceania. Finally, the use of Google Translate potentially distorted qualitative data.

### **COVID-19 DRM: findings**

The COVID-19 DRM report identifies the impact of the pandemic on disabled people as ‘catastrophic’ and calls for ‘urgent action’ to safeguard disabled people’s rights (Brennan et al., 2020: 7). The findings suggest that states have failed to take adequate and sufficient measures to protect the rights of disabled people during the pandemic; in many cases, no such measures have been taken (this failure resonates with the low rate of responses from governments and human rights authorities). Moreover, states have implemented measures that have resulted in violations of disabled people’s rights, including the rights to life and liberty – for example, through ‘imposing dangerous lockdowns on overcrowded institutions, and through heavy-handed

enforcement of public security measures' (Brennan et al., 2020: 7). The authors of the report highlight four areas of special concern:

- (1) undermining of the lives, rights and dignity of disabled people in residential institutions;
- (2) breakdown of essential services in the community such as supply of food, medication, and personal assistance;
- (3) disproportionate harms experienced by underrepresented groups within the broader disability group, including disabled children, disabled women, and disabled homeless persons;
- (4) denial of access to basic and emergency healthcare due to disability-based discrimination in the allocation of medical resources.

In disability policy, the issues of institutionalisation, lack of community services, intersectional harms, and inadequate healthcare are not new, but the pandemic has made them worse. The COVID-19 DRM is first and foremost a call for action. The initiative is still ongoing, and the survey findings have been used for awareness-raising. We endorse the report's recommendations, in particular: development and enactment of deinstitutionalisation plans, including emergency deinstitutionalisation; provision of immediate access to essential supplies and support in the community, including food, medicines, and personal assistance; adoption of special provisions to protect the rights of those most affected, including people with intellectual and psychosocial impairments, as well as people who experience intersecting injustices such as disabled girls and women; guaranteed access to healthcare for all disabled people, without discrimination on the basis of disability; and inclusion of disabled people and their organisations in the design, planning and implementing of the COVID-19 responses on all levels of government.

## **COVID-19 DRM: disability studies response**

We prioritise COVID-19 DRM's findings and recommendations for action because they stem from disabled people's experiences and because they may save lives. As an emancipatory, anti-oppressive activity, disability studies needs not (only) interpret the world but (also) engage in a struggle to change it. However, in a world that is already changing so rapidly, interpretation may be the only way to guide change towards emancipatory, anti-oppressive ends.

### ***COVID-19 and the individual model of disability***

The findings of the COVID-19 DRM strongly suggest that policy responses to the pandemic have been more harmful for disabled people than the pandemic itself. However, government communications and the mainstream media have overwhelmingly steered the attention towards the latter by focusing on the (presumed) enhanced susceptibility of disabled bodies to the virus. This has reinvigorated the medicalisation of disability and has articulated with discourses of individual vulnerability and responsibility that have had undermining, demeaning and pathologising effects for disabled people. Completing the circle, discourses of individual vulnerability have justified harmful policy responses, including enforced confinement to residential institutions. In some cases, homeless disabled people have been rounded up and sent to institutions; bans on leaving institutions (read: infection hotspots) have been widely imposed.

In effect, with COVID-19, the ghost of the individual model of disability, putatively exorcised by developments in disability studies and human rights legislation (notably, the UN Convention on the Rights of Persons with Disabilities) over the last several decades, has returned to the

global disability policy stage with a vengeance. This regression may shape the post-pandemic contours of disability policy. The recognition of the danger calls on disability studies scholars to revisit the basic tenets of (and debates around) the social model of disability. Such a revisiting needs to be intersectional. Echoing policy responses during non-exceptional times, policy responses to the COVID-19 pandemic have prioritised non-disabled, adult, male, financially secure urban dwellers – consider the effects of home schooling on women and disabled children, or of distance working on people with poor access to technology and internet. The consequences for disabled people who deviate in more than one way from this intersectional norm have been dire.

### ***COVID-19 and institutionalisation of disabled people***

The COVID-19 DRM confirms that in many countries, residential institutions have become focal points of infections, suffering and death during the pandemic. Media representations and government communications have tended to explain this situation with the individual vulnerability of residents, in concert with the individualising trends mentioned above. However, it is oppressive structures rather than vulnerable bodies that take centre stage in the COVID-19 DRM report. These structures – the structures of institutional care – emerge when people are forced to live in special places and groups to receive support with everyday tasks and specific needs. The proponents of deinstitutionalisation have regarded this as wrong in non-exceptional times; during the pandemic, the consequences of forcing disabled people to live in congregated settings to receive support have been catastrophic.

The COVID-19 DRM report provides abundant evidence that the problems that characterise residential care in general – including confinement, block treatment, surveillance, abuse,

neglect, overmedication, and lack of transparency and accountability – have either worsened or become more conspicuous since the first lockdowns in March 2010. A striking example is provided by this report on the situation in a residential institution in Quebec, Canada: ‘There were people dead in their beds, others laying on the floor and some others with three layers of diapers and dehydrated.’ (Brennan et al., 2020: 23) Revisiting the basic tenets of the independent living movement and philosophy could help resist the temptation to exceptionalise such accounts by attributing them to the extraordinary situation of an infectious disease that has gotten out of control. Independent living philosophy would also help reconstruct the support networks shattered by the pandemic by prioritising disabled people’s self-determination and preventing further regression towards institutional care.

### ***COVID-19 and the biopolitics of disability***

Healthcare and control are inseparable, and due to medicalisation, disabled people are exposed to control through healthcare (and other forms of ‘care’) to a greater extent than non-disabled people. However, the COVID-19 DRM report has provided evidence that disabled people across the world have been discriminated against in allocation of medical resources, most conspicuously during medical triage – a respondent from the United Kingdom has even suggested that a ‘eugenics programme has been undertaken covertly’ (Brennan et al., 2020: 42). In effect, the emergency created by the COVID-19 pandemic has shifted the biopolitical process of controlling disabled people’s lives through healthcare interventions towards a thanatopolitical process of letting disabled people die through denial of access to healthcare (Davis, 2020). ‘Thanatopolitics’ is politics that lets or makes people die, as opposed to ‘biopolitics’ that enhances life. According to Giorgio Agamben (1998), every biopolitics is essentially thanatopolitics, not least because enhancing the life of some entails decisions about



letting or making others die. For our purposes, it suffices to argue for unconditional access to healthcare and other necessary support in exceptional times, yet without letting healthcare and other forms of ‘care’ off the hook in non-exceptional times.

In sum, the policy responses to the COVID-19 pandemic have illuminated the dire consequences of the continuing individualisation of disability, the ongoing institutionalisation of disabled people, the fragility of existing community-based supports, and the dark side of biopolitics. We need to attend to these issues without exceptionalising the socially created injustices of the pandemic. These injustices are underpinned by systemic flaws that predate the pandemic. The findings of the COVID-19 DRM do not (only) reveal catastrophic exceptions but (also) catastrophic rules of disability policy making. It is these rules that need to be the primary targets of the post-pandemic efforts at reconstruction.

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