Review

Disability-inclusive vaccine equity framework for persons with disabilities in India: A call to action

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Introduction

COVID-19 has worsened long-standing organisational and structural inequalities for individuals with disabilities.[1,2] Equality can only be effective if everyone's needs are the same. This is absolutely not the case with disabled people, as they have different needs specific to their disabilities.[3] Although the government and policymakers claim not to discriminate, this is not borne out on the ground. For example, there is a lack of captioning or sign language interpreters in most health promotion and media interviews, effectively excluding the deaf; vaccination centres remain inaccessible to the disabled; and the CoWin vaccine registration website is inaccessible to the blind, preventing them from registering.[3] The challenges continue as none of the circulars released by the Ministry of Home Affairs during the lockdown or thereafter mention people with disabilities under "vulnerable groups".[4] All of these structural inequalities are rooted in ableism, which refers to actions or policies that regard individuals with disabilities as "invisible, disposable, and less than human" while assuming able-bodiedness as society's benchmark state.[5] This oppression of people with mind-body differences is also intersectional, which the Convention on the Rights of Persons with Disabilities (CRPD) refers to as 'multiple identities,' including characteristics like class, cast, gender identity, sexual orientation, migrant status (homelessness), higher weight (comorbidities) and religion. Such intersectionality contributes to making a disabled person more vulnerable and at higher risk for COVID.

COVID-19 Vaccine Inequity in India

On January 16, 2021, India began its immunization campaign against COVID-19, and on May 1, 2021, it implemented a universal vaccination policy, allowing anybody over the age of 18 to get vaccinated. However, in the list of pandemic vaccine priority groups, disability was missing. The prioritization concept adopted by the National Expert Group on Vaccine Administration for

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COVID-19 (NEGVAC) lacked representation of health professionals with disabilities, and organizations of doctors with disabilities were never involved in the development of vaccine priority groups by either NEGVAC or the Indian Council of Medical Research (ICMR). [6]

There is ample evidence that people with disabilities comprise a highly vulnerable group. Disability-related deaths accounted for 60% of COVID-19 deaths, 3.7 times higher than the overall UK population.[7] There is evidence that Down syndrome has a death rate up to ten times that of the general population.[8] Among COVID-19 mortality risk factors, intellectual disability is second only to age.[9] Those with intellectual disabilities have a higher risk of dying from COVID-19 than those who have congestive heart failure, renal disease, or lung disease. The findings reveal that people with intellectual disabilities are 2.5 times more likely than the general population to get COVID-19, 2.7 times more likely to be hospitalised, and 5.9 times more likely to die from the infection.[9] In India, we do not have any data on this.

According to numbers given by the Health Ministry during the last session of Parliament, only 4,018 people with disabilities had gotten both doses of COVID-19 vaccine as of November 28, 2021.[10] There were 8,390 people with disabilities who got their first dose through the CoWIN portal, as mentioned by the Minister of State. However, the government itself countered this data in the ongoing Supreme Court Case that is seeking proper vaccination facilities for people with disabilities when their affidavit mentioned that 23,678 disabled people have been vaccinated.[11] The Additional Solicitor General stated that the figure of 23,678 came from persons who used their unique identity disability cards (UDID) to get vaccinated and that others might have availed different IDs. In short, we have no way to collect disability disaggregated data despite the Rights of Persons with Disabilities Act (RPDA) 2016 which is in place. As stated in Section 19(2) (f), and more explicitly in the Concluding Observation, of the Committee on the Rights of Persons with Disabilities in India's country report:

"*In view of target 17.18 of the Sustainable Development Goals, the Committee recommends that the State party rely on the methodology of the Washington Group short set of questions on disability statistics to collect, analyse and disseminate data on its population of persons with disabilities, in cooperation with organizations of persons with disabilities, disaggregated by gender, age, ethnicity, disability, socioeconomic status, … ensuring both disability-specific and disability-inclusive or mainstream data collection.*"[12]

As there was no vaccine equity, the discrimination continued in 2021. The Centre dismissed Karnataka's request to set up COVID Vaccination Centres (CVCs) outside of health facilities (old age homes) in March. [13] In Delhi, CVCs were set up in schools, and even malls, but not in old age homes, halfway homes, or institutions for persons with disabilities. Finally, after outrage, NEGVAC in May recommended Near to Home COVID Vaccination Centres (NHCVC) for the elderly and people with disabilities.[14] However, there is often a slip between the cup and the lip. A centenarian woman with an age-related disability in the capital of India struggled to get vaccinated at home despite the suggestion from "Doctors with Disabilities: Agents of Change" (a pan-India group of health professionals with disabilities who advoacte for social justice) that a doctor and a nurse (government officials) who have a disability themselves should provide home vaccination.[15] The organisation also highlighted another marginalised community, the transgender community, who, along with the disability community, had faced historical abuse in medical establishments and deserved dedicated efforts to bridge health inequities.[16]

In September, 2021, public interest litigations

were filed in the High Courts of Mumbai,[17] Delhi,[18] Chennai,[19] as well as in the apex court by the Evara Foundation.[11] Jolted by the demand for the right to health and for vaccination for the disability community, the Health Ministry was forced to recommend vaccination for disabled people at their places of residence using mobile vaccination teams. Further, the Supreme Court of India, in January 2022, directed the Ministry of Social Justice and Empowerment (MSJE) to invite suggestions and responses from all stakeholders and domain experts in the area of disability, and thereafter, the Ministry of Health and Family Welfare should take a decision on whether any modifications or changes were required to make the existing framework of vaccination for the disabled more effective. As a result, the MSJE has issued a public notice seeking suggestions by February 10, 2022.

The lack of disability health equity data has led to omissions in the pandemic response for this group.[20] It is hard to develop evidence-based policies and programmes that are inclusive of people with disabilities unless we have access to disability statistics like we saw above. The threat of ableism to health equity is significant. Included in the solution must be the inclusion of researchers with lived experience of disability.[20] Similarly, allies have been calling for “amplifying people with disabilities in health leadership” to bridge the gap between ‘us’ and ‘them’.[21] As an organisation of health professionals with disabilities, Doctors with Disabilities: Agents of Change take hope from the Supreme Court of India's decision to review the best practices and this paper is an attempt to offer suggestions based on lived experiences of disability in line with the inclusive equality principle enshrined in the human rights model of disability.[22,23]

Disability-inclusive Vaccine Equity Framework

In the global response to vaccine equity, people with disabilities are left behind. So far, only 3% of people in low-income countries have received a vaccine, out of around 7 billion doses given worldwide. Among the ‘missing billion’ (15% of the disabled across the globe), 80% live in developing countries, and 69.9% (18 million as per 2011 Census of India) of disabled people live in rural areas in India. As detailed in the previous section, we do not have data to know the number of vaccinated disabled people. The United Nations Human Rights Office has declared that “affordable, non-discriminatory access to the vaccine is a human right”.[24] Taking this as an overarching aim and using the principles of non-discrimination and reasonable accommodation, we propose a disability-inclusive vaccine equity framework with CRPD’s human rights model of disability at its centre. The human rights model of disability recognizes that “disability is a social construct and impairments must not be taken as a legitimate ground for the denial or restriction of human rights. It acknowledges that disability is one of several layers of identity. Hence, disability laws and policies must take the diversity of persons with disabilities into account. It also recognizes that human rights are "interdependent, interrelated, and indivisible”.[25] The General Comment No. 6 states that CRPD is based on the concept of inclusive equality:

"*Inclusive equality is a new model of equality developed throughout the Convention. It embraces a substantive model of equality and extends and elaborates on the content of equality in: (a) a fair redistributive dimension to address socioeconomic disadvantages; (b) a recognition dimension to combat stigma, stereotyping, prejudice and violence and to recognize the dignity of human beings and their intersectionality; (c) a participative dimension to reaffirm the social nature of people as members of social groups and the full recognition of humanity through inclusion in society; and (d) an accommodating dimension to make space for difference as a matter of human dignity.*"[25]

The box gives details of a suggested Disability-inclusive Vaccine Equity Framework for Persons with Disabilities in India based on the four dimensions of the inclusive equality model. The framework lists specific measures to achieve disability-inclusive vaccine equity; the measures are in line with legal obligations due under the RPDA 2016 and the Mental Healthcare Act, 2017. The overarching goal of the framework is that COVID-19 vaccines should be affordable to all persons with disabilities and should be accessible without discrimination.

Box

Suggested specific measures in keeping with essential principles of Disability Rights[25]

Principle of Non-discrimination

A) Dimension of the Inclusive Equality Model: Redress the social and economic disadvantage associated with disability

* Promote healthcare during the time of natural disasters [COVID-19 pandemic] and other situations of risk [Section 25(20)(i)]
* Redistribute resources (minimize digital divide) as majority of people with disabilities live in rural areas and may not be able to book vaccination slots online. Provide free healthcare in the vicinity specially in rural areas [Section 25(1)(a)]
* RPDA mandates provision of priority in attendance and treatment [Section 25(1)(c)] which should be extended to priority vaccination; people with disabilities should not stand in queues at CVCs or NHCVCs
* Use clear, transparent masks for people with hearing impairments to allow lip-reading

B) Dimension of the Inclusive Equality Model: Address stigma, stereotypes and prejudice based on disability

* Persons with disabilities should not be asked to prove disability
* People with some specified disabilities (athetoid cerebral palsy, person affected by leprosy, amputees, intellectual disabilities, visual disabilities) face difficulty during biometrics (thumb impression and iris scan) and therefore do not have Aadhar cards. Many CVCs insist on the card despite a Supreme Court order on not making it mandatory. People with disabilities should not be coerced and any other identity card be used.
* Wherever possible, people with disabilities should be strongly encouraged to use UDID as data on number of people with disabilities receiving COVID-19 vaccination is not available.
* Homeless people with psychosocial disabilities face issues in following the Government's Test/Track/Treat strategy. As approved by the Delhi High Court, use "9999999999" as a dummy phone number and the address of labs or hospitals for COVID-19 testing of homeless people with mental illness. The court directed the Central government to use the ID of the police officer as an ID proof for homeless people with mental illnesses.[26] The same should be used for vaccination [Section 3 (3) of the Mental Healthcare Act, 2017]
* Consent for homeless people with psychosocial disabilities can be navigated by Nominated Representatives (NR). For example, at Institute of Human Behavior and Allied Sciences, Delhi, the Ashray Adhikar Abhiyan serves as institutional NR.
* States should identify persons with disabilities with high support needs (HSN) as mandated under Section 38 of the RPDA 2016 and such people should be provided with at-home vaccination under special provisions enshrined in the Act. For example, Rule 19(2) of the Delhi Rights of Persons with Disabilities Rules, 2018 calls for framing schemes to provide assistance to HSN. All States should similarly frame schemes for HSN explicitly providing at home vaccination help.
* NHCVCs should be constituted at leprosy colonies, mental health institutions and old age homes.

Box (continued)

Principle of Reasonable Accommodation

C) Dimension of the Inclusive Equality Model: Enhance participation and voices of people with disabilities

* The Department of Empowerment of Persons with Disabilities (DEPD) has set up nine National Institutes (NIs) as autonomous bodies focusing on specific types of disabilities, and 21 Composite Regional Centres (CRCs). Their invisibility during COVID has seriously hampered disability-inclusive efforts.[27] They should be directed by the Apex Court to help people with disabilities book vaccination slots through phone or live assistance. Multiple booking methods should be developed rather than an over-reliance on one app/website.
* Schedule second/booster dose at the same time as the first.[28]
* Those who do not show up at subsequent appointments must be supported by a home visit from the District Social Welfare Officer.
* Provide free accessible transport, pick and drop, as in Delhi elections.
* The District-level Committee on disability (Section 72), State Commissioners for Persons with Disabilities [Section 80(g)] and the Chief Commissioner for Persons with Disabilities [Section 75(1)(h)] are tasked with monitoring and implementing the provisions of the RPDA and schemes and programmes meant for persons with disabilities. They should serve as nodal officers at each hierarchal level with accountability fixed. Many States do not have full time Commissioners and States like Maharashtra (hot spot for omicron surge) have not even drafted State rules to implement RPDA.
* The Central Advisory Board on Disability (CAB) is the highest disability policy-making body [Section 65(2)] at the Centre involving disabled persons organizations. The tenure of the first CAB expired on 7th November, 2020, in accordance with Section 61(1) of the RPDA. It has been more than a year and the new CAB is yet to be constituted.
* All States should be directed to involve/constitute State Advisory Boards on Disability.
* People with disabilities in general and health professionals with disabilities in particular are the real experts on disability. The latter have not been involved in NEGVAC or similar high level expert bodies. 'Doctors with disabilities' are explicitly mentioned as domain experts in the Rule 4(1)(c) of Delhi Rights of Persons with Disabilities Rules, 2018 and Rule 4(c) of the Jammu and Kashmir Rights of Persons with Disabilities Rules, 2021.
* Similarly, researchers with disabilities are missing from ICMR Committees on disability and COVID research.
* Research findings will not be generalizable for the entire community if participants with disabilities are not involved in trials. The nodal department (DEPD) has yet to constitute a Committee for Research on Disability [Section 6(2)(ii)].[29] Only Delhi has constituted a State Committee for Research on Disability to date;[30] other States have failed the legal mandate.

D) Dimension of the Inclusive Equality Model: Accommodate differences by achieving structural change

* All information (before, during, post-vaccination) must be available in multiple and accessible formats: easy-to-read, audio/video, braille, high contrast and large font, accessible infographics, sign language interpretation, local language, plain text, pictorial representation, and text-to-speech compatible.[28]
* All NIs must provide accessible awareness material catering to their specified disabilities: National Institute for the Empowerment of Persons with Visual Disabilities (NIEPVD), Intellectual Disabilities (NIEPID), Multiple Disabilities (NIEPMD), Locomotor Disabilities (NILD), Mental Health and Rehabilitation (NIMHR), Ali Yavar Jung National Institute of Speech and Hearing Disabilities (AYJNISHD), Pt. Deendayal Upadhyaya National Institute for Persons with Physical Disabilities (PDUNIPPD), Swami Vivekanand National Institute of the Rehabilitation Training and Research (SVNIRTAR), Indian Sign Langauge Research and Training Centre (ISLRTC).

Box (continued)

D) Dimension of the Inclusive Equality Model: Accommodate differences by achieving structural change (continued)

* Reasonable accommodation be provided as per the type of disabilities and CVCs should have facility to administer the injection in lying down position or at sites other than the deltoid as per comfort.
* PHCs and mohalla clinics to convert into few dedicated sensory clinics for children and youth with learning disabilities and autism to allay their fears and anxiety about syringes, PPE and hospital noise.
* Vaccine-hesitant parents (VHPs) are more open to vaccination than parents who resist all vaccines.[31] Many parents, particularly those of autistic children, mistakenly believe vaccines caused their child's autism.[32] A recent study found that 23.6 % of parents of children with autism spectrum disorder were vaccine hesitant.[33] National Institute for the Empowerment of Persons with Intellectual Disabilities, Secunderabad, should work with autism centres to conduct sensitization workshops for VHPs.

Global Best Practices

In line with '*Nothing About Us, Without Us*', researchers and health professionals with disabilities at Johns Hopkins Disability Health Research Center and the Center for Dignity in Healthcare for People with Disabilities in the USA launched the COVID-19 Vaccine Prioritization Dashboard to help the disability community as well as policy makers.[34] In Canada, the Ontario COVID-19 Science Advisory collective provided possible accessible pathway towards out-of-home as well as in-home vaccination process for people with disabilities.[28] The *No Body Is Disposable* Coalition was founded to fight disability-based COVID-19 triage discrimination and is now advocating priority vaccine access to high risk COVID with the intersectionality of people with disabilities, fat people, old people, people with HIV/AIDS and other chronic illnesses.[35] The initiative for Health Equity Advocacy and Research (iHEAR), based in Sangath, Bhopal, is a novel attempt from the Global South in that it considers lived experience as an expertise and works to address structural inequities in COVID-19 vaccine access and uptake among transgender and disabled communities in India by involving transgender and disabled people as collaborators, research assistants, and advisory board members for community-based participatory research.[36]

Conclusion

In the landmark Supreme Court decision in Vikash Kumar vs. UPSC, Justice DY Chandrachud stressed on inclusive equality and the enactment of RPDA as a 'watershed event in providing a legal foundation for equality and realization of the rights of the disabled'.[37] The judgement established the linkage between reasonable accommodation and non-discrimination, which serve well as principles in the suggested framework. Further, the use of measures from the inclusive equality model add strength to the disability-inclusive vaccine equity framework which is also justified under the obligations of the disability legislations in India. Such an approach to COVID-19 vaccination - based on human rights - might help people with disabilities with vaccine access and policymakers with vaccine equity. The time has come and we must act now.

Conflict of Interest statement: Dr. Satendra Singh is a collaborator in the iHEAR Vaccine Equity Project for the transgender and disabled communities.

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