

Delivering a disability-inclusive COVID-19 vaccine programme

Guidance note

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Background and rationale

People with disabilities are at an increased risk of COVID-19 (UN, 2020a; WHO, 2020), and are likely to have greater risks of experiencing more severe symptoms, complications, or even death (Armitage and Nellums, 2020). Article 25 of the UN Convention on the Rights of Persons with Disabilities (CRPD) reinforces the right of people with disabilities to attain the highest standard of healthcare, without discrimination. However, people with disabilities have reported experiencing exclusion, discrimination and neglect during the response to the pandemic.

As vaccine programmes are now starting to be rolled out, it is time to reflect on how to ensure that every person has equitable access, and that the most at-risk are reached. The vaccine rollout must not exacerbate existing inequalities. It is therefore necessary to design an inclusive and accessible programme, where targeted strategies will consider the needs of diverse groups in access to information, skills training for healthcare providers, accessible vaccine centres, and prioritisation.

This guidance note is primarily aimed at healthcare workers, health planners and other mainstream health delivery agencies involved in vaccination programmes, to ensure an inclusive approach to planning, financing, implementing and follow up. It will also be of use to organisations of people with disabilities (OPDs) and other civil society organisations to advocate for disability-inclusive vaccine programmes.

Methodology

This guidance note was developed by reviewing the literature around disability-inclusive vaccination programmes, as well as key informant interviews with stakeholders including NGOs, OPDs, disability activists and health planners. Interviews and focus group discussions were held with people with disabilities in the UK. This note draws on the experience of vaccine rollout and planning in several countries – India, Bangladesh, Kenya, and Liberia. The UK has also been included to enable learning from its national rollout.

Ten key recommendations

This guidance note focuses on ten key areas where vaccination programmes can ensure that people with disabilities are not left behind. Recommendations are designed to be contextualised to develop national guidance and policy for vaccine rollout that is inclusive of people with disabilities.

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1. Meaningful consultation

There was little evidence of consultation with OPDs and disability organisations around vaccine rollout strategies. Where consultations were held with disability organisations in Bangladesh and the UK, recommendations for disability-inclusive strategies were often ignored and promises were not kept. In Bangladesh, a formal letter was sent by a disability-focused NGO, but no action has been taken on its recommendations. A cultural shift is needed for the genuine inclusion of people with disabilities, including the co-development of policies, vaccine rollout strategies and procedures.

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[Vaccine] strategies need to be devised through consultation. The solution will come from people with disabilities themselves. They know what kinds of difficulties they experience.

NGO representative, India

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Recommendation:

Hold multi-stakeholder consultations on the development of a disability-inclusive vaccination strategy. This should include people with disabilities and OPDs, disability organisations, NGOs, civil society, and government representatives. Include recommendations from consultations in rollout strategies and frameworks. Ensure representation of people with disabilities in all vaccine committees and working groups.



2. Prioritising people with disabilities

People with intellectual impairments are often at increased risk of COVID-19. The UK Office for National Statistics found that people with intellectual impairments are 3.7 times more likely to die from COVID-19 than people without an intellectual impairment (ONS, 2021). However, they are often missed out in priority lists. In the UK, people with intellectual impairments had been included under the umbrella of 'vulnerable', which was low on the priority list. On 24 February 2021, following advocacy by civil society, NGOs and the media, the government changed the priority lists, meaning that 150,000 people with intellectual impairments will now be prioritised to receive the vaccine.

In most of the lists reviewed, eligibility criteria were based on age or frontline worker status. Very few gave specific priority to people with disabilities. This is despite OPDs in some countries making specific requests to include people with disabilities as a priority group. Some lists gave some priority to people living with 'chronic health conditions' or who are considered 'vulnerable'. This fails to consider social aspects of disability, excluding people who do not have chronic conditions but rely on personal assistants or are less able to social distance, putting them at increased risk.

Recommendation:

Vaccine rollout strategies should give priority to people with disabilities and their support networks as a specific at-risk population. Priority lists should be responsive to new data and feedback from OPDs and disability organisations to ensure that they give sufficient priority to people with disabilities and their support networks, such as personal assistants, family carers, and people working in disability-related services. These groups should be considered essential workers.

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[The priority lists] talk about people with vulnerability as a broad statement. It would be good to see the details of what they consider vulnerable to be.

NGO representative, Kenya

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People with intellectual impairments are 3.7 times more likely to die from COVID-19 than people without an intellectual impairment

3. Accessibility of vaccine rollout

Vaccines in India are being rolled out through an implementation chain that starts with primary health centres and runs through to community health centres. Local government buildings (Panchayat Bhavan) are being repurposed as outreach centres for vaccine distribution. However, as some of these buildings are old, they may not be accessible to people with disabilities.

Bangladesh uses an online app for vaccine registration. This app is not accessible for people with visual impairments as it does not support screen reading software. The use of pictures in the app, while helpful for people with low literacy, makes it difficult to navigate for people with low vision.

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[Health workers should] go to their homes if they can't go to the vaccine centre, the people who give the vaccine should go to their homes if they can't get out.

NGO representative, UK

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It's about the journey, not just the needle.

NGO representative, UK

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Recommendation:

Vaccine centres must be accessible for people with a range of different disabilities. Disability accessibility audits should be undertaken to ensure that all vaccination centres have ramps or step-free access and are fully accessible. In addition to ensuring that mainstream services are disability-inclusive, additional services should be targeted specifically towards including people with disabilities – a ‘twin-track’ approach (DFID, 2000). This should include outreach to people with specific impairments (particularly people with sensory or intellectual disabilities), at-home vaccinations for people who are unable to reach vaccine centres, and transportation services.

Recommendation:

Work with OPDs to develop flexible registration processes that are accessible for all people with disabilities. Web-based services should be fully accessible, while ensuring respect for private life and confidentiality of health-related information. Technology and mobile companies should work with organisations with expertise in accessible technology, such as Leonard Cheshire, to develop accessible registration apps and portals, which should be reviewed and tested by OPDs to confirm their usability. Registration should also include offline, low-tech registration for people who do not have access to data or technology.

4. Accessible information and communication

In the UK, even where materials were developed in a range of formats, this was not made widely known and vaccine letters were often sent in inappropriate formats to people with sensory impairments. UK Government COVID-19 press conferences still rarely include sign language interpretation for people with hearing impairments (although those in Scotland and Wales now do).

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There needs to be more information to do with disability [and vaccines] ... disabled people get left out, they're always talking about able-bodied and not the disabled... not having enough detail about disability.

Person with disabilities, UK

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I would like [vaccine information] in pictures then they don't have to read it to me.

Person with disabilities, UK

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Recommendation:

Work with national OPDs to develop vaccine information in a range of formats so that it is accessible to all people with disabilities, and promote availability of accessible formats widely. National briefings should always include sign language interpretation and subtitling. Train health workers and community volunteers to communicate information about vaccines to people with disabilities.

Recommendation:

Properly resource OPDs so that they can become partners in rollout information campaigns that reach the most marginalised populations and ensure that messages are clear, inclusive and accessible.

5. Affordability

There was no evidence of current national budgets for COVID-19 vaccine programmes that include funding allocations for people with disabilities.

Financing for vaccination rollout should consider a range of factors, including:

1. Delivering vaccines free or at minimal cost for people with disabilities.
2. Accounting for additional costs required for programmes to target people with disabilities.
3. Covering transportation and additional costs faced by people with disabilities.

In Bangladesh and India, vaccines are being distributed at no cost to the target population through government health centres. However, individuals still need to get to the vaccination centres, which often involves out-of-pocket expenditure for transport and personal assistance. This additional cost may be unaffordable for people with disabilities.

Recommendation:

Vaccines are a global public good, and should be made free of charge to all people. Ring-fenced funding should be allocated in the budget to address additional costs of reaching and including people with disabilities in the vaccine rollout (e.g. subsidised transportation). People with disabilities and their support networks should access vaccination on a free and informed consent basis. Social protection programmes already in progress can be refocused towards vaccine distribution targeting people with disabilities.

There was no evidence of current national budgets for COVID-19 vaccine programmes that include funding allocations for people with disabilities



6. Intersecting factors

Researchers from the UK found that inequalities experienced on the basis of health, poverty and ethnic identity are associated with a greater risk of contracting and dying from COVID-19. They recommend door-to-door vaccine provision to tackle vaccine inequalities and reach all people, including people with disabilities (Treloar and Begum, 2021).

In Liberia, mobile clinics which travel from village to village using motorbikes have been effective in distributing polio vaccinations to reach inaccessible populations. This existing infrastructure could be used to distribute COVID-19 vaccines.

Recommendation:

Intersections of risk should be considered when designing vaccination programmes. Populations at greater risk will vary in different contexts but may include age, gender, ethnicity, refugee status, geography and poverty. All electronic information systems related to vaccination must collect data disaggregated by age, gender and disability. Planners should work with OPDs, particularly those specific to at-risk populations (e.g. women with disabilities), to ensure that they are reached by vaccine programmes.

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Especially in the remote corners, getting the information is very difficult... [fragmented information] doesn't give a clear picture of what is happening, so it will have a lot of adverse effects.

NGO representative, India

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Recommendation:

The vaccine rollout should include strategies to reach people with disabilities in rural areas. Consider repurposing existing health infrastructure to ensure that people with disabilities in rural areas have access to vaccines. This infrastructure must be made accessible to all people with disabilities.

7. Leadership as disability advocates

Leonard Cheshire in Kenya already works closely with the National Council of Persons with Disabilities (NCPWD) on a livelihoods project. Such partnerships and close collaboration can be built upon to ensure that when the rollout strategy is developed it has the expected reach to people with disabilities. It would also provide the opportunity to advocate for disability representation on the vaccine rollout committee and technical working group.

Recommendation

Health implementers should become advocates and champions for people with disabilities. They should show strong leadership in disability-inclusive vaccine promotion and implementation, working in partnership with OPDs and disability organisations.

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If [government] say that vaccine centres should be inclusive, then everyone will follow.

OPD, Bangladesh

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When it comes to a crisis like COVID, usually matters of inclusion are relegated. There is a need to engage and there is need for sensitisation, especially for the Ministry of Health, so that they are able to understand matters of persons with disabilities.

OPD, Kenya

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8. Disability awareness training

In the UK, an individual with breathing difficulties who used oxygen cylinders to breathe arrived at a vaccine centre with a two-hour oxygen supply. However, the wait for vaccinations was over five hours. When the individual asked the staff at the centre if they could be prioritised, they were told that this was not an option, and that they should come back another day. This lack of sensitivity to the situation of the person with disabilities caused unnecessary distress and was discriminatory.

Recommendation:

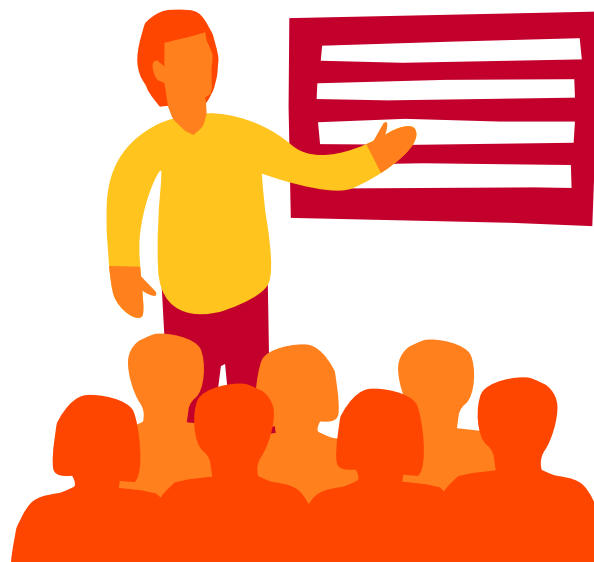
National and community OPDs should provide disability awareness training to all people involved in vaccine rollout. This includes health workers and volunteers, as well as ministry officials and health planners with responsibility for designing and steering the vaccine programme at local and national levels. Health workers should be trained to support people with complex support needs. Funding to OPDs should be provided to enable them to deliver the trainings.

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There's a disproportionate representation of [training for] carers in elderly or dementia care... In the last four years everything I have attended has been geared towards that age group.

Care home coordinator, UK

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9. Promoting acceptance

Several countries emphasised the importance of high-profile individuals expressing support for the vaccines and making their own vaccination public. This includes political figures but also community leaders and high-profile OPD members and people with disabilities. This can promote acceptability and address hesitancy and negative fake news. However, in Bangladesh a workshop was held with OPD leaders, and out of the 13 that attended, none were registered for vaccination. This is a missed opportunity for local level advocacy and promotion of vaccine acceptance.



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Until [the vaccine] is fully tested there will be hesitancy. The people know it takes years and now we have done it in 8-9 months.

NGO, India

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[Fake news] comes when there's no information being released from official channels. It requires information from the actual source.

Person with disabilities, Liberia

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Recommendation:

Work with existing information channels, including community leaders, health volunteers and town criers, as well as social media, to disseminate vaccine information that is accessible to all people with disabilities. Promote high-profile individuals, including people with disabilities, in encouraging vaccine acceptance.

10. Community attitudes

A Leonard Cheshire survey undertaken in Kenya and Bangladesh found that over half of Kenyans surveyed (57%) and more than a third of Bangladesh respondents (39%) had been subjected to discrimination based on their disability during the COVID-19 outbreak.

Recommendation:

Work with OPDs and community leaders to sensitise community members to understand the risks faced by people with disabilities and why they should be prioritised for vaccines. Ensure that people with disabilities are represented in community meetings. These should be accessible to all people with disabilities.

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People don't understand why people with disabilities may require vaccinations. Many people believe that people with disabilities don't get sick, there's a lot of misconceptions out here.

OPD, Kenya

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Further information

Why has the European Union not included people with disabilities as a priority in the vaccination of Covid-19?, EDF Open letter to EU institutions (October 2020)

Human Rights Report: Impact of Covid-19 on persons with disabilities, EDF (2020)

Reach the furthest behind first: Persons with disabilities must be prioritized in accessing COVID-19 vaccinations, International Disability Alliance (IDA)

Credit and disclaimer

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