

How can health and social care services promote the safety and well-being of people with intellectual disabilities during the COVID-19 pandemic in LMICs?

The question and the problem

Globally, there are 108 million people living with intellectual and development disabilities (IDD). Evidence repeatedly shows that people with IDD are more likely to experience co-morbidities, yet tend to face several barriers to access health care services. This has resulted in a widespread health inequality, with evidence from high-income countries indicating that people with IDD live on average 20 years less compared to those without intellectual disabilities. It is clear that people with IDD are also at substantially higher mortality risk from COVID-19, particularly people with Down Syndrome. The global COVID-19 pandemic has also contributed to further challenges to the physical and mental well-being among people with IDD as well as people with disabilities in general. In this brief, we have summarised the current evidence on strategies that would facilitate the safety and well-being of people with IDD.

Recommendations

- Recommendation #1: People with IDD should be prioritised for COVID-19 vaccination, in particular people with Down Syndrome
- Recommendation #2: Vaccine promotion campaigns for people with IDD should be inclusive, person-centred, and focussed
- Recommendation #3: Reasonable adjustments should be made to clinical policies and practices to ensure equity of access and provision for people with IDD
- Recommendation #4: Robust behaviour support response plan should be put in place for people with IDD, particularly those with behaviours of concern.
- Recommendation #5: Strengthen data collection to assess the impact of COVID-19 on people with IDD as well as their caregivers
- Recommendation #6: Take a collaborative approach including people with IDD and civil society organisations to inform all policies and programmes that facilitate their safety and well-being during the COVID-19 pandemic

“Prioritization of the access to COVID-19 vaccines should follow a human-rights approach, considering: (1) infection risk and severity of pre-existing diseases; (2) social vulnerabilities; and (3) potential financial and social effects of ill health.”

[Sekalala 2021]

Challenges

Challenge #1: COVID-19 pandemic disproportionately affects people with IDD.

- Data from the UK suggest that people with IDD are approximately 4-5 times more likely to be hospitalised for COVID-19, and 7-8 times more likely to die, compared to the general population. They are also more likely to die at a relatively young age compared to the general population. Furthermore, the risk is greater among those with moderate-to-profound type of severity, and with an underlying health condition such as epilepsy, mental health condition, difficulty in swallowing, Down's syndrome, and dementia. These findings are consistent with patterns of elevated health and mortality risks pre-pandemic; Respiratory conditions are leading causes of early death among people with IDD.
- People with IDD are more likely to become infected with COVID-19 as a result of exposure to carers, residency in care homes and/or lack of accessible information on protective measures.

Challenge #2: Vaccine availability may be limited, particularly in LMICs, where vaccination uptake is hampered by perceived barriers.

- There is great global inequity in the availability and supply of vaccines. As of October 2021, while 35% of the world population have been fully vaccinated only 2.5% of people in low-income countries have received at least one dose. On the contrary, over 90% of people with IDD in England received at least one dose of COVID-19 vaccine by the 1st quarter of 2021.
- There is robust evidence that COVID-19 vaccinations are safe and effective in reducing the adverse effects of COVID-19. Although there is a concern regarding generalisability of the trial findings to specific population groups including people with IDD, a recent modelling study showed that the proportion of people with Down's syndrome who fall in the top 5% of high risk of adverse outcomes despite getting vaccinated is very small (0.04%). While the acceptance for COVID-19 vaccination is very high in England, there are reports of vaccine hesitancy from certain population groups. Some of the reasons include lack of understanding about vaccine eligibility, concern about side effects, reservation about the effectiveness of beliefs that the vaccination is not effective, perceptions of not being at sufficient risk from SARS-CoV-2, being against vaccines in principle, and not having the time. Contextual factors including attitudes (i.e., the positive and negative evaluations of the vaccines) and beliefs (e.g., beliefs about capability to take up vaccines, beliefs about the consequences of having a vaccine) have been cited as important explanatory factors.

Challenge #3: Healthcare policies and practices do not provide quality or need-based reasonable adjustments to people with IDD.

- Several studies show that healthcare professionals lack specific knowledge and understanding of intellectual disability and have limited experience of working with people with IDD. This lack of knowledge and inexperience can give rise to negative attitudes and misconceptions. As a result, provisions for reasonable adjustments are often overlooked.
- People with IDD are more likely to experience serious adverse outcomes due to COVID-19 and require intensive therapy such as mechanical ventilation and oxygen therapy. However, there are reports of reduced compliance with the treatment protocol such as wearing oxygen mask resulting to worsening of respiratory complications.
- Information barriers exist to taking part in vaccination programmes, as information is not provided in accessible formats (e.g. Simple language for people with intellectual disability). Facilities where vaccination occurs may be physically inaccessible or transport to them may be inaccessible. People with may rely on carers in accessing vaccination, creating a further barrier to access.

Challenge #4: There has been a negative impact on the health and well-being of people with IDD as a result of 1) policies and strategies measures put in place to minimise the spread of COVID-19 infections, and 2) the disruption of routines services.

- During the COVID-19 pandemic, there have been an increase in the incidence of behaviour of concern such as verbal or physical aggression, withdrawal, self-harm, and property damage among people with IDD. Additionally, they are at greater risk of experiencing loneliness, agitation, anxiety, distress, and in some cases increased challenging behaviour.
- Behaviours of concern are influenced by environmental factors such as the physical environment, inadequate staff communications, substantial reduction in the availability and access to face-to-face services, disrupted social interaction opportunities, limitations to personal freedom, restricted living environments, disruptions to routines, the absence of staff not trusted or known to the person with IDD, staff turnover, and not having contact with their family. The disruption of routine services, such as special education, social interaction or physiotherapy, have been common and deleterious for people with IDD.

Challenge #5: Lack of inclusive data collection on the pandemic situation of people with IDD

- Adequate data collection systems can ensure that people with intellectual disabilities receive the right types of health protection actions including prevention, treatment, and mitigation measures at the right time. However, a recent scoping review found that there is lack of data on COVID-19 trends among people with IDD. Absence of accurate data on the impact of COVID-19 on people with IDD can also make it difficult to accurately identify the need for health services including lobbying for prioritisation of COVID-19 vaccination
- Where data collection systems do exist they are often incomplete. For instance, England has GP Learning Disability registers, but they may include only 23% of adults with IDD. Lack of data collection systems risks potential under-reporting of COVID-19 cases and under estimation of COVID-19 related deaths. This risks the generalisation of measures targeted at the general population to people with IDD.

Challenge #6: Lack of representation of people with IDD in research

- People with IDD have often not been consulted in COVID-19 related research. Involving disability advocates in the design and monitoring of public health and policy responses to the COVID-19 pandemic is a key element to assure and promote the mainstreaming of disability rights in all response programs. These participatory approaches in policy design and implementation can avoid discriminatory practices, rights violation, and promote reasonable adjustments in policies and practices to prevent health and social disparities.
- In order to learn about the impact of the pandemic in the lives of people with IDD, it is essential to capture important and relevant experiences, which require research to take a co-productive collaborative approach with people with IDD, families, carers and civil society organisations.

How did we find answers

We conducted a review of epidemiological data and systematic reviews assessing the risk of COVID-19 death and/or hospitalisation as well as potential strategies to reduce the impact of COVID-19 among people with IDD. Majority of the data came from high income settings. We only focussed on the literature written in English.

Policy priorities

The inclusion of people with IDD should be incorporated into national and international policies on COVID-19 vaccination, and this may require more than good will, effective governance, guidelines, and advocacy strategies. Meaningful inclusion will need to be reflected in planning, budgets, vaccination campaign strategies, reasonable adjustments to clinical practices and policies, communication, training of healthcare workers and partnership with locally-based civil society organisations. The unprecedented impact of COVID-19 pandemic on the lives of people with IDD further emphasises the urgent need calling all nations, particularly in LMIC, to pay attention to the Article 31 of the UNCRPD regarding statistics and data collection. Robust data collection system, disaggregated by age and gender, is urgently needed to assess the impact of COVID-19 pandemic on people with IDD as well as to inform appropriate preventive and responsive measures. Finally, multiple stakeholders including people with IDD should participate in all stages of planning, implementation and monitoring policies and programmes for managing COVID-19 pandemics.

Evidence-informed Recommendations and Actions

GAPS & RESEARCH NEEDS

Data is required on the risks of COVID-19 mortality and hospitalisation for people with IDD from low and middle income countries.

In-depth reviews of the spectrum of actions in response to the pandemic to support the needs of people with IDD, including inclusive vaccination programmes are required to learn from the global experience and to prepare and plan for the future.

Task shifting using lay community health workers are considered to facilitate mental health interventions for people with IDD in LMIC. What does this mean? Is there a simpler way of saying it? Further research can explore whether such a model can be adopted in LMIC to replicate the role of intellectual disability specialist

Key Recommendations

People with IDD should be prioritised for COVID-19 vaccination, in particular people with Down's Syndrome

Actions

People with IDD should be prioritised to receive the COVID-19 vaccination. In the short-term, vaccine programmes should engage locally-placed civil society organisations to ensure that programmes are appropriate for people with IDD, including:

- *Accessibility of programmes (informational and physical);*

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- *Acceptability of processes, including identification of people with IDD. In the longer term, countries should consider establishing Intellectual/Learning Disability registers to support health service prioritisation, as has happened in England. Disability awareness should be included within vaccination distribution protocols and training. Training can be supported through supervised placements, resource packs, workshops, e-learning resources and service user-led training.*

Vaccine promotion campaigns should be inclusive of people with IDD, meaning that they are person-centred, and focus on measuring the performance of the actual behaviour, i.e. getting the vaccine

Vaccine efficacy/effectiveness, vaccine safety, and adverse vaccine side effects are the most influential factors that affect people's willingness to vaccinate. Vaccination campaigns should be tailored to people with IDD and their carers, including the need to consider literacy as well as avoiding jargons (e.g. scientific terminology), so that their specific information needs and that of carers are clearly addressed and are informed by evidence. Present the information using story-telling techniques where people with intellectual disabilities are the centre of the story (e.g., see [Beyond Words](#) ; [CDC](#)). The information can include social stories to explain the wearing of personal protective equipment (PPE). Campaigns should include short messages that are relevant, and explicitly discuss the facts about the vaccines, without over-emphasising the health benefits of vaccination. Vaccine eligibility should be clear, which may involve tailoring messages as new information becomes available. Health authorities designing campaigns should review the delivery preferences of target populations to ensure messages are accessible and acceptable. Text message prompts for vaccination coming from the General Physician carries greater weight, and can include information about virus prevention and clarifying any common misunderstandings about the vaccination. When using other communication modes such as email or postal mail include a map of the vaccination centre. Furthermore, identify inconsistencies in messages from uncontrolled sources such as social media to dispel the impact of any negative propaganda regarding the effectiveness of vaccines. Increase the awareness of people with IDD and their carers on the risks of the virus to their own health and the health of others. Frame the message to emphasise positive beliefs about one's own health and that preventative behaviour is within one's control. Additionally, provide clear public health messages tailored to people with IDD regarding mitigating strategies such as managing health and hygiene, early identification of COVID-19 symptoms, and the appropriate contact details to get further information, guidance, and support.

Reasonable adjustments should be made for people with IDD to clinical policies and practices to ensure equitable healthcare access and provision

People with IDD should receive reasonable adjustments during their interactions with health and/or social care services. This may include outpatient appointments, community health care centres for vaccination, or hospitalisation due to COVID-19. Adjustment needs should consider the following aspects: physical features, auxiliary aids and services, policies and procedures, and behavioural and emotional adjustments. In high-income countries, intellectual disability specialist nurses have been found to play a major role in ensuring that people with IDD receive continuous and consistent health care. As the specialist nurses have established prior rapport with people with IDD they can facilitate safety and well-being through obtaining consent to treatment (e.g. using oxygen masks) and ensuring person-centred care. People with IDD and/or their carers can be offered to have a telephone consultation with the nurse prior to visiting the vaccination clinic to assess their suitability to receive the vaccine, and explore the likes and dislikes to ensure that the subsequent visit to the clinic is person-centred. WHO recommends offering vaccines to people with disabilities at home or using mobile clinics to overcome barriers related to accessibility. When communicating with people with IDD, health care professionals should convey a single information at a time, speak slowly, use the local language and in short sentences. Staff wearing PPE should introduce themselves, use a photograph on the protective clothing to help with identification, address the service user by their name, and adopt a positive tone. Family members and carers play a significant role in the support, health, and well-being of people with IDD for e.g. during the period of hospitalisation they help with feeding and personal care, facilitate communication and are involved in discharge planning. However, if there is a no-visitors policy or in the event of the main carer becoming ill, then alternate strategies such as health care professionals substituting the role of carers or provision for virtual communication to take place between people with IDD and family members should be provided.

<p>Robust behaviour support response plans should be put in place for people with IDD, particularly those with behaviours of concern</p>	<p><i>Assess the impact of COVID-19 experience on the mental health and overall well-being of people with IDD. Monitor and address immediately any behavioural changes that might arise during the course of the pandemic including timely access to psychosocial supports and services and behaviour support specialists.</i></p> <p><i>Family members and carers should have access to training, information and resources in positive behaviour support, developed, and delivered by behaviour support specialists. Additionally, educate carers and people with IDD on the signs of infection with COVID-19 along with behavioural measures to reduce the spread of infection.</i></p> <p><i>Behaviour support plans should include relevant safeguarding mechanisms such as monitoring and reporting the use of restrictive practices.</i></p>
<p>More data should be collected to assess the impact of COVID-19 on people with IDD as well as their caregivers, which would then inform health and social care priorities</p>	<p><i>Allocate resources to establish a robust data collection system specifically for people with IDD, disaggregated by age and gender. This is essential to monitor the impact of COVID-19 among people with IDD and thereby inform the planning and provision of the necessary care and support, e.g. approaches to measure and facilitate access to mental health services.</i></p> <p><i>Collect data on relevant health outcomes related to COVID-19 such as infection, illness, hospitalisations and deaths among people with IDD; and any adverse effects experienced by people with IDD as a result of the COVID-19 vaccination. Additionally, record any social factors such as type of home or accommodation, number of people living in a household, and exposure to multiple support workers that can potentially increase the risk of infections.</i></p> <p><i>Governments should provide regular updates, in accessible forms, on the COVID-19 vaccination coverage for people with IDD.</i></p> <p><i>Further research should be conducted with both people with IDD and their caregivers, to obtain data regarding their lived experience during the pandemic. This can then inform the development of potential strategies to address the negative impact of future pandemic such as social inclusion and reducing caregivers' strain.</i></p>
<p>Take a collaborative approach including people with IDD and civil society organisations to inform all policies and programmes that facilitate their safety and well-being</p>	<p><i>People with IDD and their respective civil society organisations should have the opportunities to actively engage in the development, implementation, monitoring, and evaluation of policies and programmes that concern them.</i></p> <p><i>A recent study reported a list of competencies required, for all stakeholders including both with and without an IDD, to facilitate effective participation of people with IDD in inclusive research. They include:</i></p> <ul style="list-style-type: none"> ● <i>Establishing a trusting relationship – allocate sufficient time to get familiarised with the project, people, and environment; all stakeholders should have the basic attributes such as being respectful, honest, reliable, motivated, and realistic expectations.</i> ● <i>Communication – listening skills and the ability to transfer information; and opportunity to give, ask, and receive feedback.</i> ● <i>Collaboration – share tasks and responsibilities; provide clear guidance in terms of the specific tasks such as goals, roles, and expectations; opportunity to practice the task in advance.</i> ● <i>Capacity development – undertake need-based skill assessment followed by appropriate training to acquire the necessary skills. Similarly, support civil society organisations such as organisations for people with disabilities with resources required to engage at different stages of the policies and programmes, e.g. ethics committee access, data analysis tools.</i> ● <i>Support network – assign a named contact person to facilitate integration of people with IDD to the team as well as clarifying any queries that might arise at the onset. Actively engage with people with intellectual disabilities, carers, and civil society organisations in potential projects, in meaningful roles rather than a tokenistic gesture, to inform policies and programmes such as to:</i> <ul style="list-style-type: none"> ● <i>explore effective accommodation strategies to the pandemic measures, including any changes and/ or adaptations to access health and social care services (e.g. use of technology to provide virtual visiting and telemedicine systems) as well as mitigation measures to pandemic response (e.g. home schooling, working from home, recreational activities).</i> ● <i>design and evaluate the effectiveness of various vaccination campaign strategies as well as receiving vaccinations in the community settings including place of residence. Additionally, explore future pandemic response strategies, e.g. algorithms or guidelines on how to make future pandemic management accessible and inclusive.</i>

Conclusion

People with IDD are at high risk of adverse COVID-19 outcomes and should be prioritised for vaccination. In addition to providing inclusive access to health care and provision, further evidence is needed to inform appropriate preventive and responsive measures to minimise the harm from the COVID-19 pandemic.

Acknowledgements

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