Thinking beyond the inclusiveness of “Disability competencies for an Indian Medical Graduate” in normal as well as crisis conditions - A community perspective

Dear Editor,

In the article titled “Disability-inclusive compassionate care: Disability competencies for an Indian Medical Graduate,” the authors have pointed out beautifully that the new curriculum of the Medical Council of India (MCI) lacks disability-related competencies for the Indian Medical Graduates. But we feel that not only the IMGs, the concept should be percolated down to the community level on an urgent basis. We need disability-inclusive compassionate care at the individual level, community level, and at the national level during normal or emergency situations, besides inclusion in MCI curriculum (long term vision).

People with disability (PWD) often suffer from poor health. They face lower literacy levels, poor finances, and poor environmental conditions. This accentuates the adverse conditions and many obstacles they face in their routine life. They have greater vulnerability to comorbidities like pain, UTI, bedsore, pneumonia, malnutrition, injury, osteoporosis, etc. All PWD need access to optimum health care services.

Implications of COVID-19 pandemic are much different for the PWD, who are more likely to have co-morbidities that make them more vulnerable to acquire the infection. They are more likely to under-recognize the risks, having a lesser compliance with the public health measures, and under-reporting suspected illness that may be associated with COVID-19.

Since 24th March 2020, India is under nation-wide lockdown. This has made the situation difficult for PWD, especially their activities of daily life. There is no evidence of any specific official guidelines for care PWD.

PWD is considered as high risk and neglected population in any type of crisis faced by people. For example, the fatality rate of PWD has higher (2.06%) than the general population during the tsunami in Japan in 2011. PWD may not be prepared for emergencies. Although, The United Nations Convention on the Rights of Persons with Disabilities (CRPD) Article 11 called upon States Parties to take “all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.” But in ground-level its implementation is very difficult indeed.

Many barriers prevent their access to various health, education, employment, and transport-related services. This is due to a lack of adequate policies, standards, information, communication, accessibility, or funding. What makes their plight more poignant is the gross lack of their participation in the decision-making process that affects their lives. Among them, women with disabilities, children, and intellectually disabled persons face more problems.

It is often difficult for the PWD to adhere to all recommended preventive measures in contributing towards COVID-19 prevention. As a result, PWD have poorer health-related outcomes.

PWD are at heightened risk to contract COVID-19 or face adverse consequences of the infection because of the following reasons:
1. PWD may experience physical barriers in accessing to hygienic facilities for personal care. They may not even be able to visit washrooms personally for frequent hand washing.
2. Few PWD use wheelchair or any assistive devices for their movement, which may also be handled by the potentially infected caregivers. This can accentuate their chance of contracting the infection.
3. It is exceedingly difficult for the most PWD to maintain physical distancing.
4. PWD service providers also face many problems, like identifying PWD, lack of training, lack of specific guidelines, logistics, etc.
5. COVID-19 pandemic may limit the capacity of caregivers and care-settings to provide support for PWD as they are disconnected from their families, and traditional caring mechanisms by the community or family members have become non-functional.

Many countries (Italy, USA) have made harsh policy decisions to give priority to life-saving treatments/ventilators to the younger population who have more chances for survival. Sadly, older people and PWD have been de-prioritized as far as health services provision is concerned.
Following measures are urgently needed at individual, community, and national level to protect disabled persons as the pandemic accelerates:*

1. PWD must receive COVID-19 prevention-related information through appropriate channels.
2. PPE to be provided to PWD
3. PWD should be included in COVID-19 preparedness plans.
4. Zero tolerance for any institution refusing care to the PWD.
5. Assured access to COVID-19 prevention/control services for PWD
6. Establishment of an expert committee for ensuring PWD welfare in COVID-19 crisis
7. Customize ‘Arogyasetu’ (A mobile application for combatting COVID-19 for all people) for PWD

It is early to say that these actions can address all the inequities among disabled people, but it can be a good start.

Health systems and organizations should be proactive to such changes and initiate discourses engaging communities and policymakers. It is necessary to recognize that community members may have better insights regarding local challenges and resources that may be useful for planning future health and social care. On the other hand, the policymakers may need to understand how existing gaps can be addressed engaging local, regional and national resources and strategies. The role of the healthcare providers, in this way, extends beyond delivering medical services. Protecting PWD during this pandemic and afterwards would need participatory decision making and healthcare leadership.

We need to help the PWD at the individual level by giving priorities to them to access the preventive/control measures for COVID-19 pandemic. This needs to be done in an effective way with full empathy so that they do not feel that they are left alone during this crisis. As a society, it is our duty to assure creating an enabling environment for PWD in COVID-19 crisis. There is also a need to address barriers to their participation in all activities, particularly because everybody is feeling rather claustrophobic in their homes during the LOCK-DOWN scenario. Top priority should be given to the inclusion of PWD while planning for the protection and promotion of their rights and dignity in COVID-19 crisis as well as normal situations. We also conclude that we must build a disability-inclusive compassionate care ecosystem which should be robust one and the IMGs should play a leading role in the future.

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Sudip Bhattacharya¹, Md Mahbub Hossain², Amarjeet Singh³, Surabhi Mishra¹

¹Department of Community Medicine, Himalayan Institute of Medical Sciences, Dehradun, Uttarakhand, India, ²Department of Health Promotion and Community Health Sciences, School of Public Health, Texas A & M University, Texas, USA, ³Department of Community Medicine and School of Public Health, PGIMER, Chandigarh, India

Address for correspondence: Dr. Sudip Bhattacharya, Department of Community Medicine, Himalayan Institute of Medical Sciences, Dehradun, Uttarakhand, India. E-mail: drsudip81@gmail.com

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