COVID-19 as social disability: the opportunity of social empathy for empowerment

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Social empathy is ‘the ability to more deeply understand people by perceiving or experiencing their life situations and as a result gain insight into structural inequalities and disparities’.1 Social empathy comprises three elements: individual empathy, contextual understanding and social responsibility.2 COVID-19 has created a population-wide experience of exclusion that is only usually experienced by subgroups of the general population.3 Notably, persons with disability, in their everyday lives, commonly experience many of the phenomena that have only recently been experienced by members of the general population. Although about 1 billion people or approximately 15% of the world’s population, have some form of disability, ignorance and fear about disability and discrimination towards people with disability still persists.5 Public understanding of disability is shaped by a medical model of individual deficit, ignoring societal barriers that transpose the attribute of some type of psychological or bodily impairment into the social experience of disability.4 This is the core message of the social model of disability that recognises the role of the social environment in the experience of disability.4

While there are many personal and social aspect of disability that people without a disability may never experience, there is an opportunity for the population-wide experience of COVID-19 to change others’ perceptions of people with disability. The reported differential impact of COVID-19 on persons with disabilities highlights systemic barriers and their impact on those left behind by the social system.5 6 The conflating of disability with ‘comorbidity’ or ‘frailty’ is not due to any biological predilection for the virus but rather to implicit ableist assumptions that the ‘elderly’ or persons with pre-existing ‘conditions’ are similar to people with disability. This also ignores the intersectionality of discrimination (gender, income, ethnicity and education) that compounds and heightens risk for persons with disability.4 6

The COVID-19 experience may offer contextual experience of the prepandemic lives of persons with disabilities and foster greater social awareness, responsibility and opportunities for change towards a more inclusive society.

► Information, family and social relationships, health protection and healthcare, education, transport and employment should be accessible for all groups of the population. The means must be developed and deployed to ensure equity – the deployment of resources so that people with different types of needs have the same opportunities for living good lives in inclusive communities.

► We have learnt from COVID-19 that inclusive healthcare and universal access should be the new normal, that its provision as a social good is both unifying and empowering for society as a whole.

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Summary box

► COVID-19 has conferred new experiential knowledge on society and a rare opportunity to better understand the social model of disability and to improve the lives of persons with disabilities.

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(UNCRPD): ‘Living independently and being included in the community’.7 The COVID-19 experience has given some a sense of what it must be like to live in institutions and not being able to ‘get out’, or living in a house in the community but still feeling apart from the local community. Isolation and loneliness are a common experience for some people with disability.6

Feeling well informed—having access to good information—has, for some, been a struggle in COVID-19 times. UNCRPD Article 21 concerns ‘access to information’; due to the COVID-19 pandemic, the general population have experienced the challenges of receiving information that is not always clear or understandable.5 6 This is similar to the everyday experience of some people with disabilities who have to contend with public health information that is rarely available in accessible formats (sign language, captioning, easy-to-read or braille documents).

There have also been reports of some people being made to feel ‘different’ because of their COVID-19 status. Article 5 of the UNCRPD relates to ‘Equality and Non-Discrimination’.7 The onset of COVID-19 has shown that people might be discriminated against based on nationality, age or other attributes because of the perceived predilection for COVID-19.8 9 The advent of COVID-19, may have created anxiety about contamination, and fearful reactions to and stigmatisation of those who are believed to have come in contact with it. This may even extend to the development of prejudice towards whole groups—Asian people—the vast majority of whom obviously have no association with COVID-19. The recent plan by the Chilean government to issue ‘release certificates’ to persons recovered from COVID-19 is another instance of use of illness as a divisive factor.10 This may be representative of the experience of legitimacy/illegitimacy experienced by some people with disability.

Access to healthcare for persons with or without COVID-19 has become difficult and is related to the Article 25 of the UNCRPD that describes ‘right to health’.5 COVID-19 has led to prioritisation of people who receive healthcare services, with the concept of ‘worth’ attached to individuals, based on pre-existing health status, with cancelled, delayed or suspended services.6 11 12 These challenges typify the barriers to accessing healthcare experienced by persons with disabilities, due to limited accessible services, poor understanding of individual needs, and lack of appropriate equipment.13

Reduced opportunities for or access to education, work and employment are the focus of Articles 24 and 27, respectively.7 The COVID-19 experience offers insights into the experience of loss of meaning, loss of opportunity to participate, loss of income, living on benefits but not being able to contribute, loss of identity as an independent and valued asset of the community and perhaps an inability to work or study remotely due to lack of accessibility.5 However, we now have a greater understanding as a society that alternative work and/or education formats are possible and are effective, which may result in increased chances for persons with disabilities and equalise opportunity in the future.

These few examples provide the general population an opportunity for social empathy and action to enhance social inclusion for people with disability. We offer the following recommendations to ensure that this moment of collective social insight is not squandered, repressed or simply forgotten as we rush back to ‘normal’:

► First, it obvious that being forced to stay indoors is not pleasant for anybody, nor is it socially acceptable for others to be lonely or isolated. It is important to promote varied mechanisms for interaction, inclusion and participation within and across our communities for persons with disabilities.

► Second, information should be accessible to all groups of the population, and alternative means of communication should be incorporated systematically to inform and enable all persons based on their own needs and abilities.

► Third, some population groups are more likely to experience discrimination and to be pushed into the corners of society. Social policies that promote equity—the distribution of resources so that people with different attributes have the same opportunities—in society will create a society for all.

► Fourth, we have learnt from COVID-19 that inclusive healthcare is desired by all, that it has the potential to weave us together and that no one should be denied access based on personal attributes. Universal healthcare should be the new normal not a privilege.14

► Finally, we now understand the socioeconomic experiences of vulnerable groups in settings where social welfare is absent.12 15 Social protection and benefits are among the measures recommended by the International Labour Organization to fight COVID-19.16 As we come out of COVID-19, it is important to recognise the purpose and meaning of engaging in work, for all, across all abilities. Alternative means of working and studying should allow for greater accessibility for everyone.

COVID-19 has conferred new experiential knowledge on all of us. We have a rare opportunity to understand and better the lives of persons with disabilities for whom some aspects of the COVID-19 experience are enduring. This allows us greater understanding of the importance of implementing in full a social and human rights model of disability, as outlined in the UNCRPD. To not learn from history may well doom us to repeat it, but to not learn from our experience of the present, is to willfully neglect the opportunities of the moment. As a society we have learnt that we are better than that?

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REFERENCES


