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PERSPECTIVES

Guaranteeing the Health Rights of People with Disabilities in the COVID-19 Pandemic: Perspectives from China

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Abstract: The question of how to guarantee the health rights of people with disabilities, and their health equity in particular, is frequently neglected in infectious disease pandemics. The international response to the ongoing COVID-19 pandemic is no exception in this regard. This neglect is related to other forms of marginalization and exclusion, as people with disabilities are generally poorer and more vulnerable than their non-disabled counterparts. Sustainable Development Goal 3 lacks an appropriate human rights language that enshrines equality and inclusivity in pandemic prevention work and related policies and legislation; and, as a result, it does not sufficiently guarantee the health rights of people with disabilities. This paper draws on China's pandemic prevention work to extract relevant lessons, and seeks to explain how decision-making systems and resource allocation mechanisms impact on the health rights of people with disabilities. It discusses the unique roles of justice and legislation in helping to guarantee the health rights of people with disabilities in an infectious disease pandemic, and concludes that future research should more closely consider how Sustainable Development Goal 16 can support Sustainable Development Goal 3.

Keywords: COVID-19, health equity, laws, infectious disease pandemic, IDP, judicature, people with disabilities, sustainable development goal, SDG

Introduction

Sustainable Development Goal 3 (SDG3)—"Ensure healthy lives and promote well-being for all at all ages"—is a broad health goal that calls for the achievement of universal health coverage.[1] The Coronavirus (COVID-19) outbreak, which the World Health Organization recognized as a pandemic on 11 March 2020, presents a clear challenge to the realization of SDG3, and specifically to guaranteeing the health rights of people with disabilities during the critical stage of an infectious disease pandemic (IDP).

People with disabilities are more vulnerable during pandemics, and this is mainly because they frequently require assistive devices such as wheelchairs, which greatly increases the likelihood they will be exposed to coronavirus.[2] They will also need to periodically access nursing services, and this makes it more difficult for them to maintain the social distancing that is an essential part of pandemic prevention. Many people with disabilities also have specific underlying diseases, which means that COVID-19 is even more dangerous to them.[3] Taking people with intellectual disability as an example, the latest analysis of the mortality

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data of COVID-19 cases shows that the mortality rate of patients aged 17 and younger with intellectual and developmental disabilities (IDD) is more than 160 times that of patients of the same age who do not have IDD.[4]

In a briefing delivered on May 6 2020, UN Secretary-General Guterres emphasized that: "We must guarantee the equal rights of people with disabilities to access healthcare and lifesaving procedures during the pandemic"[5] But although Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) ('Situations of Risk and Humanitarian Emergencies') requires countries to take all necessary measures to ensure the protection and safety of those with disabilities in crisis situations, SDG3 still lacks the human rights language that would guarantee the health rights of people with disabilities in an IDP crisis situation. This is confirmed by the fact that only four of its targets relate to healthcare and lifesaving procedures that can be applied to the COVID-19 pandemic. These are:

3.8.1 Coverage of essential health services.

3.b.1 Proportion of the target population covered by all vaccines included in their national programme.

3.b.3 Proportion of health facilities that have a core set of relevant essential medicines available and affordable on a sustainable basis.

3.d.1 International Health Regulations, capacity and health emergency preparedness.[6]

None of these targets address the relative vulnerability of people with disabilities in a way that promotes the rational allocation of health resources in a pandemic, and nor do they demand equality and inclusiveness from emergency preparedness and IDP response.

China's previous efforts to improve the health system and legislation in accordance with SDG3 did not sufficiently plan for people with disabilities, and they were not included in the emergency preparedness and response.[7] In the critical situation caused by the COVID-19 pandemic, people with disabilities, who have a relatively weak risk resistance capacity, are facing greater challenges. Between January 2020 and April 2020, a large number of Chinese cities were locked down to fight against the COVID-19 pandemic, and public services were generally reduced or suspended. This further increased the difficulties that people with disabilities encountered when they sought to obtain nursing services and access health resources.

In the initial period of the outbreak, people with disabilities usually faced a very challenging situation. Institutional oversight and/or neglect could have had very serious, or even fatal, consequences for people with disabilities.[7] This paper draws on China's actions and lessons from the pandemic to reflect on the extent to which the lack of human rights language in SDG3 obstructed the country's efforts to guarantee the health rights of people with disabilities. It highlights deficiencies in the legislation and emergency response plans and evaluates the extent to which these rights were actually guaranteed.

Guaranteeing the Health Rights of People with Disabilities in the Pandemic and Achieving Health Equity in China

After the initial outbreak, people's mobility was curtailed in a short period of time, and every confirmed indigenous case was quickly identified, quarantined, and treated free-of-charge.[8] This meant that the spread of the virus was quickly contained.[9] Information was collected from conventional media and social media and interviews with disabled people and the organizations that represent them. Analysis then revealed that the factors that affect the realization of health equity in IDP are more diverse than SDG3 had expected.

The inclusivity of the decision-making system for pandemic prevention has significantly impacted the effectiveness of efforts that seek to guarantee the health rights of people with disabilities in the pandemic. The uncertainty that accompanies COVID-19 and similar infectious diseases means it is highly probable that epidemic prevention policies and legislation will have blind spots and irrational content to some extent. Experience from China also confirmed that decision-makers had to efficiently collect information, provide feedback, correct errors and make decisions amidst ongoing chaos.

If this decision-making process is not sufficiently inclusive, it will negatively impact the realization of health equity in IDP. For example, the Law on Prevention and Treatment of Infectious Diseases (LPTID) establishes that when an infectious disease breaks out, governments across various levels (national, provincial, municipal and county) in the country should quickly establish a pandemic prevention command institution that can command all local administrative agencies and health and police departments. It also establishes they should also obey the command of higher headquarters[10,11] – this stipulation allowed China to effectively regulate the society a short period of time after

the start of the outbreak, and it helped to successfully reduce population movement during the Lunar New Year.

But the lack of language that guaranteed the rights of people with disabilities in LPTID resulted in the demands of some people with disabilities being ignored in the initial stages of the outbreak. This meant that people with disabilities were dangerously exposed at a time when COVID-19 was spreading most rapidly.[7] The Government acknowledged the problem and set up a hotline that enabled people with disabilities to contact local pandemic prevention decision-making teams (all calls were recorded for later inspection by higher headquarters and supervision departments). Decision-makers received severe punishments if they were found to have failed to have failed to respond to reasonable requests within a given timeframe (usually 1–3 workdays). This helped to guarantee that the needs of people with disabilities were met in many regions, including Wuhan (the previous epicenter, where human resources and materials were most desperately required). A representative of Mutual Aid Group for People with Disabilities in Wuhan recalled:

> There were 500 people in my mutual aid group. All of us were organ transplant recipients in Wuhan. After transplantation, we could not do heavy work or work for long periods of time. At the same time, we needed to take immune preparations twice a day, or we would quickly die due to organ rejection. After the lockdown of Wuhan, we found that the hospitals where we normally got prescribed medicine were requisitioned as designated hospitals for novel coronavirus, and they would no longer provide other medical services. Hence, we lost the access to immune preparations, and the amount of immune preparations we stored was usually available for less than 15 days. We asked for help in many ways, but it was useless. In the end, I called the mayor's hotline with the intention of trying. I hadn't expected that the community officials and volunteers would deliver the medicine to every one of our group within 48 hours. About ten days later, the government informed us that the immune preparations that could only be prescribed in hospitals earlier were available at the nearest pharmacies. We all survived, and I'm lucky and proud to live in this country.
>
> –Mrs. Ling, a liver transplant recipient
>
> Personal communication, May 12, 2020

China also established an efficient and transparent Internet-based resource allocation mechanism, which made a critical contribution to the achievement of health equity in the pandemic. It was difficult for people with disabilities to store materials during IDP because any kind of shopping was an additional burden on them. They usually had to ask for help to carry what they had purchased, which increased the danger they would be exposed to the virus. The pandemic also caused a shortage of face masks and various other materials. In the initial stages of the outbreak, difficulties associated with travel and panic buying meant that people with disabilities could not obtain sufficient material, For example, some paraplegic wheelchair user are forced to use plastic bags as a substitute after running out of diapers.[7]

In response, numerous online groups were established via instant messaging Apps (including WeChat in China) and a large number of material suppliers, transporters and consumers were invited into the online groups for districts or communities. The Government's coordinated sales, logistics and terminal delivery meant it could achieve the transparent and efficient distribution of materials during city lockdown. Residents in the epidemic area could order materials in the online groups and community cadres and volunteers could send materials to each residential building in accordance with the quota. The elderly and the disabled would have materials sent directly to their homes.[12]

The transparent process of the distribution mechanism and supply chain in the online group increased the recognition of the fairness of the resource allocation mechanism by enterprises and residents, and this made the system sustainable during the pandemic. The Government's command and coordination made it possible for people with disabilities to use online groups to obtain health service resources that were rarely available from general commercial channels during the IDP. For example, when the hospitals were overcrowded in the initial stages of the outbreak, a large number of institutions were forced to suspend nursing services for people with disabilities. Shanghai municipal government responded by organizing family physicians and people with disabilities into various communities that then established online groups. Family physicians did not only provide online diagnosis, treatment and drug distribution for people with disabilities across the Internet, but also extended necessary nursing services to severely disabled people.[13]

On April 8, 2020, the lockdown of Wuhan was lifted. On May 9, 2020, there were only 372 confirmed cases, and 79,401 patients had been cured and discharged from hospitals.[14] In China more generally, there were 84,416 confirmed cases in a population of 1.3 billion.[15] The data

suggests that the country's efforts to guarantee the health rights of people with disabilities achieved remarkable results in the period after the initial outbreak: on February 5, Hainan Province announced that none of its 500,000 people with disabilities were infected;[16] on March 2, Fujian Province reported that none of its 300,000 blind people showed signs of infection; and on March 29,[17] Nanjing City announced that none of its 530,000 people with disabilities were infected.[18] Taking into account the difficulties associated with the peak of the pandemic in January 2020 and the fact that the three regions have a combined population of almost 60 million, this was a considerable achievement. Although the specific national public health data has not yet been collected, Zhang Haidi, chairman of the China Disabled Persons' Federation, told the media that according to incomplete statistics, the COVID-19 infection rate of Chinese disabled persons is far below the average.[19]

More Importance Should Be Attached to the Support of SDG16 for SDG3

We found that justice had a remarkable role in China's efforts to achieve health equity amidst the pandemic, and noted that SDG16 ("Peace, Justice and Strong Institutions") was more important than we had expected it to be.

People with disabilities are disadvantaged in terms of their level of education and physical attributes and this makes it more difficult for them to defend their legal rights through litigation.[20] This is one reason why they present an easy target at moments of social disorder created by critical situations. But the guidance of the Supreme Court has helped the Chinese judiciary to generally recognize judicial activism, and this has obliged the judiciary to provide judicial relief for various social injustices and to use its authorized power to guarantee social development.[21] This activism has been shown during the pandemic.

First, efficient and targeted judicial actions (that were premised on the insight there is "no health without peace"[22]) provided people with disabilities with a relatively stable social order during the pandemic. A stable social order is a prerequisite for the implementation of pandemic prevention work and it is also necessary to maintain the health and safety of people with disabilities, who are more likely to be victims of violent crimes during IDP. At an early stage of the outbreak, social panic and shortages resulted in theft (of medical materials), attacks on medical personnel and police (by people pretending to be pandemic prevention personnel) and burglaries. People with disabilities were not spared, and a mobility scooter was stolen in Tianjin (unfortunately this was not an exceptional or isolated incident).[23]

The Chinese courts adjusted their judicial policies, with the aim of assigning the best judges to criminal cases that had the potential to disrupt epidemic prevention. The initiation of public prosecution by procuratorates gave courts the power to pass sentences in 3 days.[24] Rapid publication of these precedents helped the Police to stabilize the social order. Data from the Supreme People's Procuratorate of the People's Republic of China suggests that the number of criminals arrested between January and March 2020 was 41.8% lower than the previous year.[25] A stable social order did not only guarantee the safety of pandemic prevention personnel, but also helped to safeguard people with disabilities and the stored medicinal materials.

The activities of the Chinese courts also helped to alleviate the economic impact on people with disabilities. Members of this group generally tend to be poorer than non-disabled counterparts,[26] and the economic depression caused by the pandemic is likely to exacerbate this ("many people with disabilities may not have enough money to stockpile food and medicine or afford the extra cost of home deliveries").[27]

The Chinese courts have remitted the cost of litigation for people with disabilities, which means their rights can be more easily safeguarded in the pandemic. It is especially helpful for those fighting against redundancy, as it enables them to maintain a basic income. The courts also established a national judicial aid system in 2015, which enables the state to provide financial relief to the plaintiff who has won the lawsuit but cannot obtain compensation because the defendant has no ability to pay. Local courts have used it during the pandemic to give priority relief to disabled civil litigants or criminal victims.

Each of the two families of disabled criminal victims in Hubei Province who lost their source of income to the pandemic received judicial aids of approximately $4200 through this system.[28] Social stagnation however made it difficult to enforce sentences in favor of people with disabilities or victims. The courts responded by asking the Executive Board (the agency responsible for compulsorily enforcing the sentence of the court for incoordinate litigants in China) to prioritize the applications of people with disabilities. For example, a person with disabilities in Nanchang quickly received compensation (around $

14,000) for a traffic accident during the pandemic, which enabled him/her to survive.[29]

But it is difficult for an active judiciary to completely compensate for blind spots in the legislation, and this has restricted China's efforts to promote health equity through interventions that seek to guarantee the health rights of people with disabilities during the pandemic. The optimization of the relevant national legislation therefore needs to be taken seriously.

For example, the legal system should provide a more reasonable litigation path to the realization of the interests of persons with disabilities. The provisions of the Chinese procedural laws establish that generally binding rules or orders issued by the government against the public (so-called "abstract administrative actions") cannot be sued.[30] In IDP, this means that when a few pandemic prevention policies for the public damages or neglects the rights of people with disabilities, they will not be able to defend their rights through litigation. Article 54 of the Law on the Protection of Disabled Persons (LPDP) states that "people's governments at all levels and relevant departments shall take measures to facilitate the access of people with disabilities to public information". However, even at the time of writing, epidemic prevention policies in a few areas of China still lack information accessibility regulations Poor information access exposes people with disabilities, including those with hearing/visual impairments and intellectual disabilities, to greater health risks. But the affected are not able to file a lawsuit based on the spirit of LPDP and are only able to "offer suggestions" to the legislature or local government.[20]

More importantly, legislators should stipulate that relevant departments should count disability data when collecting public health data. Disability is a human trait similar to age, race, and gender. In Article 31, UNCRPD requires States Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention.[31] In IDP, this means that States Parties are obliged to adjust their legal systems to distinguish between disabled and non-disabled groups when they count key public health data such as mortality and infection rates in IDP, so as to ensure that the statistical data can be reflected in the realization of the health rights of the disabled groups in the IDP. The United States, France, Russia, Britain, China, and the major countries in the world are all parties to UNCRPD. However, until recently, the health status of persons with disabilities has not been widely included in public health surveys, data analysis and health reports. We are still extremely lack of effective information for public health experts to reveal the impact of COVID-19 on people with disabilities, and we still rely on indirect information to a large extent.[32] Due to the lack of disability data, it is difficult to track a considerable number of high-risk groups, and their detection rate is also unknown.[33]

Conclusions

China's experience demonstrates the many factors that affect the realization of the health rights of people with disabilities during IDP. These include the equality and inclusiveness of the emergency plan, the pandemic prevention legislation and decision-making system, the efficiency and sustainability of the resource allocation mechanism and the degree of access to public health information. This paper concludes that more appropriate human rights language should be formulated in SDG3, as this will help people with disabilities to acquire an equal life and health guarantee. This will in turn help to promote and uphold the principle of health equity.

The guiding role of SDGs across the world means that the problems of people with disabilities in China are also experienced across the world. Catalina Devandas Aguilar, the UN Special Rapporteur on the Rights of People with Disabilities, observes that people with disabilities "feel they have been left behind" in the current pandemic.[27] Each country should take into account the World Health Organization's (WHO) warning that COVID-19 may coexist with humans for a long time.[34] They should also refer to China's experience and lessons and ask if its people with disabilities have an equal life and health guarantee in the current pandemic. The perspectives of people with disabilities should also be incorporated into the discussion of the goals and targets of SDG3. The question of how SDG16 can support SDG3 should also be asked before these discussions begin.

Abbreviations

IDD, intellectual and developmental disabilities; IDP, infectious disease pandemic; LPDP, Law on the Protection of Disabled Persons; LPTID, Law on Prevention and Treatment of Infectious Diseases; PRC, People's Republic of China; SDG, Sustainable Development Goal; UN, United Nations; UNCRPD, United Nations Convention on the

Rights of Persons with Disabilities; WHO, World Health Organization.

Data Sharing Statement

Not applicable.

Consent for Publication

Mrs. Ling has provided informed consent for the text to be published.

Ethics Approval and Consent to Participate

The Mutual Aid Group for People with Disabilities in this article adheres to correct guidelines regarding organ transplants, that all organs were donated voluntarily with written informed consent, in accordance with the Declaration of Istanbul.

Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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Disclosure

Qi Wang reports being a member of the China Law Society, standing director of China Civil Procedure Law Research Institute. The authors declare that they have no other potential conflicts of interest.

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