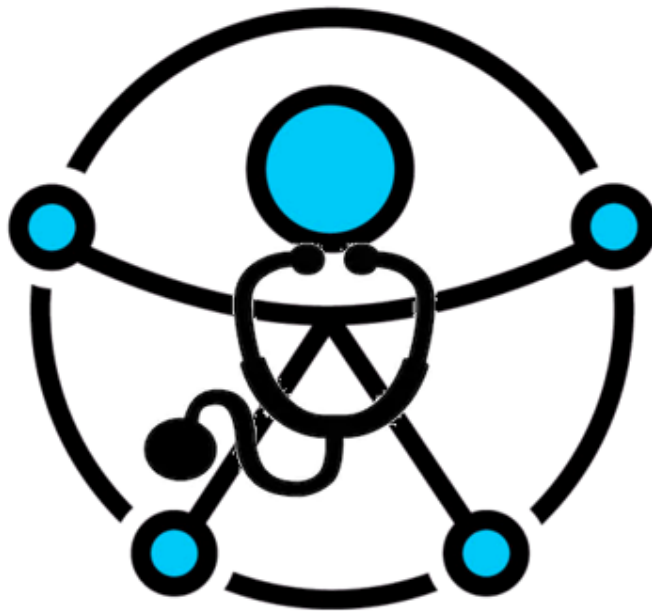


**RECOMMENDATIONS FOR HEALTH PROTECTION OF PEOPLE WITH  
DISABILITIES DURING OUTBREAKS: LESSONS LEARNED FROM THE  
2019 NOVEL CORONAVIRUS**





RECOMMENDATIONS FOR HEALTH PROTECTION OF PEOPLE WITH DISABILITIES DURING OUTBREAKS:  
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## Credits

Authors: Carlos Kaiser, Executive Director of Inclusiva NGO/ TG Disability Disaster Risk Global Focal Point, Loreto Brossard; Deputy Executive Director of Inclusiva NGO

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- To the UNDRR for their tremendous work protecting people with disabilities always

## Acronyms index

**CoV:** Coronaviruses

**CRPD:** Convention on the Rights of Persons with Disabilities

**MERS-CoV:** Middle East Respiratory Syndrome

**nCoV:** Novel coronavirus

**PwD:** People with disabilities

**SARS-CoV:** Severe Acute Respiratory Syndrome

**UDHR:** The Universal Declaration of Human Rights

**WHO:** World Health Organization



## Introduction

The fact that the 15% of the world human population are people with disabilities is a relevant fact. Although being more than one thousand million, the lack of comprehensive inclusive health policies that follow a human rights-based approach people with disabilities make them more vulnerable to outbreaks.

According to the World Health Organization between 110 million and 190 million adults have significant difficulties in functioning. Rates of disability are increasing due to population ageing and increases in chronic health conditions, among other causes. People with disability have less access to health care services and therefore experience unmet health care needs.

These facts must change, we need society, governments and agencies to improve their efforts as a priority, People with disabilities cannot wait any longer.

May this book be a useful tool to shape a better world

**Carlos Kaiser**

**Executive Director Inclusiva NGO**

**TG Disability Disaster Risk Reduction Global Focal Point**



## Disease outbreaks

A disease outbreak<sup>1</sup> is the occurrence of disease cases in excess of normal expectancy. The number of cases varies according to the disease-causing agent, and the size and type of previous and existing exposure to the agent

Disease outbreaks are usually caused by an infection, transmitted through person-to-person contact, animal-to-person contact, or from the environment or other media.

Outbreaks may also occur following exposure to chemicals or to radioactive materials. For example, Minamata disease is caused by exposure to mercury.

Occasionally the cause of an outbreak is unknown, even after thorough investigation.

## Zika virus disease

Zika virus disease is caused by a virus transmitted primarily by Aedes mosquitoes, which bite during the day.

Symptoms are generally mild and include fever, rash, conjunctivitis, muscle and joint pain, malaise or headache. Symptoms typically last for 2–7 days. Most people with Zika virus infection do not develop symptoms.

Zika virus infection during pregnancy can cause infants to be born with microcephaly and other congenital malformations, known as congenital Zika syndrome. Infection with Zika virus is also associated with other complications of pregnancy including preterm birth and miscarriage.

An increased risk of neurologic complications is associated with Zika virus infection in adults and children, including Guillain-Barré syndrome, neuropathy and myelitis.

## 2019 coronavirus outbreak

According to the World Health Organization Coronaviruses (CoV) are a large family of viruses that cause illness ranging from the common cold to more severe diseases such as Middle East Respiratory Syndrome (MERS-CoV) and Severe Acute Respiratory Syndrome (SARS-CoV). A novel coronavirus (nCoV) is a new strain that has not been previously identified in humans.

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<sup>1</sup> WHO [https://www.who.int/environmental\\_health\\_emergencies/disease\\_outbreaks/en/](https://www.who.int/environmental_health_emergencies/disease_outbreaks/en/)



WHO states that “As with other respiratory illnesses, infection with 2019-nCoV can cause mild symptoms including a runny nose, sore throat, cough, and fever. It can be more severe for some persons and can lead to pneumonia or breathing difficulties. More rarely, the disease can be fatal. Older people, and people with pre-existing medical conditions (such as, diabetes and heart disease) appear to be more vulnerable to becoming severely ill with the virus.

## The world must protect the health of people with disabilities against 2019 novel coronavirus and other outbreaks

According to the World Health Organization World Disability Report, people with disabilities are 15% of the global population. More than one billion people are living with disabilities. Of this number, between 110 million and 190 million adults experience significant difficulties in functioning. It is estimated that some 93 million children – or one in 20 of those under 15 years of age – live with a moderate or severe disability. The number of people who experience disability<sup>2</sup> will continue to increase as populations age, with the global increase in chronic health conditions. National patterns of disability are influenced by trends in health conditions and environmental and other factors, such as road traffic crashes, falls, violence, humanitarian emergencies including natural disasters and conflict, unhealthy diet and substance abuse. There are legal and practical reasons to protect the health of people with disabilities against 2019 novel coronavirus outbreak

### Legal reasons:

The protection of the health of people with disabilities against 2019 novel coronavirus and other outbreaks follows a human rights-based approach, it is a conceptual framework for the process of human development that is normatively based on international human rights standards and operationally directed to promoting and protecting human rights. It seeks to analyse inequalities which lie at the heart of development problems and redress discriminatory practices and unjust distributions of power that impede development progress<sup>3</sup>.

The World Health Organization states that “understanding health as a human right creates a legal obligation on states to ensure access to timely, acceptable, and affordable health care of appropriate quality as well as to providing for the underlying determinants of health, such as safe and potable water, sanitation, food, housing, health-related information and education, and gender equality”.

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<sup>2</sup> WHO global disability action plan 2014–2021: better health for all people with disability, WHO 2015  
Available in: [https://apps.who.int/iris/bitstream/handle/10665/199544/9789241509619\\_eng.pdf](https://apps.who.int/iris/bitstream/handle/10665/199544/9789241509619_eng.pdf)

<sup>3</sup> UNICEF [https://www.unicef.org/policyanalysis/rights/index\\_62012.html](https://www.unicef.org/policyanalysis/rights/index_62012.html)



The WHO also said that “A States’ obligation to support the right to health – including through the allocation of “maximum available resources” to progressively realise this goal - is reviewed through various international human rights mechanisms, such as the Universal Periodic Review, or the Committee on Economic, Social and Cultural Rights. In many cases, the right to health has been adopted into domestic law or Constitutional law”.

A rights-based approach to health requires that health policy and programmes must prioritize the needs of those furthest behind first towards greater equity, a principle that has been echoed in the recently adopted 2030 Agenda for Sustainable Development and Universal Health Coverage.

1. The first important aspect is Universal Declaration of Human Rights (UDHR). The UDHR is a milestone document in the history of human rights. Drafted by representatives with different legal and cultural backgrounds from all regions of the world, the Declaration was proclaimed by the United Nations General Assembly in Paris on 10 December 1948 (General Assembly resolution 217 A) as a common standard of achievements for all peoples and all nations. It sets out, for the first time, fundamental human rights to be universally protected.
  - The UDHR Article 25. (1) states “Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control”.
  
2. The next one is the Convention on the Rights of Persons with Disabilities (CRPD)<sup>4</sup> has served as the major catalyst in the global movement from viewing people with disabilities as objects of charity, medical treatment and social protection towards viewing them as full and equal members of society, with human rights.
  - People with disabilities have right to health, Article 25 of CRPD specifies that "persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability."
  - It is important to connect Article 25 of CRPD with Article 17 of the Convention “Protecting the integrity of the person” that states that every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others.

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<sup>4</sup> "General Assembly Adopts Groundbreaking Convention, Optional Protocol on Rights of Persons with Disabilities" (Press release). New York: United Nations. 13 December 2006





## Practical reasons

15% of the global population have disabilities, that is to say that one out every five persons is a person with disabilities.

Per every person with disability there are at least one family member. So, when facing diseases what happens with people with disabilities would at least affect 30% of society.

## Ethical reasons

People with disabilities faced barriers to access health services. According to WHO global disability action plan 2014–2021 the origin of these barriers lies in, for example, inadequate legislation, policies and strategies; the lack of service provision; problems with the delivery of services; a lack of awareness and understanding about disability; negative attitudes and discrimination; lack of accessibility; inadequate funding; and lack of participation in decisions that directly affect their lives. Specific barriers also exist in relation to persons with disabilities being able to express their opinions and seek, receive and impart information and ideas on an equal basis with others and through their chosen means of communication.

WHO global disability action plan 2014–2021 states that “these barriers contribute to the disadvantages experienced by people with disability. Particularly in developing countries, people with disability experience poorer health than people without disability, as well as higher rates of poverty, lower rates of educational achievement and employment, reduced independence and restricted participation. Many of the barriers they face are avoidable and the disadvantage associated with disability can be overcome. The World report on disability synthesizes the best available evidence on how to overcome the barriers that persons with disability face in accessing health, rehabilitation, support and assistance services, their environments (such as buildings and transport), education and employment”

The logical conclusion is that these barriers would cost lives of people with disabilities. Governments and health related agencies must eliminate the above-mentioned barriers as an integral part of their plans.

## Problems faced by people with disabilities and their families

People with disabilities and their families face barriers, during outbreaks could cost lives. These barriers are:

### Caregivers, people with severe disabilities, quarantine and barriers

- There is a lack of protocols established to take care of quarantined people with disabilities
- Possible death of people with severe disabilities because of hunger, thirst due to isolation from their caregivers as a result of a quarantine

### The case of Yan Cheng

Newsweek BY KASHMIRA GANDER. Yan Cheng, 17, died on Wednesday, January 29, in central China's Hubei province, the South China Morning Post reported citing Beijing Youth Daily which had spoken to officials. Hubei is at the epicentre of the outbreak of the new coronavirus that has killed almost 200 people. The cause of the boy's death was unclear.

Cheng had cerebral palsy, a neurological disorder which can make it difficult for a person to move and maintain their balance and posture. They can also suffer from stiff muscles and uncontrolled movements. On Friday, January 17, the teenager's father Yan Xiaowen and 11-year-old brother left Wuhan for a village about 90 miles away in Huahe township, Hong'an County, as part of the Lunar New Year celebrations.

Yan, 49, contracted a fever about three days later, and on Friday, January 24, he was isolated by officials at a health facility. According to the South China Morning Post, Yan was diagnosed on Monday, January 27, with the new coronavirus and hospitalized. Yan, who had alerted a Wuhan charity of disabled people which notified Hubei's Disabled Person's Federation, pleaded for someone to look after his son. Yan said he was worried local Community Party officials were not providing his son with the right care in his absence.

He claimed party officials in his village had said his son was fed only twice between January 24 and Tuesday, January 28. He wrote on Weibo on Tuesday, according to the South China Morning Post, that Cheng "cannot move his body, he cannot speak or look after himself. He has already been at home by himself for six days, with nobody to bathe him or change his clothes and nothing to eat or drink."

Community Party officials were due to send the father and Cheng to an isolation hotel on Wednesday, January 29, so they could be cared for at the same time, according to a report from the Damihexiaomi group which advocates for people with disabilities, cited by the South China Morning Post. However Cheng died on Wednesday afternoon. Yan's account has since been deleted. According to Damihexiaomi, Cheng's aunt said she fed and changed his clothes on a number of occasions.

A spokesperson for the Huahe Township told the Beijing Youth Daily that Hongan County officials had launched an investigation into the death. The spokesperson said "there is no way we could have left a boy with cerebral palsy at home with nobody looking after him." Newsweek has contacted China's National Health Commission for comment.



## Prohibitive costs

According to WHO affordability of health services is one of the main reasons why people with disability do not receive needed health care in low-income countries - 32-33% of people without disability are unable to afford health care compared to 51-53% of people with disability.

## Communicational barriers

Communications are paramount to promote health and prevent disease, but great amount of information is not shared following inclusion standards.

- Deaf people need that news and press conference about an outbreak include certificated sign language interpreters validated by deaf people community.
- Web site accessibility must ensure that blind and low vision people can read key information about an outbreak.
- Factsheets must be accessible for blind and low vision people can read key information about an outbreak
- Health staff must know sign language or at least have certificated sign language interpreters validated by deaf people community.

## Physical barriers

- Many health centers don't have accessibility to their facilities. That fact produces more vulnerabilities for people with disabilities to cope with outbreaks.
- Due to urban barriers and lack of accessible public transit systems present in several cities around the world, people with disabilities have difficulties to go to hospitals.

## Higher rates of premature death

According to WHO, Mortality rates for people with disability vary depending on the health condition. However an investigation in the United Kingdom found that people with mental health disorders and intellectual impairments had a lower life expectancy.



## Inclusive health protection of people with disabilities during outbreaks indicators

1. Percentage of health services that have implemented an explicit program to bring medical services to people with disabilities at local level during an outbreak
2. Percentage of health services that have implemented an explicit program to bring medical services to caregivers of people with disabilities at local level during an outbreak
3. Percentage of governmental agencies that have implemented an explicit program to assist people with severe disabilities that have their caregivers quarantined during an outbreak
4. Percentage of health services facilities that have accessibility
5. Percentage of informative campaigns about outbreaks that have certified sign language interpreters validated by deaf community
6. Percentage of informative materials about outbreaks that have accessible format

## Recommendations

- Human rights-based approach for the health protection of people with disabilities and their families is a must
- Data collection and dissemination of disability-related data and information is a must
- Inclusive indicators of health protection of people with disabilities and their families must be validated and used in order to check gaps and advances
- Funds are needed in order to be effective in the protection of people with disabilities and their families during outbreaks
- Protocols must be established to take care of quarantined people with disabilities
- Protocols must be established to reduce/ avoid possible death of people with severe disabilities because of hunger, thirst due to isolation from their caregivers as a result of a quarantine
- Deaf people need that news and press conference about an outbreak include certificated sign language interpreters validated by deaf people community.
- Web site accessibility must ensure that blind and low vision people can read key information about an outbreak.
- Factsheets must be accessible for blind and low vision people can read key information about an outbreak
- Health staff must know sign language or at least have certificated sign language interpreters validated by deaf people community.
- Health centers must have accessibility in their facilities. That fact produces more vulnerabilities for people with disabilities to cope with outbreaks.



- Urban barriers and lack of accessible public transit systems present in several cities around the world must be eliminated to avoid that people with disabilities have difficulties to go to hospitals.
- People with disability are knowledgeable about their own health conditions, and that health-care personnel support and protect the rights and dignity of persons with disability<sup>5</sup>.

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<sup>5</sup> Disability and health Key facts, WHO 16 January 2018. <https://www.who.int/news-room/fact-sheets/detail/disability-and-health>



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