

# Disabled persons in viral pandemics: the example of Covid-19



# **Disabled persons in viral pandemics: the example of Covid-19**

**Working paper  
by David Alexander**

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# Viral pandemics and Covid-19

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## Introduction

Emerging infectious diseases pose a very special problem for modern society. Viral pandemics result from a wide variety of factors. These include transmission of new viruses from animal to human hosts and their diffusion around an increasingly interconnected world; a lack of immunity to a new disease and the dangerous effects of the immune system's overreaction to the intrusive micro-organism and a lack of knowledge of the characteristics of the virus. If unchecked, the dissemination of a virus can be exponential and thus both fast and widespread. Antiviral palliative drugs must be found and vaccines created and manufactured, which takes time, during which the virus can wreak havoc on people, society and economy.

Human history teaches us that the mass diffusion of infectious disease is a recurrent phenomenon. It is a sort of "wave disaster", in which the disease ebbs and flows in society as attempts are made to control it, to reduce the rate of infection and to combat its effects. Unlike other disasters, a pandemic is by definition global, or, if not universally present, it is at least highly international. Rates of infection and mortality will vary from place to place, and dynamically over time, but once an emerging disease is established internationally, it requires considerable effort and resources to bring under control. Moreover, this is a lesson that has long been evident, as major epidemics have always been a feature of human existence. The "Black Death" of bubonic, pneumonic and septicaemic plague in the mid-1300s was a case in point. Although it peaked over the period 1347-1351, it recurred many times and is still prevalent in the modern world.

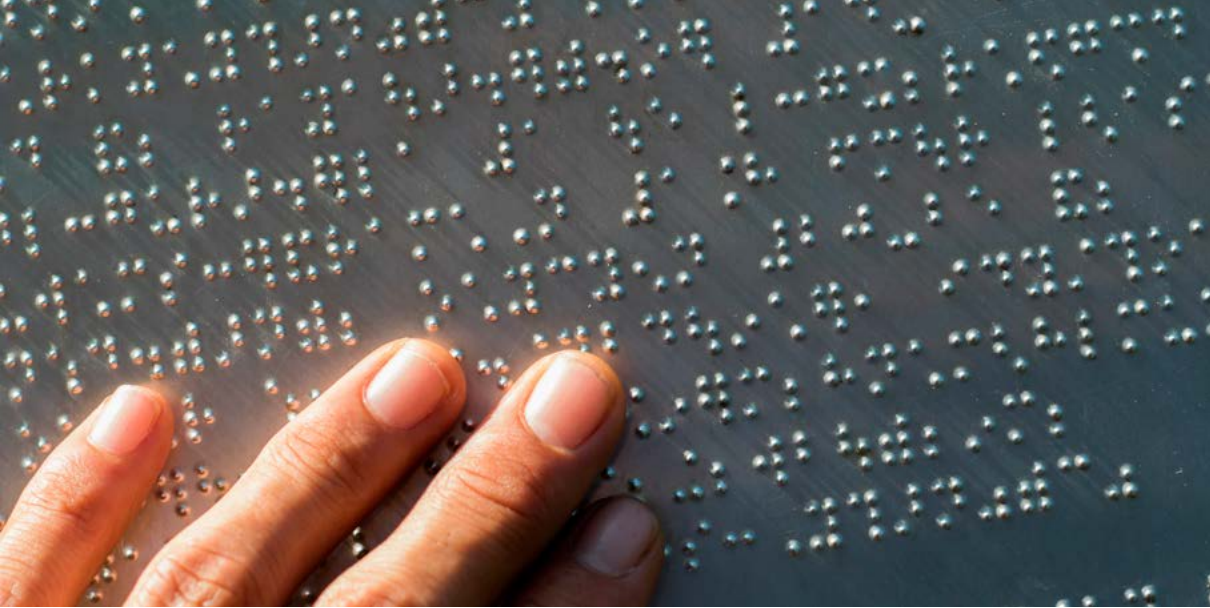
Pandemics are a multidisciplinary problem. Their effects are partly medical and partly socio-economic and psychological. They can lead to drastic mutations in patterns of economic activity and human behaviour. Rather than reducing or annihilating inequality, they tend to accentuate it. The poor, the uneducated, the sick and frail, and the disadvantaged in society are at much greater risk when a pandemic arrives. They may lack the means, the agility and the information to enable them to avoid situations in which there is an elevated risk of contagion. They may lack immunity and resistance to the depredations of the virus.

“Covid-19” is the common term for the dissemination of the sudden acute respiratory syndrome (SARS) virus SARS-CoV-2, which emerged in 2019 and became a pandemic around March 2020. By late September 2020, almost 32 million people had contracted the disease and 970 000 had died as a result. Hence, the case–fatality rate was about 3%, although highly variable over time and from place to place. Viral infections vary in their lethality and rate of spread. Covid-19 is about three times less lethal than the 2002–2004 SARS outbreak, but it spreads more rapidly. However, it is slower to spread and incubate than non-seasonal influenza viruses tend to be.

Since its first appearance, massive academic, scholarly and scientific effort has been devoted to Covid-19 worldwide. During the first three months of 2020, 67 new papers on the disease were published on average every day in the scientific press. Since then, the number has increased substantially. There is a widespread desire, not only to understand this new emerging disease in all its characteristics, but also to provide solutions to the many problems it has created. There is also a need to learn from the experience of dealing with Covid-19 to be better prepared for the next virus to proliferate.

One important question about Covid-19 is the degree to which it differs from pandemic influenza. In clinical, virological and epidemiological terms, there are distinct differences, but in terms of emergency planning, the contrasts are much less marked. The impact of a viral pandemic is balanced between the medical-epidemiological consequences and the social, psychological and economic effects. It is difficult to determine which are greater. Hence, the management of a pandemic, whether it be influenza or another kind of virus, requires a truly multidisciplinary effort, with emphasis on logistics and great effort devoted to developing emergency planning scenarios (Alexander D. 2020).

Ethics, fairness and equity demand that efforts be made to counter the discriminatory effects of the pandemic. There is now a burgeoning literature on the impact of Covid-19 on people with disabilities. It reveals their particular vulnerabilities and disadvantages relative to non-disabled people, but also the ways in which their special needs can be accommodated. The present report reviews these three elements. It can be considered as an extension of previous work for the Council of Europe on people with disabilities and major emergencies or disasters (Alexander and Sagromola 2014, Sagromola, Alexander and Kelman 2015). As the Covid-19 pandemic differs substantially from other disasters in magnitude, scope, reach and effects, it merits separate treatment.



## People with disabilities and their needs in a pandemic

The World Health Organization (WHO) estimates that there are one billion disabled people in the world today. About 61 million of them live in the United States (18.5% of the population) and 11 million in the United Kingdom (16.2% of the population (Kuper et al. 2020, Armitage and Nellums 2020)). Owing to a lack of registration or adequate census, and variations in the definition of “disabled”, in many countries it is difficult to gauge the size of the disabled population, but in most cases it probably constitutes of about 16-18% of the total population. About 77 million people, 1% of the world population, have some form of serious intellectual or developmental disability (IDD, Linehan et al. 2020). In the USA, between 2.6 and 4 million people with IDD live in community settings (Landes, Stevens and Turk 2020).

There is a very wide spectrum of disabilities, and many degrees of seriousness. From motor and mobility issues to cognitive and sensory deprivation, from short-term to permanent conditions, and from children to the elderly, the range is enormous. This means that in a pandemic, as in any other disaster, people with disabilities should not be considered as a “category”. They should be treated as individuals with specific needs. Disability is not a defect. It represents a challenge to provide more equitable conditions and thus fulfil society’s moral responsibility to be fair and reasonable to those of its members who are disadvantaged and potentially vulnerable. During a pandemic, as in any other crisis, emergency, disaster or situation of risk, people with disabilities should be treated as protagonists wherever and whenever possible, not as passive “victims”.

Despite these reflections, many people with disabilities have greater-than-average vulnerability to viral infection. There is, of course, an intersection between old age and disability. Not all elderly people are disabled, but disability becomes more likely with the bodily deteriorations that age can cause. A person whose disability can be considered an underlying health condition may have a heightened risk of morbidity or mortality due to the virus, especially if the condition involves respiratory



difficulties (Kuper et al. 2020). People with disabilities more generally experience the “intersectionality of disadvantage” (Goggin and Ellis 2020), or in other words, the summation of multiple risk factors.

Disabled people have many of the same fears and undergo the same stresses that are experienced by non-disabled people, but they may be dealing with the prospect of more serious consequences (Cortis and Van Toorn 2020). For example, physical distancing cannot realistically be maintained for people who need assistance with personal hygiene, movement, dressing and so on (Boyle et al. 2020). Moreover, blind people often rely on touch to find their way (Goggin and Ellis 2020).

People with cognitive impairments may have difficulty in understanding the information that they need to protect themselves. They will then be reliant on the vigilance of their carers, especially during quarantine (Courtenay and Perrera 2020). Researchers have suggested that the cognitively disadvantaged may find it difficult to communicate the symptoms of Covid-19, resulting in potential delays in receiving diagnosis and treatment, and in the application of measures to contain the spread of the virus (Boyle et al. 2020). It would be wrong, of course, to blame them for this. If a person has a disability that involves communication difficulties, they may be particularly at risk in an intensive care unit, through inability to communicate needs and symptoms to medical staff who are not specialists in this form of disability. Simple language and easy-to-understand information are thus vitally important assets. Moreover, banning visitors from hospitals may be necessary in terms of infection control, but it can have adverse effects on disabled people who normally require help with living arrangements, as well as moral support from their circle of relatives and friends (Boyle et al. 2020). Care must be taken to interpret and guide the actions of people who cannot properly understand the risks involved with managing viral infections (Grier et al. 2020).

The risks are, of course, not limited to medical centres. People with disabilities who live alone may suffer isolation. The elderly may have lost friends and partners, and they may suffer long-term deterioration in their health, leading to disability (Victor and Bowling 2012). Those who are able to venture outside their homes may feel unsafe when streets are deserted as a result of lockdown (Brooke and Jackson 2020). Moreover, there is always a risk that health visitors and social carers may bring the virus into people’s homes, an issue that is dealt with below in relation to care homes. Conversely, so-called “rationed responses” to a pandemic can very severely affect people with disabilities who live at home. If carers refuse to make house visits, then this can create difficult problems for the disabled who need manual help with basic functions such as getting up in the morning, washing and going to the toilet (Maroto and Pettinicchio 2020).

On a more positive note, many people with disabilities are good at adapting to adversity and are well aware of the sources of help or emotional support (Martz and Livneh 2007). They may use religion, humour or fatalism to help them cope. On the negative side, they may in some cases resort to denial, which enables them to escape from the harsh reality of pandemic restrictions. Other maladaptive coping mechanisms involve substance abuse, detachment, behavioural disengagement, self-blame, guilt and venting (Umucu and Lee 2020).



## Residential care

A significant number of people with disabilities live in residential care settings. Sometimes, the reason for this is merely the frailty that goes with old age. In other instances, individuals need specialised care and assistance (Boyle et al. 2020). In Milan (Italy), the Pio Albergo Trivulzio is a large care home with a staff of 1 600 and 839 beds for residents. In March and April 2020, some 203 people died of infection related to Covid-19 in this institution. At that time, nearly a quarter of this institution's residents had recently been discharged from hospitals in order to create surge capacity for the growing influx of Covid-19 patients. They had not been tested for the virus and staff had not been given adequate personal protective equipment (PPE) or encouraged to use PPE. The resulting scandal led to a criminal inquiry. Likewise, in the United Kingdom, 6 686 care-home residents had died by 1 May 2020, a far higher proportion than in other sorts of institutions, except for hospitals. Similar patterns of mortality evolved in Sweden.

In many countries, care homes use agency staff and during the Covid-19 pandemic it was found that these were carrying the virus from one care home to another. Once this problem had been tackled by testing the workers and restricting access to the residents of care homes, the solution was unfortunately to impose isolation. Deprived of visits by family members and friends, the elderly and disabled suffered a fall in morale, with potential consequences for immunity (Safta-Zecheria 2020).

In some cases, where severe difficulties were experienced in bringing the care-home infection problem under control, residents were sent to live with their relatives, but usually with no added support. This created situations in which families had to maintain employment but also practise full-time care. Provision of support under such circumstances (including legal advice about employment rights) would help avoid the breakdown of family care and would thus stop a disabled family member from being taken back to the care home while it is in crisis (Rose et al. 2020).



## Forms of discrimination

The Council of Europe has identified elimination of discrimination against people with disabilities as a priority area for action (Council of Europe 2017: 17). At the global level, Article 25 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD, 2007) requires member states to ensure that the provision of healthcare does not discriminate against people with disabilities (Gulati et al. 2020). Article 11 deals with risk situations and humanitarian emergencies, calling on member states to guarantee the protection and safety of people with disabilities in conflict, humanitarian emergencies and disasters. Qi and Hu (2020) noted that Chinese law on the control of infectious diseases does not take account of this article, or, indeed, of the CRPD at all.

It is common that disease epidemics become politicised, bringing a tendency to blame the victims either for having the disease or for “creating a predicament” (Sutton 2005). The logical extension of this is to sacrifice them (Goggin and Ellis 2020). Nowhere is this more evident than in triage protocols for Covid-19. In March 2021, the UK National Institute for Health and Care Excellence (NICE) published guidelines for the critical care (NG191 – 2021). These suggested that triage decisions be made by employing a clinical frailty scale to assess a person’s ability to withstand invasive treatment. The guidelines were retracted later the same month when it was found that they biased decisions against people with disabilities, who may be frail but should never be considered “expendable” as a result (Courtenay and Perrera 2020). In fact, various countries used a “one-size-fits-all” approach to procedures, and this proved to be inherently discriminatory against people with disabilities as it encouraged clinicians to think of them as having lower survivability, purely on the basis of a relatively strong frailty score (Goggin and Ellis 2020). Nonetheless, frailty overlaps with the concept of comorbidity. Both of them contribute significantly to the definition of disability (Kow and Hasan 2020).

It was found that frailty scales in general can lead to the denial of treatment to people with disabilities, perhaps on the basis of assumptions about the outcome of the procedures that are not borne out by subsequent developments (Abrams and

Abbott 2020). This stems from a pervasive tendency of the non-disabled, including doctors and nurses, to rate the quality of life of people with disabilities rather lower than the disabled themselves rate it (Savin and Guidry-Grimes 2020). Although some disabilities can reduce life expectancy, this is not a valid reason for denying patients treatment, even in times of acute rationing of medical services (Wasserman, Persad and Millum 2020). Solomon, Wynia and Gostin (2020) noted that the ability to predict long-term survival is at the best of times poor, and perhaps more so with a disease whose full characteristics are only slowly brought to light.

In stark contrast to the 1918-1920 influenza pandemic, the SARS virus that has produced Covid-19 appears to have a more serious impact on the elderly than on younger people. This, of course, includes many old people who have disabilities, either through age or through intersection with pre-existing conditions.

Ageism (see the glossary at the end of this report) implies that the death of elderly people is less important than that of younger individuals (Brooke and Jackson 2020). Age should not be used in a negative manner as a proxy assessment of skill and ability (Singh 2020). Goggins and Ellis (2020) termed this the “biopolitics of disability”.

Ableism is the counterpart of ageism, in that it represents discrimination on the basis of a person’s functionality. It assumes that all minds and bodies should work in the same way, thus imposing a highly debatable concept of “normality”, representing what is or is not acceptable under given circumstances, and acceptable for people with disabilities and, by consensus, society in general. In a viral pandemic, it may lead to discrimination such as giving ventilator support to an able-bodied person rather than someone with a disability. This can create a form of medical apartheid (Bagenstos 2020). It all adds up to what Abrams and Abbott (2020) have defined as “underlying casual brutality”. Injustices that existed before the arrival of the disease are magnified during the pandemic when there are more opportunities to perpetrate them (Brosemer et al. 2020). The World Health Organization recommends that to promote fairness during pandemics people with the disease not be referred to as “Covid-19 cases”, “victims” “Covid-19 families” or “the diseased” (WHO 2020a). Nor, of course, should pejorative terms be applied to anyone who becomes ill with a virus and also has a disability. Overall, societal attitudes must improve, so that the “everyday emergencies” that people with disabilities experience are not considered as inevitable and unavoidable, especially when they are exacerbated by pandemic conditions (Pineda and Corburn 2020).

Various other forms of discrimination have been noted during the Covid-19 pandemic. For example, in China, due to restrictions on trans-border commerce, certain medicines could not be purchased on international markets and they were not available domestically (Qi and Hu 2020). In Europe, despite the Schengen agreements on open borders, restrictions on international movements and commerce have had a negative impact. In some cases, imported medicines have had to be procured through ministerial requests. When people have sought therapy abroad, specific agreements have had to be negotiated on a case-by-case basis. Unilateral closures of borders may have reduced the spread of the virus, but they have also hampered efforts to combat it.

In Australia, people receiving disability support pensions were not eligible for income support when they lost their employment or were placed on furlough. Disabled people are individuals who have individual needs. Concentration on providing healthcare to the population as a whole has sometimes led to neglect of those needs, potentially with fatal consequences (Qi and Hu 2020).

In the end, disability is a way of life as much as any other, and it should not prevent people from living through a pandemic to the best of their potential and abilities (Abrams and Abbott 2020).

## Disabled workers

Cortis and Van Toorn (2020) noted that during Covid-19 there has been poor planning for the disabled workforce and an apparently severe effect on rates of employment. Support services have been curtailed or disrupted and new barriers to familiar routine have appeared, many of them stemming from the closure of vital services. In Canada, workers with disabilities started the Covid-19 pandemic with structural disadvantages that included declining employment rates, uneven shift patterns and static wages or salaries. The effect of the coronavirus crisis has been to force a proportion of disabled people out of the workforce. Loss of support has led to increased absenteeism and the failure of some employers to make special provisions for the safety of workers with disabilities has also kept them away from workplaces (Maroto and Pettinicchio 2020). In the European Union, the employment rate of people with disabilities prior to Covid-19 was only three quarters that of people who are not disabled (Eurostat 2019). Research by the European Association of Service Providers for Persons with Disabilities showed that in April 2020 in Europe 82.6% of workshops and training centres for people with disabilities were closed (Bignal and Gouvier-Seghrouchni 2020: 15). Jesus, Landry and Jacobs (2020) identified an opportunity to improve prospects using telework, but they noted that the incidence of this among people with disabilities did not increase as rapidly as it did in the general population.

Finally, there is a special category of workers who are elderly parent carers (Courtenay and Perrera 2020). These are usually retired people who care for disabled family members but may have problems of their own, especially under lockdown conditions or when medical and social support is curtailed. Support is an important issue for both the carers and the disabled. It will probably be considered an “essential service”, but self-isolation, lockdown or other care priorities may reduce its availability (Den Houting 2020).





## The ethics of managing a pandemic from the point of view of people with disabilities

Review of issues such as discrimination and reduction of support prompts a discussion of the ethics of managing the pandemic in the light of the needs of people with disabilities. At the most basic level, society has a duty to protect and safeguard its most vulnerable members, and how it does so can be a measure of its civility (Singh 2020). Despite this, the term “vulnerable” must be used with care, as it may oversimplify situations and human relations.

Ageism and ableism amount to a form of structural discrimination. The ethical alternative is to take account of a person’s values, beliefs and preferences. Prejudice should not be a motive for imposing medical rationing, which should not be based on stereotypes. In other words, human worth is not determined by freedom from disabilities. Among the indices employed in triage we find the concept of quality-adjusted life years. These discriminate by failing to take into account the value of clinical evidence about a patient’s condition, that personal satisfaction may be independent of quality years, that people have different preferences in their lives and that comparisons with non-disabled people may be illegitimate in moral and ethical terms (Singh 2020). The solution is to ensure that medical procedures, including triage under the pressure of potentially overwhelming numbers of sick patients, are agreed with experts in medical ethics (Solomon, Wynia and Gostin 2020).

## The need for data

Many authors (e.g. Ienca and Vayena 2020) have emphasised the importance of collecting and carefully interpreting detailed data during a viral pandemic. Commonly, data on the impact of the disease are collected without specific reference to people with disabilities. It is therefore important to include a range of disability categories in the data collection process (Kuper et al. 2020). Data are needed in order to design the right kind of health protection, to improve measures and to ensure equity in access to and quality of care (Boyle et al. 2020). Where there is direct use of data, for

example in symptom trackers, account should be taken of any additional needs related to disability, including interpretive material for those with sensory or cognitive difficulties (Kuper et al. 2020).

The following sections contain observations on the impact of a pandemic on people with particular kinds of disability, on their needs and on the specific solutions to the problems created by the pandemic relative to each kind of disability.





## Cognitive impairment: intellectual disabilities and mental health conditions

While people with physical disabilities may endure functional decline if they are denied rehabilitation therapy, people with mental health conditions can find that their symptoms worsen during a pandemic. Experience suggests that the mental health of the general population is likely to suffer during lockdown, or as a result of family and employment difficulties. The mental condition of people with disabilities may be significantly worse. Psychiatric support and physically distanced therapies (where these are possible) are of great importance here (Kuper et al. 2020). Lockdown can also create an enclosed environment that people with intellectual disabilities can find frightening or oppressive (Tazaki 2020).

Developmental disabilities include cerebral palsy and Down syndrome. Intellectual disability may include impairments of mobility, cognition or ability to communicate (Stevens and Landes 2020). People with intellectual disabilities tend to have generally poorer physical health than do non-disabled members of the population. They also need close contact with carers and sometimes with their peers (Cuyppers et al. 2020). They may also be living in a state of social disadvantage. Lockdown can deprive such people of daily exercise and much-needed fresh air, which can lead to heightened anxiety and in some cases paranoia. If lockdown leads to problem behaviour, this may be difficult to manage within the constraints of physical distancing. Positive behaviour support plans must be adjusted as much as possible to the prevailing conditions. In the event of the failure of such plans and emergence of severely negative behaviour, the usual procedures for detaining people may need to be adapted to the constraints of physical distancing, difficult though this may be (Courtenay and Perrera 2020).

Another special case is autism. Autistic people and their families tend to suffer a high incidence of auto-immune disorder. About 10% of autistic people have comorbid physical disabilities. Although there is a risk that giving physical assistance to people with autism spectrum disabilities will spread the virus, there is no alternative, as physical help cannot be dispensed with (Den Houting 2020).

People with intellectual or developmental disabilities are generally more susceptible than average to death from pneumonia, and this is of course a heightened risk during a viral pandemic in which lung failure may be the principal source of mortality (Boyle et al. 2020, Cuypers et al. 2020, Stevens and Landes 2020). In fact, among people with Down syndrome, respiratory infections are the leading cause of death (O’Leary, Cooper and Hughes-McCormack 2018). More generally, comorbid physical disorders are more common in people with intellectual disabilities than they are in the general population and hence life expectancy tends to be shorter (Courtenay and Perrera 2020).

Regarding morbidity rather than mortality, people with cognitive difficulties may find themselves overwhelmed by the information on the pandemic, which leads them to over-focus. They will need information to be provided sparingly and in accessible formats, and at the same time appropriate information on how to cope during the pandemic must be supplied to carers (ibid.).

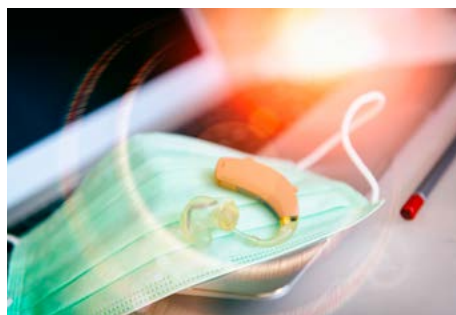
People with intellectual disabilities live in a wide variety of settings, from own home to care home, hospital or assisted living (Alexander et al. 2020). They are likely to have strong routines and will need to be prepared for the changes and restrictions that a pandemic will bring. Sudden change can make them anxious and can exacerbate mental health issues (Courtenay and Perrera 2020).

A special case is represented by Japan, where four million mental illness patients are accommodated in medical facilities. A quarter of all psychiatric beds in the world can be found in Japanese institutions. This means that changes in mental health stressors, such as those caused by a pandemic, can have a disproportionately large impact on the availability of healthcare (Tazaki 2020).

## Young people with disabilities

Many children with disabilities have special educational needs. These tend to be met, if they are met at all, in specialised educational institutions, or with specialised help embedded in regular schools. Lockdown during the progress of a viral pandemic can lead to the mandatory closure of all schools. The children must then be educated at home for an indefinite period. In the words of Asbury et al. (2020) “Carefully developed routines have been disrupted; support networks have disintegrated; and parents have been asked to do a job that trained teachers find challenging, without any training. These changes have happened abruptly...”

The families of disabled children with special educational needs routinely endure higher-than-normal levels of stress. When parents are forced to become full-time carers they may feel overwhelmed and suffer burnout (Asbury et al. 2020). At the end of lockdown, there will be the added task of re-establishing routines back at school (Toseeb et al. 2020). Meanwhile, parents





may need specialist advice or support (perhaps including speech or language therapists), help in designing educational activities and procuring materials, help with outdoor activities, if these are permitted, assistance with shopping and food provision (many children with special educational needs have restricted food preferences), and employment protection if a parent is prevented by care responsibilities from working either from home or in the workplace (Toseeb et al. 2020).

During pandemic lockdowns and school closures, online provision replaces face-to-face teaching. This may not be well adapted to the needs of children with cognitive and learning disabilities (Fitzgerald, Stride and Drury 2020). The problem is almost universal: in the first six months of the Covid-19 pandemic, 189 countries suspended school education. Children who have visual impairments or deafness may find that educational provision online is not compatible with the assistive technology upon which they rely in order to learn (Patel 2020). In developing countries, the assistive technology may simply be unavailable to the majority of potential users - and so may the infrastructure that enables distance learning. A pandemic offers an opportunity to raise awareness of children's fundamental human right to education, to treatment with dignity and respect, and to equal access to the means to learn (Schiariti 2020).

Children with autism spectrum disorder find it hard to develop social interaction skills (Patel 2020), while children with developmental disabilities such as autism and Down syndrome are strongly disadvantaged by disruption of their normal daily routine (Singh 2020). Finally, children with neurological disabilities can be highly susceptible to death from respiratory conditions, including those associated with viral pandemics (Boyle et al. 2020).

## Spinal cord injury

One form of disability that can be particularly difficult to manage is spinal cord injury (SCI). People with this form of impairment may be dependent on equipment and physical assistance for daily activities, and as they are likely to have internal organs that are compromised, they may be susceptible to infections of the urinary tract, respiratory infections and fevers. Diagnosis can be complicated, which is an added risk during a pandemic in which the virus has a high degree of lethality (Alexander M. 2020). SCI can cause uncontrolled hypertension, which causes the patient to suffer cerebral and spinal subarachnoid haemorrhage, seizures or pulmonary oedema, all potentially life-threatening conditions (Korupolu et al. 2020).

SCI can benefit substantially from telemedicine, a field that has grown up recently and rapidly. It permits physical distance to be maintained in order to limit the risks of infection. It is efficient in terms of reducing travel and medical transportation. It can be used to monitor and adjust programmes of home therapy so as to ensure the best physical outcome for the SCI patient (Stillman et al. 2020). Telemedicine is discussed in more detail below in the section of this report on solutions.

## Osteoarthritis

One disability that is common in the elderly is osteoarthritis, although it also occurs in some younger patients. This may be present with comorbid conditions, thus requiring a complicated care regime. Examples of comorbidity include diabetes, heart disease and asthma. Osteoarthritis disability, especially chronically disabling joint problems, can be managed by a combination of dietary, nutritional, medical, lifestyle and environmental measures, including risk management (Marks 2020). Promoting general health, ensuring communication and listening to the sufferer, allaying fears, ensuring an adequate diet (with vitamin D supplements) and providing ready-cooked meals can all help keep the disability from worsening during a pandemic situation. Information on healthy choices, light exercise where possible, use of assistive devices (frames, cranes, etc.) and attention to risk factors can also help (ibid.).



Those older adults who already have chronically painful debilitating osteoarthritis of one or more joints, which is the most common musculoskeletal disease affecting older people, may also be more susceptible to infections than are healthy age- and gender-matched adults as a result of their debilitated state and oftentimes comorbid health conditions such as diabetes, heart disease and asthma (ibid.).

## Visual and hearing impairment

Like people with leprosy and limb deficiency, the blind, deaf-blind and partially sighted tend to be dependent on assistance that involves touch, despite the requirements of physical distancing during a pandemic (Singh 2020). Inability to follow hygiene and hand sanitation protocols may make the visually impaired more susceptible to viral infection. They may suffer loss or reduction of the facilities on which they characteristically depend. Information about the pandemic may not be given in accessible form, and it may appear on websites that are not suited to automated screen reading (which is available on, for example, Microsoft Windows). As with other forms of disability, disruptions of personal support systems may render the visually impaired more at risk under pandemic conditions, and they may be stigmatised. Eyecare services may be curtailed or withdrawn during lockdown. One particular problem is the use of masks, which can stop people with hearing difficulties from reading the lips of people who speak to them. Transparent masks can help solve this problem, but they are neither widely available nor widely used.



## Other issues

Most forms of cancer treatment are immunosuppressive (Marks 2020). Following treatment, the immune system can take six months to recover, during which time shielding and isolation may be necessary, as the patient will be severely debilitated and highly susceptible to illness (Savin and Guidry-Grimes 2020). The demands made by a pandemic on hospital facilities may lead to the suspension of cancer treatment. Late diagnosis and delayed treatment can, of course, be fatal in terms of the unchecked growth and proliferation of the disease. For those who survive, the incidence and treatment of cancer are indications that disabilities can be temporary as well as permanent.

All patients who require dialysis treatment during a pandemic are considered to have an increased level of risk. Ikizler and Kliger (2020: 312) noted that “The possibility of a prolonged pandemic raises the very real threat of equipment shortage and supply chain deficiencies.” They also set out a protocol for the prevention and control of a virus in dialysis facilities. Furthermore, Ma et al. (2020) concluded that haemodialysis (HD) patients are at particular risk and dialysis units are high-risk areas during a viral pandemic. They suggested that attention should be devoted to preventing cardiovascular events in HD patients, as these may be collateral effects of the virus.

In some cases during the Covid-19 pandemic, lockdown led to the closure of blood donation facilities. This is a dangerous situation for thalassemia patients and people who are dependent on regular transfusions (Singh 2020).

Dental care during a pandemic is highly challenging, as transmission of the virus must be avoided during the treatment of patients by the dentist. Patients with intellectual difficulties may be particularly anxious or scared when they sit in the dentist’s chair and hence they may be unco-operative and difficult to control, especially when the dentist is fully clothed in personal protective equipment (Picciani et al. 2020).

Lastly, people with motor or some forms of cognitive disabilities may be forced to live a sedentary life and thus are at risk of obesity. In some viral pandemics this is an added risk factor.



## Covid-19 as a source of disability

Covid-19 is known to have debilitating sequelae as a result of the impact of the virus on the central and peripheral nervous systems. The virus may migrate to the brain or organs may be compromised by severe respiratory problems and the consequences of intensive care. The result can be immobilisation syndrome or critical neuropathy-myopathy. This is an illustration of how a viral pandemic can not only worsen pre-existing conditions (perhaps fatally), but also make people disabled. The proportion of patients thus affected appears to be highly variable with the strain of virus and the clinical history of the patient (De Sire et al. 2020). Disability may be temporary or permanent.

Rehabilitation of the respiratory system is essential, as it would be among survivors of acute non-seasonal influenza. Climatotherapy can be used to recover pulmonary function (Masiero, Maccarone and Agostini 2020). Where serious impairment of bodily functions has occurred, it is an interdisciplinary problem that requires intervention by a variety of specialists (Falvey and Ferrante 2020). Telemonitoring and telerehabilitation are recommended in the post-acute phase. For some patients, specifically those with muscular and skeletal problems, bathing in mineral-rich water may help, as well as reducing stress and anxiety. It can also help patients to recover their balance and ability to walk (Masiero, Maccarone and Agostini 2020).

## Solutions to problems

Viral pandemics have a propensity to exacerbate divisions in society between the advantaged and the disadvantaged. For people with disabilities, often among the latter category, their experience of the pandemic has much to do with access to healthcare and social services and their ability to communicate and understand other people's communications, with or without special assistance. As Annaswamy, Verduzco-Gutierrez and Frieden (2020) noted, "Significant, long-term changes in technological, regulatory, and legislative infrastructure and custom solutions to unique patient and health system needs are required to address these barriers going forward in order to improve healthcare access and outcomes for persons with disabilities."







For protracted periods of time, telemedicine may be the only access that the disabled have to health services, especially if they are suffering the effects of lockdown. It is important to ensure that telemedicine does not present unnecessary barriers to the disabled. It must therefore be designed with their special needs in mind, in relation to the physical setup, equipment used, access and communication processes (ibid.). Communication should use all available means to be accessible to as wide a spectrum of people with disabilities as possible. For example, if healthcare personnel wear transparent face masks, deaf people can read lips (Armitage and Nellums 2020).

Planners need to concentrate on ensuring that physical distancing and self-isolation during a pandemic do not adversely affect people with disabilities who are dependent on the provision of services that suddenly become incompatible with hastily imposed protocols and measures. There must be continuity of delivery of food, medicine and personal care (ibid.). Safe ways of easing restrictions on visits by family members to care homes can ease the situation during a long period of lockdown. Routine symptom and virus testing can ensure prompt intervention if staff or residents of care homes become infected with the virus. Local businesses can be persuaded to provide services, not only in a safe manner that limits the risk of contagion, but in a way that is acceptable to people with disabilities (Boyle et al. 2020). Pineda and Corburn (2020) describe this process as part of “urban disability justice”, something that is always required but needs special surveillance and measures during a pandemic in order to ensure that standards are not lowered.

Assistive technology must be employed to support people with disabilities by creating accessible educational platforms. Technologies that can assist disabled students include word processors, proofreading programs, spellchecking programs, speech recognition, speech synthesis, optical character recognition systems and talking calculators. Inclusiveness must be extended to social media as well. This is a matter of upholding digital rights and ensuring social equity (Toquero 2020).

In terms of a summary of general measures for enabling and protecting people with disabilities during a viral pandemic, one cannot do better than quote the recommendations of WHO (2020b).

### People with disability should:

- ▶ avoid crowded spaces and transport where possible
- ▶ stock enough food, medication and other essential products for at least two weeks
- ▶ shop online or by phone where possible and ask family, friends or caregivers for help
- ▶ regularly clean and disinfect assistive products such as wheelchairs and white canes
- ▶ put a plan in place to ensure continuity of care and support
- ▶ identify organisations, hotlines and people who can be asked for assistance if needed.

### Caregivers should:

- ▶ tell the person one is taking care of or their family and seek medical help early if anyone of them has viral symptoms
- ▶ if one suspects that the person one is taking care of has symptoms, wear a medical mask, wash one's hands thoroughly and seek medical help immediately
- ▶ make sure any assistive products are regularly cleaned and disinfected
- ▶ keep a list of public services and community organisations that can help
- ▶ plan ahead with the person one is taking care of to ensure continuity of care, including medication and other supplies, additional medical care, psychosocial and mental health support, and any other requirements such as repairing or replacing assistive products.

### Governments should:

- ▶ ensure that all health care facilities are accessible, including testing and isolation services
- ▶ make all public health information accessible to people with all forms of disabilities
- ▶ engage persons with disability and their representatives in planning the pandemic response
- ▶ ensure that financial compensation schemes cover people with disability, and mandate flexible work arrangements for them, their families and caregivers
- ▶ ensure continuity of services and support in case the number of available caregivers may be reduced, including fast-track training opportunities for new workforce
- ▶ provide a hotline in multiple formats (telephone, e-mail, SMS, easy language apps, etc.) for people with disabilities so that they can ask questions and raise concerns
- ▶ ensure that service providers and caregivers for people with disability have access to personal protective equipment and virus testing free of charge.

### Health care workers should:

- ▶ adopt alternative ways of providing health care such as home visits, telephone consultation and video conferencing to maintain services for people with disability deliver information and communicate in diverse formats to suit the different needs of people with different disabilities (without relying solely on either spoken or written information)
- ▶ deliver sufficient support for people with disability with more complex needs
- ▶ make sure that health workers are aware of the potential impact of Covid-19 on the health and living conditions of persons with disabilities.

### Disability service providers should:

- ▶ develop and implement service continuity plans in consultation with people with disabilities, their families and other local agencies
- ▶ if resources for continuity plans are not available, consider engaging the community and asking for additional support, particularly from people in relevant disciplines (e.g. nursing, physical therapy, occupational therapy)
- ▶ communicate frequently with people with disability and their support networks to provide targeted information about the pandemic, making sure all information is accessible
- ▶ train the disability care workforce in infection prevention and control
- ▶ continue to provide sufficient support for people with disability who have complex needs.

## Summary and conclusions

Viral pandemics are inevitable occurrences. Non-seasonal influenza, for example, appears to have a recurrence interval of 35-40 years, although the actual incidence is highly irregular (Nguyen-Van-Tam and Hampson 2003). SARS-type pandemics appear to have a longer recurrence interval, but all viral pandemics involve newly emerged strains of the disease in which its behaviour and characteristics are initially very poorly known, and there is no vaccine, immunity or antidote.

Austerity, political polarisation, conflict and identity politics have all tended to reduce the welfare function of society. The ways in which this has happened, and the extent to which it has occurred, vary from country to country. Pandemics abruptly throw into sharp relief the need for solidarity and the provision of welfare. One would hope that the threats and hazards posed by the arrival of a viral pandemic would unify society in a common aim to look after its vulnerable members and ensure a fair distribution of the chance of survival. Sadly, this is often not how it turns out. Whether by misguided priorities or failure to plan, the vulnerable are all too easily left behind.

In pandemics, “disability” can mean the intersection of mental (psychological) and physical problems. People with cognitive, intellectual or developmental disabilities may be at disproportionately high risk in physical terms, as well as suffering



potential loss of morale and psychological support. People with physical disabilities such as spinal cord injury, which have sequelae in other parts of the body, may be at particularly high risk of the impact of viral infection. People with suppressed or dysfunctional immune systems will carry some of the greatest risks of morbidity and mortality caused by the pandemic virus.

Three problems characterise the plight of the disabled during a pandemic situation. The first is the risk that triage for acute care may degrade their priority relative to non-disabled people, something that has been demonstrated to contravene basic medical ethics. The second is the withdrawal or curtailment of routine support mechanisms, coupled perhaps with difficult problems caused by the need for physical distancing in order to reduce infection risks. The third is the imposition of “blanket”, “one-size-fits-all” measures that do not take the needs of the disabled properly into account. With respect to disasters and major emergencies, people with disabilities need individual plans and assistance, in contrast to the group approach employed to safeguard the general population (Alexander and Sagromola 2014). This is challenging because it is resource intensive. However, it can be achieved with co-operation between civil protection services, health services, social services, disability support organisations and, wherever possible, disabled people as protagonists. Although a pandemic is a very different kind of disaster to most other forms, the same principal is broadly true when planning for one.

First, problems must be recognised in the context of the scenario created by the pandemic. Second, technology can be employed in order to provide new and efficient solutions, for example through telemedicine and telemonitoring. Third, medical ethics must be respected and used sensitively to ensure the survival and dignity of people with disabilities and to guard against discrimination. As noted at the beginning of this report, disability is not a problem: it is a challenge. Facing up to that challenge can help to build a better, fairer society for all.





# Glossary

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**Ableism:** societal attitudes and practices that discriminate against and devalue people who have or are perceived to have disabilities (Savin and Guidry-Grimes 2020)

**Ageism:** prejudice and discrimination against older people, based on the idea that one's age is a measure of skill and ability.

**Case–fatality rate:** the proportion of patients with a disease or condition who die of it.

**Comorbid:** denoting a medical condition that occurs in the same patient together with another.

**Disability:** a state that may make it difficult for a person to carry out certain activities or to interact with their immediate environment. It may involve dependency in carrying out activities of daily living.

**Lockdown:** Confinement of people to their homes or home area and closure of shops, offices, factories, venues, etc., in order to reduce the spread of the virus by restricting social contact.

**Morbidity:** illness or injury, whether fatal or not.

**Mortality:** death.

**Pandemic:** the international or global dissemination of a disease among different human populations. There is no quantitative threshold at which a mere epidemic becomes a pandemic, and hence the recognition that a disease has reached pandemic status is somewhat arbitrary.

**Physical distancing:** keeping 1-2 metres away from someone who might be infectious due to the range in which droplets and aerosols containing the virus are spread in a potentially dangerous concentration. It is sometimes known as 'social distancing', but this does not imply lack of *social* contact.

**Self-isolation:** remaining at home when someone has symptoms of Covid-19, been in contact with someone with symptoms, or on return from overseas; usually recommended for 14 days, rather than for an extended or continued time period.

**Welfare:** The provision of care to a minimum acceptable standard to people who are unable adequately to look after themselves.



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The World Health Organization (WHO) estimates that there are one billion people with disabilities inhabiting our planet today. They suffer from a wide spectrum of disabilities, ranging from motor and mobility issues to cognitive and sensory deprivation, and from short-term to permanent conditions. In times of a pandemic, such as Covid-19, disabled people should be treated as individuals with specific needs. The main aim of this publication is to identify ways to overcome the challenge to provide more equitable conditions. This helps societies to fulfil their moral responsibility to be fair and inclusive in respect of those of its members who are disadvantaged and markedly more vulnerable during a pandemic period.

Created in 1987, the European and Mediterranean Major Hazards Agreement (EUR-OPA) is a platform for co-operation between European and Southern Mediterranean countries in the field of major natural and technological disasters. Its field of action covers the knowledge of hazards, risk prevention, risk management, post-crisis analysis and rehabilitation. It has to date 24 member states.



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The Council of Europe is the continent's leading human rights organisation. It comprises 47 member states, including all members of the European Union. All Council of Europe member states have signed up to the European Convention on Human Rights, a treaty designed to protect human rights, democracy and the rule of law. The European Court of Human Rights oversees the implementation of the Convention in the member states.

