10. Disabled people’s deaths don’t count

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Part II

Infection and (increasing) marginalisation
Disabled people’s deaths don’t count

How a protected characteristic offered disabled people little protection during this pandemic

_Ellen Clifford and Mark Dunk_

Most at risk, but we don’t count

‘Less of a terrible loss’ – this was how a journalist described the COVID-related deaths of disabled people and those from more disadvantaged communities during the first wave of the pandemic. Others around the world echoed the sentiment (Neilson, 2020). We find ourselves in a situation where disabled people are most at risk of COVID-19 yet their needs have been disregarded within official responses to it globally.

Lindsey Lee, a former World Health Organization technical officer, has identified three distinct but related dimensions of disabled people’s increased risk from COVID-19: (1) increased risk of contracting the disease related to reliance on daily contact in order for support needs to be met and, to residential placements in environments that make physical distancing difficult; (2) increased risk of developing a severe case due to a combination of increased barriers to healthcare; and (3) increased risk of negative secondary consequences from the COVID-19 response due to, for example, cancelled or delayed health treatment for other conditions (Lee, 2020).

In developing their responses to the pandemic, governments have widely failed to consult disabled people or to consider the impacts of their strategies on the most disadvantaged in society. This is in spite of legal duties, such as the duty on public bodies in England, Wales, and Scotland to pay due regard to policy impacts on people with protected characteristics, and
human rights legislation. A global report on disability rights during the pandemic drew ‘the worrying conclusion that states have overwhelmingly failed to take sufficient measures to protect the rights of persons with disabilities in their response to the pandemic. … Perhaps most troubling of all, it highlights that some states have actively pursued policies which result in wide scale violations of the rights to life and health of persons with disabilities, as well as impacting on a wide range of other rights’ (Brennan, 2020:7).

One significant finding of the COVID-19 Disability Rights Monitor study was that disabled people ‘report being left behind in countries regardless of their level of development, across both wealthy and developing states’ (Brennan, 2020:7). Disabled people of all ages have been disproportionately represented among those who have died. Across Europe and North America, disabled and older people living in care homes have accounted for such a shocking proportion of deaths that the OECD has called on states to address ‘the pre-existing structural problems in the long-term care (LTC) sector’ that the crisis has both highlighted and exacerbated (OECD, 2020). This chapter examines the COVID-19 response and its impacts on disabled people in one such wealthy state: England.

Devolution of power in the United Kingdom has often meant that since 2010 disabled people have been disadvantaged more greatly in England compared to the devolved administrations of Scotland, Wales, and Northern Ireland (Reed and Portes, 2018). In relation to the pandemic, there is significant differentiation between the approaches taken. However, there are certain facts and statistics relevant to this chapter which concern the UK more widely than England and where this is the case, this is stated.

Context

Britain was once considered a world leader in support provision in rights protections for disabled people. Significant independent living advances enabling disabled people to live in the community regardless of impairment, and
ground-breaking disability anti-discrimination legislation were granted in response to sustained campaigning by disabled people themselves. Progress has since been reversed through a deliberate programme of austerity and welfare reform measures implemented by the UK government and that has been found to have inflicted ‘grave and serious violations of disabled people’s rights’ (Disability Committee, 2016).

In 2019, health spending as a share of UK Gross Domestic Product remained at its lowest level in a decade (Health Foundation, 2019). That same year, the Association of Directors of Adult Social Services accused the government of putting tens of thousands of older and disabled people at risk of being denied basic support, such as help with washing and dressing by their ‘failure to get to grips with the escalating financial crisis in social care’. £7.7 billion had been cut from adult social care budgets in England (Butler, 2019), with a further £700 million of cuts made by the end of 2020 – although two thirds of directors were not wholly confident they could be delivered.

It is now widely understood that austerity and welfare reform were not a necessary response to the financial crisis but rather a political choice made by successive governments. This strategy prioritised economic interests over the health and wellbeing of the populace and is also evident in the UK government’s approach to the pandemic. In June, a former member of the UK government’s scientific advisory group argued that Britain’s death toll from COVID-19 could have been halved if lockdown was introduced a week earlier (Reuters, 2020).

Disproportionate deaths

The scale of the disproportionate impact of COVID-19 on disabled people has not been reflected in the response to the crisis. Disabled people made up almost six in ten of all COVID-related deaths in England and Wales between 2 March and 14 July 2020. In all, there were more than 27,500 deaths of disabled people, compared with about 18,800 of non-disabled people. Disabled girls and women between ages
Challenges and Necessity of Co-production

9 and 64 were especially at risk compared with their non-disabled counterparts, with a rate of death 10.8 times higher (ONS, 2020).

More recent analysis from Public Health England (PHE, 2020) showed that between 21 March and 5 June people with learning difficulties had a death rate 4.1 times higher than the general population and acknowledged this was likely an under-estimation. It could be as much as 6.3 times higher than the general population because the databases used for the research do not register all deaths of people with learning difficulties. Alarmingly, for people with learning difficulties aged 18–34, the death rate was 30 times higher than for non-disabled people in the same age group. Reasons posited by the PHE for the disproportionate number of deaths among this group included prevalence of comorbidities such as obesity and diabetes as well as potential problems understanding information about how to keep safe during the pandemic. In effect, people with learning difficulties were blamed for their own deaths.

PHE failed to mention any of the numerous social factors that undoubtedly placed people with learning difficulties at greater risk and which could have been avoided had the early stage of the pandemic been handled differently by government. These include lack of PPE in group homes where it is difficult to socially distance, test and trace failures, and lack of thought given to accessible dissemination of safety messages.

PHE also omitted any reference to the ongoing Care Quality Commission investigation into unlawful use of Do Not Resuscitate/Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) notices on disabled people’s medical notes and coercion of disabled people to agree to it (CQC, 2020). Even after the NHS publicly spoke out against this practice in response to public concerns, group homes for autistic people and people with learning difficulties continued to receive communications from their local clinical commissioning groups pressing them to complete DNACPR forms for all residents.
Resistance and the limitations of legal protections

Disabled campaigners have been alert to discriminatory policymaking and practice involved in the COVID-19 response. Networks that originally formed to oppose the disproportionate impact of austerity and welfare reform measures on disabled people have monitored the situation since the early days of the pandemic. Campaigners have been kept busy taking action over numerous aspects of the pandemic response, including priority access to online deliveries for disabled people unable to leave the house, lack of COVID-19 guidance for disabled people employing personal assistants; the discharge of untested patients from hospitals straight into care homes; and initial rules banning all hospital visitors. These rules left disabled people who require additional support to understand or to be understood to die confused, misunderstood/ignored, and/or frightened.

The existing legal framework has been one of the tools that campaigners have to mitigate these avoidable harms. At the same time, the pandemic has further underlined the limitations of legislative protections already exposed by austerity and welfare reform. The Coronavirus Act has removed statutory duties on local authorities to assess the support needs of disabled people by introducing ‘easements’ to the Care Act 2014. Another easement to Section 42 duties of the Children and Families Act negatively affects disabled children with an Education, Health and Care Plan (ECHP).

Disability News Service reported in July that the UK government breached the rights of disabled people in at least 17 different ways during the coronavirus pandemic (Pring, 2020). Such findings have been described as an affront to dignity, inclusion, and equality (Tidball et al, 2020). However, the UK government continues to ignore the recommendation – issued by Parliament’s Joint Committee on Human Rights (JCHR) in September – to carry out a ‘swift lessons-learned review and a public inquiry’ (JCHR, 2020).
Secret orders

One of the issues picked up by the JCHR was how ‘decision-making relating to admission to hospital, in particular critical care, for adults with COVID-19 has discriminated against older and disabled people’. This is a particular case in point regarding the limitations of legislative protections.

In March, campaigners secured a revision of the ‘rapid COVID-19 critical care guideline’ produced by the National Institute for Clinical Excellence (NICE). The guideline originally stated that all adults on admission to hospital, irrespective of COVID-19 status, should be assessed for frailty using the Clinical Frailty Scale (CFS), and that comorbidities and underlying health conditions should be considered. In response to a public outcry and threat of legal action, NICE updated its guidelines on 25 March to emphasise the need to consider additional patient factors when interpreting the CFS score (NICE, 2020).

This was far short of the reassurance that campaigners were seeking and left disabled people completing homemade ‘hospital passports’. These documents emphasised the valuable roles they play in the community and their contributions to society and were to be taken with them should they be admitted to hospital during the pandemic. They were a grassroots attempt to resist denial of critical care.

Unprecedented steps were taken to keep large numbers of elderly and ‘frail’ patients at home and out of intensive care wards in order to avoid these services becoming overwhelmed. It also now appears that an unpublished age-based frailty score system commissioned by the UK government’s Chief Medical Advisor, Professor Chris Whitty, was behind the widespread denial of intensive care to people over 80 years old. It also excluded many disabled people over the age of 60 from life-saving treatment. Testimony by doctors has confirmed that the system was used by medics to prevent elderly patients ‘blocking’ intensive care beds. A second version increased the score for specific illnesses but lowered it for age – in other words, made it more targeted at denial of treatment on the basis of impairment as opposed to age. NHS doctors were
forced to make tough decisions about which patients to treat and who to leave to die.

Evidence that intensive care treatment is of ‘crucial importance’ for survival is reflected in the statistic that only one in nine people who died of COVID-19 were given it. A study comparing the number of COVID-19 deaths on normal wards against the number of intensive care beds said to be available in UK drew the conclusion that intensive care was being overzealously withheld (Shovlin and Vizcaychip, 2020). This finding has been linked to a ‘COVID-19 decision support tool’ in circulation in March.

Moving forwards

A number of bodies including the OECD, the World Health Organization, and the Swedish Corona Commission have called on governments to use the tragedy of care home deaths to incentivise the introduction of serious measures to address pre-existing structural issues with the social care sector. History suggests that it is unlikely that governments scrambling to ‘boost’ their respective economies in the wake of the virus will follow these recommendations. The relationship of impairment to the processes of production that makes disabled people a less ready source of profits will further compound this tendency to disregard impacts on disabled people.

The question is then, what actions can we as disabled people, service users, and health and social care practitioners take to raise awareness of how oppression and injustice, exacerbated by crises such as COVID-19, are built into the fabric of the current system? In building awareness there is a need to promote widespread, united support for alternatives that can better serve those who are otherwise discriminated and (in many cases fatally) harmed by the system.
What needs to be done

- Explore and unravel the overlaps between old age, impairment, and illness in order to better challenge mainstream narratives concerning ‘vulnerability’ that effectively devalue those who are labelled as vulnerable.
- Build support for a National Independent Living Support Service (ROFA, 2019) paid for from general taxation and free at the point of delivery, capable of supporting disabled people’s equal participation in the community and providing the social care workforce with appropriate conditions, pay, training, and profile.
- Concerted campaigning needs to happen to prevent further privatisation of the NHS and the damage this has done to disabled people through inadequate and at times abusive social care.
- Disabled people’s organisations and practitioners in the UK need to build stronger alliances with disabled people both nationally and internationally in order to share experiences and solidarity.

References

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