

Expert Report for the UK Covid-19 Public Inquiry

Module 2: Structural Inequalities and Disability

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Author statement

We confirm that this is our own work and that the facts stated in the report are within our own knowledge. We understand our duty to provide independent evidence and have complied with that duty. We confirm that we have made clear which facts and matters referred to in this report are within our own knowledge and which are not. Those that are within our own knowledge we confirm to be true. The opinions we have expressed represent our true and complete professional opinions on the matters to which they refer.

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Introduction

1. The potential for disabled¹ people to be at higher risk of harm from Covid-19 was well understood before the pandemic took full effect. In March 2020, for example, the US Centre for Disease Control commented that disabled people were at higher risk for both contracting COVID-19 and of suffering harm than those without disabilities “because of underlying medical conditions, congregate living settings, or systemic health and social inequities” (CDC, no date, paragraph 2). People with existing health issues were understood to be at greater risk. In the early stages of the pandemic the daily release of mortality figures was usually accompanied by comments such as “the vast majority of those who died had underlying conditions”. As Shakespeare et al (2022) have argued, not only were disabled people often more susceptible to the virus, but both their pre-existing inequities and the social impact of pandemic control measures put them at increased risk of harm.
2. Disabled people in the UK could (and should) have been foreseen to be at higher risk from a Covid-19 type virus due to three factors, which will be reviewed in what follows. First, some disabled people are at higher risk of a Covid-19 type viral pandemic due to intrinsic vulnerability to infection. Second, as a result of societal, structural and institutional failings disabled people in 2020 were in a weakened socio-economic situation compared to their nondisabled peers, particularly due to reforms introduced following the election of the Coalition Government in 2010. Third, many disabled people are dependent on health and social care services, which were themselves weakened as a result of the pandemic.
3. The Family Resources Survey published by the Department for Work and Pensions (2023) estimates that in 2020/21 22% of the UK’s population reported a disability. For those of state pension age 46% reported a disability and the figure for those of working age was 21%. The figure for children was nine percent. 24% of females reported a disability compared to 20% of males. The figures varied by jurisdiction, with Wales reporting the highest figure (28%), Scotland the lowest at 21% with England and Northern Ireland matching the national average of 22%. There was also large variability within each jurisdiction, for example the North East of England reported the highest levels of disability at 31% and London the lowest at 15%.
4. While equality is a reserved matter there is variation in the way the four different jurisdictions deliver their services, particularly in terms of health, education and social care and support. Throughout this report we have tried where possible to reflect and comment on this and the way it has shaped the position of disabled people.
5. Throughout this report we have tried to take this regional variation into account and have also sought to ensure that we address the issues as they apply to each of the four devolved jurisdictions.

¹ Throughout this paper we use the term disability as defined by the Equality Act (2010). Under this Act a disabled person is defined as someone with “A physical or mental impairment which has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities”.

Increased vulnerability to infection and poor outcomes from Covid-19 disease

6. Overall, it is well established that disabled people have a much narrower margin of health, face significant health inequalities and are more likely to die prematurely than non-disabled people (Heslop et al 2013a; Heslop et al 2013b, O'Leary et al 2018; Glover et al 2017). Disabled adults and children across the UK report much lower rates of good physical and mental health overall compared to their non-disabled peers (EHRC 2018). Many disabled people have comorbidities, such as hypertension, heart disease, respiratory disease, diabetes and depression, which had again been identified at an early stage as risk factors for poor outcomes from COVID-19 (Turk et al. 2020). The impact of these vulnerabilities are magnified by their poor access to health care, poverty, education, employment and increased risk of violence and abuse.

Specific vulnerabilities to Covid-19 disease

Age

7. Disability entails a strong age gradient: 12.2% of females aged 70-74 were limited a lot (16.6% in Wales), and 11.4% of men aged 70-74 were limited a lot (15.8% in Wales), rising to 47.1% of females over 90 limited a lot (50.6% in Wales) and 38.3% of men over 90 limited a lot (41% in Wales). In total, approximately half of people significantly affected by disability are over 60 (WHO 2011). The association between age and severity of outcome was well established in the very early days of the pandemic (Scientific Advisory Group for Emergencies 2022).

Impairment status and health

8. Many disabled people face a narrow margin of health and are more susceptible to viral infections. People with intellectual disabilities² have as many health conditions at age 20 and over as the rest of the population aged 50 and over, and live 20 years less than their non-disabled peers (Kinnear et al 2018). Respiratory disorders are the predominant cause of death for people with an intellectual disability (Oppewal et al 2018; Cooper et al 2020; Durvasula et al 2002; Hosking et al 2016). Risk increases with level of impairment and when compared with the general population, the relative risk of respiratory related deaths is 2.6 times higher for people with mild intellectual disabilities and 5.8 times higher for people with profound and multiple intellectual disabilities (Patja et al 2001). The most common cause of death associated with respiratory infections is pneumonia arising as a result of influenza or other respiratory infection or injury from inhalation or aspiration events. During the 2017-18 influenza epidemic, excess mortality among people with intellectual disabilities was three times higher than in the general Dutch population, occurred more often at a young age, and with a broader range of underlying causes (Cuypers et al 2020).

² Throughout this report we use the term intellectual disability as defined by the *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition* (DSM-5). Intellectual disabilities are defined as neurodevelopmental disorders that begin in childhood and are characterised by intellectual difficulties as well as difficulties in conceptual, social, and practical areas of living.

9. Many other groups of disabled people are at increased risk of respiratory infection. For example, people with multiple sclerosis are known to be at particular risk of viral infections, not only are they more prone to infection and once infected more likely to develop serious symptoms but viral infections also often lead to relapse (Oikonen et al 2011). Respiratory disorders are the leading cause of death in persons with both acute and chronic spinal cord injury (Burns 2007). People with rheumatoid arthritis have an increased infection risk and morbidity and mortality risk related to respiratory infections (Caporali et al 2008).
10. Comorbidities which affect the immune system, such as diabetes, are associated with worse outcomes from infectious respiratory diseases such as Covid-19 disease: a high proportion of people dying from the disease in Italy (Onder et al 2020) and United States had diabetes. Disabled people, particularly those with intellectual disabilities or mobility disability are more likely to be overweight and obese, which is a risk factor for worse outcomes from disease (Ells 2006).
11. It is clear that large numbers of disabled people were clinically vulnerable to Covid-19.

Difficulties with self-isolating

12. As well as intrinsic vulnerability to Covid-19 disease, disabled people's needs for care and support meant that many of them may find it much more difficult to adopt self-isolation to reduce the risk of contracting the virus in the first place. Many older and disabled people are in close contact with others when receiving care and support in daily activities (Dickinson et al 2020) and when living in group homes (Balogh et al 2016, Daly, 2020). Those disabled people in domiciliary settings often rely on a small pool of care workers who support them with intimate tasks (Glynn et al 2020). Guide-dogs do not understand social distancing, and touch is an important way of interacting for many who are blind or deaf-blind.
13. Despite higher needs for healthcare, disabled people experience inequities in access to the healthcare they need with poor access to both primary care and secondary care and large unmet need (Allerton and Emerson 2012). Healthcare providers lack knowledge and awareness of the healthcare needs of disabled people and people with intellectual disabilities and/or autism (Doherty et al 2020, Shakespeare and Klein 2013) . Disabled people have worse access to healthcare than their non-disabled peers and face increased barriers in access to services (Sakellariou and Rotarou 2017). These inequalities are well-evidenced and long standing (Barr et al 2014; Ellis and Fry 2010; Goddard and Smith 2001).
14. This evidence on health inequalities and inequalities in access to health care for disabled people, when combined with increased attention to the human rights of disabled people, has led regulatory bodies and governments to stress the importance of reducing the health inequalities experienced by disabled people (See for example Department of Health 2010; NHS England 2015; Learning Disability Wales 2019; Scottish Government 2019).

Disability and structural discrimination

15. Despite over twenty years of anti-discrimination legislation, disabled people in the UK continue to face disadvantage compared to their nondisabled peers. In their most recent review of inequality in the UK, *Is Britain Fairer?* (2018), the Equality and Human Rights Commission (EHRC) highlighted disabled people's lack of progress compared to other groups. They point to discrimination across a range of sectors throughout the lifecycle.
16. In addition to protection under the Equality Act the UK has also ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and the Optional Protocol. These aim to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms for all disabled people. In 2016 the Inquiry Concerning the United Kingdom of Great Britain and Northern Ireland carried out by the Committee under Article 6 of the Optional Protocol to the Convention highlighted a range of concerns around the impact of welfare reform on the rights experienced by disabled people. The report concluded that there had been "grave or systematic violations of the rights of disabled people". It pointed to concerns about their lack of involvement in and consultation on policy that affected their lives, the damage done by austerity measures and the lack of data on disability and equality.

Employment

17. Disabled people face discrimination in employment and, in 2018, 51% of disabled people were employed compared with 81% of non-disabled people - a disability employment gap of 30 percentage points (ONS 2018). Disabled people are also paid less on average than their non-disabled peers. In 2018, median pay for non-disabled employees was £12.11 an hour whilst for disabled employees it was £10.63 an hour, a pay gap of 12.2% (ibid). Disabled people are also more likely to be in part-time employment, around 30% work part-time, compared with around a fifth of those who are not disabled (JRF 2018).

Deprivation

18. Going into a pandemic, disabled people as a group were in a weakened situation relative to non-disabled people in the UK. According to the JRF nearly 50% of those living in poverty are either disabled themselves or live with a disabled person (ibid). In 2018, disabled adults in working-age families were much more likely to be in poverty than those who were not disabled – 39% compared with 18% (ibid). The poverty rate for disabled adults in working families was 21% compared to 14% for nondisabled working adults. The poverty rate for disabled adults in non-working families was very high at 67% (ibid). Over a third of disabled people experience material deprivation, nearly three times that of non-disabled people (EHRC 2018). The links between poverty, morbidity and mortality are well-established. Disability is associated with multi-dimensional poverty in the UK and internationally (WHO 2011).
19. As a result of the extra costs associated with disability, poverty has a disproportionate effect on disabled people. Scope (2018) estimated that disabled people on average face extra costs of £570 per month as a result of their impairment. The extra costs are experienced across the income distribution but are more concentrated in those with the lowest income.

For example, those in the highest income decile are estimated to experience extra costs of £66 per month compared to £178 per month for those in the lowest decile. The extra costs exist across the life course, affecting disabled children and their families (Shahtahmasebi et al 2011) disabled adults (JRF 2018) and older people (Hancock et al 2016).

20. Disabled people are more likely to live in inadequate housing, experience lower levels of security and are at greater risk of sexual or domestic violence, they have less trust in the justice system, are at greater risk of social exclusion, poorer access to public transport and leisure and cultural activities, and have low levels of political participation and representation. According to the EHRC (2018), disabled people are much less likely to participate in community activities, feel part of the community or have trust in the members of their community and as a result are more likely to report loneliness and isolation.
21. The pattern of structural discrimination which has become evident is clear from different areas of life. For example, poor access to transport affects not just those with mobility impairments, but also includes people with sensory impairments, neurodiversity and mental health conditions (House of Lords, 2016). Disabled people are more likely to be in poor housing: a study by the Smith Institute estimates that in the north of England one in three households with a disabled person live in non-decent accommodation (Hackett 2019). Similar findings are reported in Scotland (EHRC 2018). Links between poor housing and increased susceptibility to respiratory illness and infections are now well-established (Gordon et al 2017).

Education

22. Structural inequality is also evident in the field of education with gaps in educational attainment and employment for disabled children and young people widening rather than narrowing (EHRC, 2018).
23. Prior to the pandemic there was a widely-acknowledged crisis in provision for children and young people with special educational needs and disabilities (SEND in England and Northern Ireland; Additional Support Needs in Scotland; Additional Learning Needs in Wales). In England for example, funding for special education has not kept pace with the rise in the number of pupils identified as being in need of support (NAO 2019). Similarly in Scotland, resources were found to be insufficient to support students with additional support needs in mainstream schools (Scottish Parliament 2017; UK Parliament 2019). Wales has recently undergone a major restructuring of support for disabled children and there is little up to date evidence available. Disabled children make up a significant number of pupils who are excluded accounting for 44.9% of permanent exclusions and 43.4% of fixed-period exclusions, although there is a great deal of local variation (NAO 2019).
24. These disadvantages continue into further and higher education. In Scotland for example, disabled students were less likely than non-disabled students to successfully complete their qualification, and also less likely to be in work or further study after graduation (Scottish Funding Council, 2017).

Digital exclusion

25. Across all age groups, disabled adults make up a large proportion of adults who do not use the internet. Presence of disability is one of the strongest predictors of digital exclusion (Martin et al 2016). In 2017, 56% of adults who do not use the internet were disabled, a much higher figure than the proportion of disabled adults in the UK population as a whole, which in 2016 to 2017 was estimated to be 22% (ONS 2019a). 60% of internet non-users aged between 16 and 24 years, were disabled in 2017, a proportion that is the same as for those aged 75 years and older. Where they do access the internet, disabled people use it less (Scobie and Schlepper 2018). This is particularly the case for people with learning disabilities, dementia or sight impairment, for whom both awareness and use of online services are significantly lower.
26. There is also evidence to suggest that reliance on digital technology has increased the relative social exclusion and ultimately health inequality experienced by disabled people (Macdonald and Clayton 2013). Evidence on digital technology and health inequalities suggests that disabled people have been left behind in the migration to telehealth (Honeyman et al 2020). The needs of disabled people are often excluded from guidelines on remote healthcare provision, and digital technologies for health are often not designed with access in mind and neither are disabled people given access to digital skills training. Allied Health Profession services - for example physiotherapy and occupational therapy - are not fully equipped with clear and comprehensive guidelines and with the skills necessary to deliver telehealth consultations to disabled people (Leone et al 2022).

Security

27. Across all age groups and all impairment groups, disabled people are more likely to have experienced crime than their non-disabled peers (ONS 2019b). In the three years to March 2018, there were an estimated 52,000 incidents of disability-motivated hate crime in England and Wales each year (Home Office 2018). Disabled people feel much more at risk of crime than their non-disabled peers: for example, in England 63.6% of disabled adults said they felt "very or fairly" safe when walking alone after dark, compared with 81.3% of non-disabled adults (ONS 2019b). Similar results are found for Scotland where the figures are 64.8% of disabled people feeling safe to walk down the street compared to 80.4% non-disabled (ONS 2019b).
28. Nor is home always a safe space: just over 14% of disabled adults aged 16-59 experienced domestic abuse in 2018/19 compared to 5% of non-disabled adults. Similar disparities are found in relation to sexual assault, with 3.7% of disabled adults experiencing sexual assault compared to 1.9% of their non-disabled peers in the three years leading up to March 2018. In the same period disabled women were almost twice as likely to have experienced any sexual assault in the last year (5.7%) than non-disabled women (3.0%) (ONS 2019b).

Social Isolation and loneliness

29. Many disabled people are subject to high levels of social exclusion and segregation (Hall and Bates 2019). This is particularly the case for people with an intellectual disability and those with a mental health problem (Hall and Bates 2019, Macdonald et al 2018). Compared to

non-disabled people, disabled people are more socially isolated, they have fewer opportunities to participate in the community, have fewer friends and have less social support (EHRC 2017). Many disabled people report feeling disconnected from their communities and their social interaction is often limited to the service settings (Milner and Kelly 2008). Social isolation is felt across all age ranges. For younger disabled people, loneliness arises as a result of inaccessible transport, lack of support to continue friendships after school, and difficulties accessing the settings where other young people spend their free time, such as clubs and fast food outlets (JRF, 2002).

Disabled people and reliance on health and social care

30. Disabled people as a group have been among those most affected by the period of ‘austerity’ that followed the financial crisis in 2008. They have faced major reforms to welfare and support and this has placed them at increased risk of poverty and affected their health. In the UK, public spending cuts are associated with wider social security ‘welfare reforms’ which have redrawn the boundaries of eligibility for disability-related and other social benefits (Roulstone 2015). According to the EHRC these reforms have had a “particularly disproportionate, cumulative impact on rights to independent living and an adequate standard of living for disabled people” (EHRC 2017).
31. By the time the pandemic arrived, social care across the UK was already overstretched. Public funding cuts greatly affected the ability of disabled people or the services that work with them to respond to any external shock. By 2020 cuts resulted in high levels of unmet need, with providers and local authorities struggling to deliver quality care for the prices paid, resulting in delayed discharges from hospitals and a workforce crisis. Across the UK as a whole, public spending on adult social care fell by nearly 10% between 2009–10 and 2016–17 (Charlesworth and Johnson 2018). There has been a great deal of variation in per capita spending on social care across the UK. Table 1 shows social care spending per head across the four jurisdictions comparing 2011/12 with 2015/16.

Table 1. Social care spending per head in England, Scotland, Northern Ireland, Wales and the UK: real spending (2018/19 prices) and percentage change between 2011/12 and 2015/16

	2011/12	2015/16	% change 2011/12 to 2015/16
England	£398	£365	-8.2%
Scotland	£492	£530	7.7%
Wales	£495	£486	-1.8%
Northern Ireland	£482	£555	15.1%
UK	£485	£415	-9.1%

(Source: Lee and Stoye 2018;15)

32. The Institute for Government estimated that between 2009/10 and 2014/15, local authorities in England cut spending on adult social care by nearly 9.3% in real terms and that by 2019 social care funding had been cut by 2% in real terms compared to 2008/09 (Institute for Government, 2019). England’s lost expenditure totalled £7,220m or £168 per head by 2018-19, Wales lost £179 per head, or £440m over the period. Scotland fared relatively better, with lost expenditure of £350m or £80 per head (Social Work Scotland 2020).
33. Cuts of this scale to an already overburdened service have meant reductions in the range and quality of services; eligibility criteria have been changed to reduce access, and there has

been an increased reliance on informal care provided by family and friends (Glasby et al 2020). These cuts have included reductions in community-based services, personal budgets, state funded and/or provided care and care from the independent sector.

34. Cuts to fees paid by local authorities to care homes across the UK resulted in a sector that was badly underfunded and facing pressures from rising wage costs and rents prior to the Pandemic (Competition and Markets Authority 2017). In 2019, the King's Fund identified a growing workforce crisis in social care in England with service providers struggling to find, recruit and retain suitable staff. The 1.1 million full-time equivalent employees working in social care faced low pay and poor working conditions, with approximately a quarter of the workforce on zero-hours contracts. Between 9.2% and 12.9% of the workforce were on minimum pay (Gardiner 2015). Recruitment and retention of staff was a major problem: in 2018 there were over 110,000 vacancies in social care in England, representing about 8% of roles (Skills for Care 2018). This figure had risen by 2.5% since 2012.
35. Much of the support and services for disabled people has been provided by the third sector, voluntary and community sector organisations. They deliver services to parts of society that the state and private sectors cannot reach. However, public spending cuts have significantly impacted on this sector and its capacity to help local communities (Jones et al 2016). Clifford (2017) reports that third sector organisations involved in the delivery of health and social care have faced significant cuts in their income at a time where their need has grown considerably. Charities in the most deprived areas have been most affected, reducing their capacity to tackle the structural inequalities facing disabled people.
36. These cuts across all sectors of health and social care have greatly affected both the support disabled people receive and also their opportunities for inclusion and participation, as highlighted by the Inquiry Concerning the United Kingdom of Great Britain and Northern Ireland carried out by the Committee under Article 6 of the Optional Protocol to the Convention. Many no longer receive the level of care they require.

Conclusions and Missed Opportunities

37. It is well documented that disasters and emergencies often disproportionately impact the disability community, and the Covid-19 pandemic proved to be no exception. It exposed, intensified and reinforced pre-existing inequalities, and disabled people were one of the most affected groups.
38. Despite this, there is evidence that there was a failure both locally and across the four jurisdictions to examine the increased risk faced by disabled people (see for example Shakespeare et al 2022; Daly 2020). For instance, ONS has only in November 2022 produced the first attempts to examine the excess risk for people with hearing or vision impairment (Machaul et al 2022). In the early stages of the Pandemic, the only organisations which seemed to be exploring the impact of Covid-19 on disabled people were third sector organisations of disabled people (Cullingworth et al 2022).
39. Data on the impact of Covid-19 disease shows that the increased vulnerabilities to Covid faced by disabled people led to disproportionate impact, particularly on people with intellectual disabilities: Seid et al's (2022) systematic review showed that people with intellectual disabilities had 5.6 fold higher mortality rates. Data from Scotland also shows much higher risk of infection, severe infection and mortality among those with intellectual disabilities (Henderson et al, 2022). People with Down Syndrome have over 30-fold increased risk of dying from COVID (Williamson et al 2021).
40. While 16% of adults in the UK have disabilities, research carried out by ONS reported that in England people with disabilities made up 59% of deaths from COVID-19 (Bosworth et al 2021). The same research also found that the more disabled a person was, the greater their mortality rate. After adjusting for age differences, people whose impairment "limited their daily activities a lot" suffered a 3-fold higher mortality rate than the general public, while those whose impairment "limited their activity a little" faced 1.9-fold higher mortality rate.
41. At the outset of the pandemic, it should have been clear that disabled people were at increased risk of harm from an epidemic such as COVID. While it was established at the start that there were a number of disabled people at personal risk of increased vulnerability to the disease and these were placed on a list of those defined as being clinically extremely vulnerable people, little account was taken of the structural exclusion and discrimination experienced by disabled people. Neither was the weakened state of the services that aimed to support them considered. The pandemic placed extra burden on already overburdened services, and many were not able to respond to their clients' needs at the level and intensity required. The failure to take these two factors into account at the start of the pandemic was a major cause of the problems that were to beset disabled people during all the waves of Covid. There was also a failure to take account of the impact of poverty on disabled people and to foresee the issues this would cause, particularly digital exclusion, a disadvantage that became even more important as services and support moved online.

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