



# The World before Covid-19 for Disabled People and People with Mental Health Challenges

Contextualising the experiences of disabled people and people with mental health challenges in the United Kingdom

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## Introduction

Previous research and work to define the Trust's organisational response to Covid-19 identified six groups as being particularly likely to be disproportionately impacted by the pandemic:

- Adults with mental health challenges
- Children and young people with mental health challenges
- Learning disabled children, young people and adults
- Physically disabled children, young people and adults
- People with sensory impairments
- People at risk of domestic abuse

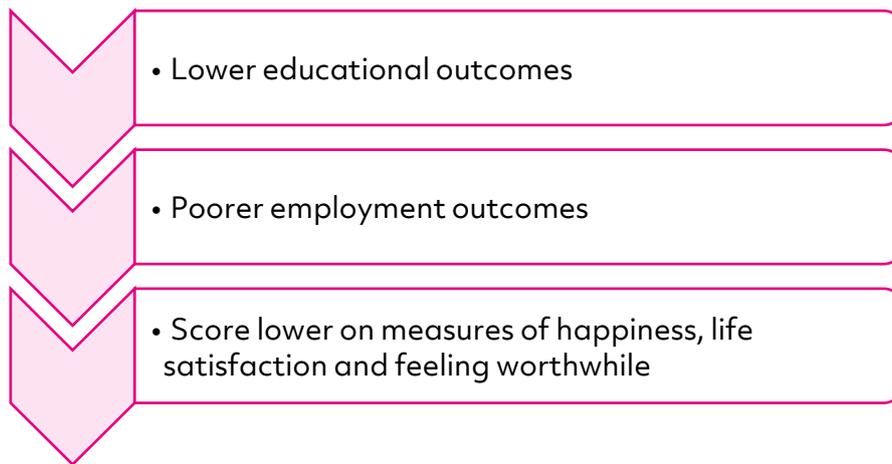
From April to June 2020, Barnwood Trust undertook a mapping exercise to understand the impact of the Covid-19 pandemic on disabled people and people with mental health challenges in Gloucestershire. The findings of this study are available in the *Our Changing World* report.

This document has been produced by way of context to complement the report and draws on local and national data looking at three core areas:

- What was life like for disabled people and people with mental health challenges **before** the pandemic?
- What local data is available about the six groups on which the mapping exercise focuses on and what does it tell us?
- What do we know from national data about how Covid-19 is impacting on disabled people and people with mental health challenges?

## Setting the Scene

Whilst the ongoing Covid-19 pandemic has brought to light the many ways the lives of disabled people and people with mental health challenges have been impacted **disproportionately**, existing research indicates that such experiences have been a perennial feature of many people's lives. According to the Office for National Statistics, compared to non-disabled people, disabled people and people with mental health challenges experience<sup>1 2 3</sup>:



This has similarly been visible within the Coronavirus pandemic as disabled people and people with mental health challenges have been more greatly impacted in terms of the **health impacts** of the virus<sup>4</sup> and the **social impacts** including access to basic provisions and services and to their mental health and wellbeing.<sup>5 6</sup>

However, to fully understand how the pandemic has changed the worlds of individuals and what can be learned from their experiences, it is important to understand what existing research tells us about the way that world looked like before. Drawing on this research, this supplement will explore disability and mental health in three key ways.

- 1) **Deprivation and Inequality:** Existing research indicates that **deprivation is a key factor of health inequality** and an experience that features heavily in the experiences of a large proportion of the disabled population. Looking at Gloucestershire specifically, we will highlight what this inequality looks like for disabled people and people with mental health challenges.
- 2) **Individual and Unique Experiences:** Disabled people and people with mental health challenges **do not have universal experiences**. Disability is a spectrum, impacting individuals in **often unique ways** and this supplement will look in greater detail at the experiences of the six groups identified above in particular.
- 3) **Covid-19 and Disability:** The broader issues that have come to light since the Covid-19 pandemic struck including the implications of the **legislative changes** in the Coronavirus Act and early indications from national data about the impact so far.

Where relevant, and where available, both national data and data from Gloucestershire will be included to further contextualise the experiences of disabled people and people within the report: *Our Changing World*.

## 1. Deprivation and Health Inequalities

Deprivation is considered a significant determinant of health inequalities<sup>7</sup> and is associated with the distribution of disabled people and people with mental health challenges in an area<sup>8</sup>.

An estimated 106,809 disabled people (16.7%) and 75,012 people with mental health challenges are living in Gloucestershire and although Gloucestershire is not considered a very deprived county, relative to the rest of England, levels of deprivation do differ across it and **some areas are considered to be amongst the most deprived in the county.**

The Index of Multiple Deprivation is a composite measure of various indices of deprivation such as income, employment, education, health and disability, amongst several others. Of the six Gloucestershire districts, the most deprived areas are Gloucester City and the Forest of Dean. Stroud District is the least deprived. Incidentally, these three districts are also the areas in which the biggest disabled populations live (by proportion of disabled people – see *table below*):

District	% of Disabled People (2011 Census) <sup>9</sup>	Estimated Number of Disabled People (Based on 2018 Population Estimates) <sup>10</sup>	Deprivation Rank (Gloucestershire, 2019 IMD) <sup>11</sup>
Forest of Dean	19.6%	16,962	2
Gloucester City	16.8%	21,720	1 (most deprived district)
Stroud District	16.7%	19,879	6 (least deprived district)
Tewkesbury Borough	16.5%	15,729	4
Cotswold District	16.1%	14,333	5
Cheltenham Borough	15.1%	17,681	3

Figure 1: Disability and Deprivation in Gloucestershire

It is also noticeable that with the exceptions of the Forest of Dean (19.6%) and Cheltenham Borough (15.1%) **Gloucestershire's disabled population is quite evenly distributed across the districts.**

Looking specifically at health deprivation and disability, there are seven localities within Gloucestershire that are amongst the most deprived in England – approximately 10,948 people or 1.8% of Gloucestershire’s population. Six of these areas are within Gloucester City and one in Cheltenham. The health outcomes of these 10,948 people are likely to be worse than those experiencing the least deprivation. Within Gloucestershire, deprivation means that<sup>12 13</sup>:

### Life Expectancy

- The life expectancy of males in the most deprived areas is 8.4 years lower than males in the least deprived.
- For females the difference is 5.4 years.

### Excess Deaths

- The difference in life expectancy is driven by excess deaths - additional deaths that occur in those living in the most deprived areas, compared to the least deprived - in coronary heart disease, COPD, stroke, cancers and dementia.

### Childhood Poverty

- Children from poorer backgrounds are more at risk of poorer health outcomes. 1 in 10 children in Gloucestershire are living in poverty.

Even within a prosperous county such as Gloucestershire, there are important health inequalities that mean **disabled people are more likely to die prematurely and are of greater risk from illnesses such as heart disease, cancer and dementia**. At the same time, 10% of the children in the county are growing up in poverty.

## 2. In Focus: Six disproportionately affected groups

From the section above, it is possible to see the challenges experienced by disabled people and people living with a mental health challenge overall. However, **not every group experiences these challenges in the same way**. The following section looks closely at each of the six groups identified as being disproportionately impacted by the ongoing Covid-19 pandemic.

It is important to note that **these groups are not discrete, and individuals may identify with several of them**. It is arguable that the experiences of these people are different to those who identify only with one group. There is already evidence from national studies that suggests individuals from Black, Asian and Minority Ethnic (BAME) groups are being disproportionately affected by structural inequalities as Covid-19 has demonstrated<sup>14</sup>. We are therefore also interested in where these two disproportionately affected communities (such as disabled people and BAME communities) intersect.

## Physical Disabilities

Physical disabilities encompass a broad range of needs from those living with diabetes, cancer and age-related to impairments, to those with long-term neurological conditions, acquired disabilities and everything in between.

In 2016, Gloucestershire County Council, in partnership with One Gloucestershire and Gloucestershire Clinical Commissioning Group undertook a Physical and Sensory Impairment Needs Analysis. The findings from this report show<sup>15</sup>:

- There are approximately 9,000 working-aged adults (aged 18-64) living with a serious physical disability and a further 30,000 living with moderate physical disabilities in the county,
- 10,600 physically disabled adults were in receipt of Disability Living Allowance (DLA)
- **The majority of people with moderate and serious needs do not use Gloucestershire's care services.** 52% of respondents in the analysis funded their own care.
- Just over a third of people receiving high-cost care packages have an acquired brain injury.

The study also found there was **a lack of a clear definition of physical impairment** within Gloucestershire County Council and also **that the more deprived an area was, the more prevalent DLA claims were**. Moreover, it indicated how there were **physical barriers to accessing healthcare** in terms of making and getting health appointments that had the potential to impact the health outcomes of physically disabled people in Gloucestershire.

## Sensory Impairments

According to the Gloucestershire Population profile for 2020<sup>16</sup>, approximately 1.4% of the population (aged 16+) reported blindness or a partial visual impairment (approximately 8,870 people) and 6.8% reported deafness or hearing loss (approximately 43,082 people).

The report states that people from across different population and age groups are affected by hearing and visual impairments, but given that they are more prevalent amongst the older population, and Gloucestershire's population is ageing, **the number of people with these impairments is likely to increase over time.**

Although categorised together as 'sensory impairments' **the experiences of individuals with hearing, visual or both types of impairment are qualitatively different.** Visually impaired people may have more challenges accessing the environment, relying on guide dogs or other sight-guiding techniques to help them access society and some may also require additional social care support<sup>17</sup>.

People with a hearing impairment, on the other hand, may be able to navigate their environments more easily but have difficulties with communication (including health professionals), literacy and accessing services due to the lack of interpreters<sup>18</sup>. For those who are registered deafblind, these challenges are compounded.

## Learning Disabilities

In Gloucestershire, learning disabled people make up around 2.3% of Gloucestershire's adult, and 5.2% of the school-aged population. There are therefore, approximately 11,913 learning disabled adults (2,437 of whom have moderate or severe learning disabilities) and 4,955 school children *known* to have a learning disability in the county<sup>19</sup>.

The figures for the number of learning-disabled people in the county are approximate. Figures about school-aged children only account for those who are known to have a learning disability and thus, do not count those who are being assessed, pre-school children or those with mild learning disabilities. It is arguably therefore that the proportion of learning-disabled children in the county is higher than shown here.

Education, Health and Care Plans (EHCPs), formerly statements of Special Educational Needs (SEN) are another measure of learning disability within the county. Children and young people with these plans are entitled to multi-agency support and are encouraged to participate in decision-making about their lives and the support they receive.

In Gloucestershire, 3,042 children and young people were reported to have an EHCP and the poorer outcomes for these children were highlighted in a recent report from the Director of Public Health for Gloucestershire<sup>20</sup>:

- Children with SEN are **10 times more likely to be in care** than those without SEN.
- 402 children with SEN were receiving some level of safeguarding support from children's social care
- During the 2016/17 academic year, **52% of permanent exclusions and 46% of fixed period exclusions related to children and young people with SEN.**

Exclusion and being in care are both themselves determinants of poor health outcomes<sup>21</sup> and the disparities for learning disabled people are further visible in national outcomes data:

<p><b>General Health</b></p>	<ul style="list-style-type: none"> <li>• Learning disabled people have poorer health than the general population - much of which is avoidable</li> </ul>
<p><b>Avoidable Deaths</b></p>	<ul style="list-style-type: none"> <li>• Learning disabled people are three times more likely to have a death classified as potentially avoidable through the provision of good quality health care</li> </ul>
<p><b>Life Expectancy</b></p>	<ul style="list-style-type: none"> <li>• Women with learning disabilities die on average 20-26 years younger than women in the general population</li> <li>• For men, the difference is 13-20 years.</li> </ul>

## People with Mental Health Challenges

Before the Covid-19 pandemic, approximately **one in four people** within the UK were said to experience a mental health problem each year. As with disability, **deprivation and inequality were also shown to contribute to the prevalence of and poorer health outcomes for people with mental health challenges.**

Every seven years, the Adult Psychiatric Study measures the prevalence of mental health challenges within England as well as key trends<sup>22</sup>. In addition, findings by the Equality and Human Rights Commission have identified key inequalities in the life expectancies of people with mental health challenges<sup>23</sup>:

### Socio-Economics

- There are links between mental illness and socio-economic context

### Risk Factors

- Most mental disorders were more common amongst people living alone, in poor physical health, and not employed. Claimants of Employment and Support Allowance (ESA) experienced particularly high rates of mental health challenges.

### Ethnicity

- There were demographic inequalities in who received treatment. After controlling for level of need, people who were White British, female, or in mid-life (aged 35 to 54) were more likely to receive treatment.
- People in the Black ethnic group had particularly low treatment rates.

### Co-Morbidity

- 1 in 3 disabled adults in England report poor mental health and wellbeing compared to 1 in 10 non-disabled adults

### Life Expectancy

- On average, men with mental health challenges die 20 years younger and women 13 years younger, than the general population.

The data above indicates mental health challenges to be prevalent in the UK population with the potential for over 16 million people to be experiencing a mental health problem in a given year. However, **it is widely anticipated that the Coronavirus pandemic has the potential to have a pervasive impact on individuals' mental health** in both the short-term, due to factors including bereavement, anxiety about the disease and isolation among

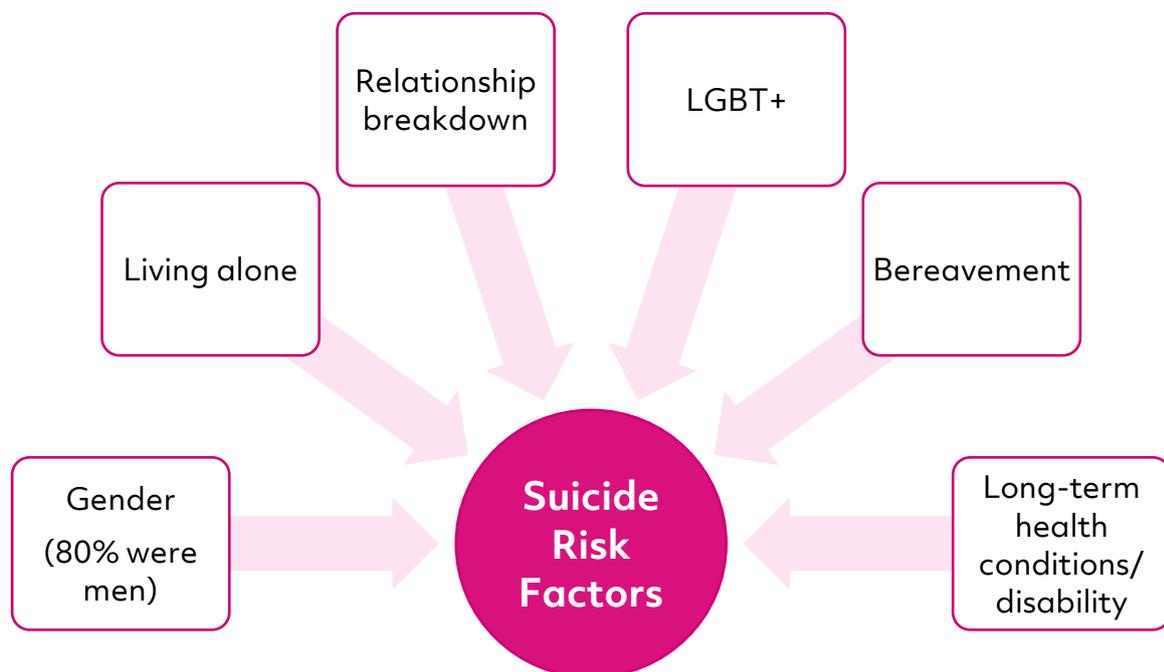
others, and in the long-term as individual's process the experiences they have just had. It is therefore possible that:

- 1) The prevalence of mental health challenges in the UK, and Gloucestershire, could increase substantially
- 2) Those with pre-existing mental health challenges could be further impacted by the pandemic<sup>24</sup>.

### ***Adults with Mental Health Challenges***

Within Gloucestershire, there are approximately 75,012 adults (aged 16+) with common mental health challenges. **Almost two-thirds of these (64%) were recorded as living with depression** and in the period 2017-18 alone, 7,610 adults were newly diagnosed. Both of these trends were said to be **increasing**<sup>25</sup>.

Prevalence of common mental health challenges are lower in Gloucestershire than the national average, however, **rates of hospital admission for self-harm and deaths by suicide have been higher than England average for a number of years**. An audit of deaths by suicide in Gloucestershire found the following risk factors<sup>26</sup>:



In relation to suicide and mental health services, the audit found that:

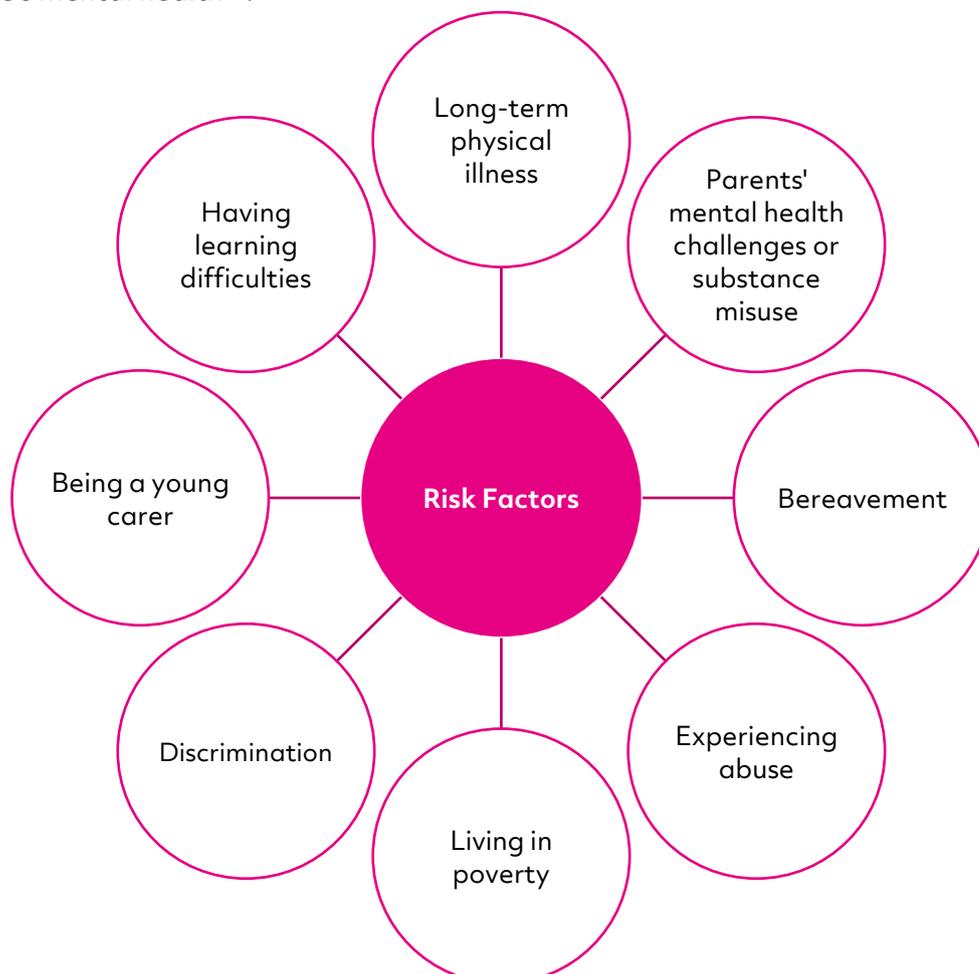
- Two-thirds had **known mental health challenges**
- 10% had been a **psychiatric inpatient** at some point in the six months before they died
- 40% had **attended A&E** in the 12 months before their death

- 25% had a **known history of self-harm or suicide attempt**.
- 22% had **alcohol** present at the time of death – one-third of these people had a **known alcohol problem**.
- 20% had been seen by **their GP, mental health services and A&E** in the year before **their death**

## ***Children and Young People with Mental Health Challenges***

Excluding dementia, **75% of mental health problems are established before the age of 15<sup>27</sup>**, whilst **20% of adolescents may experience a mental health problem in any given year<sup>28</sup>**.

Local data for the prevalence of mental health challenges amongst children and young people is limited. According to a 2017/18 report of the Director of Public Health for Gloucestershire which focused on the mental wellbeing of children and young people, around 7,075 children (aged 5 to 16 years-old) have a diagnosed mental health challenge that would require treatment in primary care or specialist mental health services. The following risk factors were identified in the report in relation to children and young people’s mental health<sup>29</sup>:



## People (at risk of) Experiencing Domestic Abuse

Due to its nature as a 'hidden crime' **the true prevalence of domestic abuse is difficult to fully know and crimes are often underreported.** In England and Wales, an estimated 5.7% of adults (2.4 million people) have experienced domestic abuse in the last year and a total of 1,316,800 domestic abuse-related incidents and crimes in the year ending March 2019<sup>30</sup> Between April 2016 and March 2018 there were 366 domestic homicides recorded in England and Wales, representing 20% of all homicides where the victim was aged 16 or over.

In Gloucestershire, 6,103 domestic abuse-related incidents were recorded in the year to March 2019 as shown in the table below:

Indicator	Gloucestershire (April 2018 - March 2019)
Number of domestic abuse-related incidents recorded by the police	<b>6, 103</b>
Number of domestic abuse-related violence against the person offences recorded by the police	<b>2, 991</b>
Number of coercive control offences recorded by police	<b>146</b>
Number of domestic homicide crimes recorded by police	<b>2 (1 male and 1 female)</b>

The relationship between domestic abuse and mental health problems such as anxiety, PTSD and substance misuse is well established in national studies - **30-60% of women with a mental health problem have experienced domestic violence**<sup>31</sup>. National statistics also highlight **disabled people and people with mental health challenges to be at particular risk of experiencing domestic abuse.** In the year ending March 2019:

- 1 in 7 disabled adults of working age had experienced a form of domestic violence (compared to 1 in 20 non-disabled adults).
- **Disabled women were more than twice as likely to experience domestic abuse than non-disabled women.**
- The same trend was also visible in men.

## Black, Asian and Minority Ethnic Groups

According to the latest Census data, approximately 8.4% of Gloucestershire’s population were from a Black, Asian or Minority Ethnic Group (BAME) – considerably lower than the national average (14.6%). The largest proportion of people from BAME backgrounds lived in Gloucester City (10.6% of the population) whilst the smallest proportion lived in the Forest of Dean (1.5% of the population)<sup>32</sup>.

A national study by the Equality and Human Rights Commission found that people from BAME groups continue to experience discrimination and inequality in:

- Education
- Housing
- Pay and living standards
- Health
- Criminal justice<sup>33</sup>

Within Gloucestershire, membership of a BAME group is associated with a range of unequal opportunities and outcomes<sup>34</sup>:

<p><b>Health</b></p>	<ul style="list-style-type: none"> <li>• Amongst people aged 65+, BAME groups were more likely than other ethnic groups to experience poor health or to have a long-term limiting illness</li> </ul>
<p><b>Housing</b></p>	<ul style="list-style-type: none"> <li>• People from BAME groups were more likely to live in social and/or overcrowded housing.</li> </ul>
<p><b>Employment</b></p>	<ul style="list-style-type: none"> <li>• Amongst people aged 25-49, BAME groups were less likely to be in higher managerial, administrative and professional occupations.</li> </ul>

Disabled people and people with mental health challenges who **also** belong to a Black, Asian or Minority Ethnic (BAME) group, can experience additional challenges. A number of national studies show that disabled people from BAME backgrounds are likely to have worse outcomes than white disabled people in areas including:

- **Education and employment** – the impact of obtaining qualifications has been reported to be higher for disabled people from BAME groups compared with white disabled people. Ethnic pay gaps were also shown to be exacerbated by disability<sup>35</sup>
- **Poverty and access to services** – BAME families with a severely disabled child have been found to experience greater poverty, less access to benefits and poorer service provision than white families<sup>36</sup>.

In relation to mental health, studies have shown that Black people are over-represented in mental health services and are more likely to receive healthcare which is coercive in nature (rather than talking therapies) including:

- Detention in hospital
- Restraint
- Medication<sup>37</sup>

### 3. Disability and Covid-19

Since the pandemic struck at the beginning of 2020, a range of studies have been carried out nationally that give a sense of the scale and its various associated impacts for disabled people and people with mental health challenges. These include:

- The social impacts
- Impacts for people with pre-existing mental health challenges
- Impacts for parent carers.

Each of these areas is explored below.

#### **The Socio-Economic Impacts of Covid-19 for Disabled People and People with Mental Health Challenges**

Throughout the pandemic, the Office for National Statistics (ONS) have been conducting regular studies into the social impacts of Covid-19 on disabled people in the UK. Data released in April 2020<sup>38</sup>(a few weeks into the lockdown) showed that:

- **Nearly half (45.1%)** of disabled adults were **very worried about the effect of the pandemic on their life** – compared to around a third (30.2%) of non-disabled adults.

Whilst later releases highlighted how disabled people were **leaving their homes less** than non-disabled people and were leaving their house for reasons associated with medical or care needs (their own, or others) than non-disabled people.

- About three-quarters of disabled people (73.4%) reported leaving their home in the last seven days for any reason, compared with over 9 in 10 non-disabled people (92.5%).
- Disabled people were **more likely to report leaving their homes for medical needs, or to provide care or help to a vulnerable person** (23.5%) than non-disabled people (13.1%) in May 2020<sup>39</sup>

At the same time, disabled adults reported being as **active** as non-disabled adults in **supporting their communities** (including checking in on neighbours and doing shopping)<sup>40</sup>.

Studies have also shown disabled people **have struggled to obtain food, medicine and other basic necessities, have concerns about inaccessible information to do with the pandemic, or have experienced increased psychological distress due to factors associated with the pandemic**<sup>41</sup>. Similarly, research carried out by the Disabled Children's Partnership<sup>42</sup> with 4000 parent carers of disabled children found that **72% reported providing a lot more care since** the beginning of lockdown, with **half of parents whose children who had previously received therapies or extra support reporting this stopping**. Furthermore, one-fifth of respondents also reported that they think they will go into debt due to the crisis.

At the same time the Research Institute for Disabled Consumers' survey of panel members identified challenges in obtaining supermarket slots, PPE for carers and accessible information, as well as reductions in health and personal care visits at home and a lack of financial support<sup>43</sup>.

## Impacts for People with Pre-Existing Mental Health Challenges

Studies by the Institute for Fiscal Studies (IFS), Young Minds, and Mind have also shown the impact of the current crisis for people with **pre-existing mental health challenges**. Findings from the IFS<sup>44</sup> include that the pandemic has '**widened mental health inequalities, with the groups that had the poorest mental health pre-crisis also having had the largest deterioration.**' This includes the disproportionate effect of the pandemic for women and young people.

In a survey of 2000 **children with pre-existing mental health challenges** carried out by Young Minds<sup>45</sup>, 32% and 51% of respondents said respectively their mental health had become '**much worse**' or '**a bit worse**' during the pandemic.



Similarly, figures published in June 2020 from a recent survey of 16,000 **people with pre-existing mental health challenges** carried out by Mind<sup>46</sup> also include 65% of adults and 75% of young people (aged 13-24) reporting that their mental health problem had **become worse** during lockdown. In addition, of those respondents who tried to access NHS mental health services, 25% were **unable to access support**.

## **The Physical Health Impacts of Coronavirus**

Finally, it has been well-documented that disabled people and people with underlying health conditions are more susceptible to the physical health impacts of Coronavirus. Statistically, **two in three deaths from Covid-19 have been disabled people and disabled women (aged nine to 64) are 11.3 times more likely to die from Covid than non-disabled women in the same age group**. For men, this figure is **6.5 times**<sup>47</sup>.

Although it is arguable that many disabled people may have underlying health conditions that increase their risk to the disease, there are arguments within the media that another contributor is the **socio-economic impacts** highlighted above that have reduced provision of care and services and access to essentials such as food<sup>48</sup>.

Moreover, in the context of the pandemic, existing health inequalities are arguably exacerbated. Some of this has already been demonstrated in early statistical releases by the Care Quality Commission (CQC). In the period between 10<sup>th</sup> April and 15<sup>th</sup> May 2020, deaths of people with learning disabilities (including some whom were also autistic) who were receiving care from services, have risen by **134%** compared to the same period in 2019 with increases across every age-band. **This equates to the deaths of 386 people with learning disabilities. 206 of these deaths were the result of suspected and/or confirmed Covid-19**<sup>49</sup>.

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<sup>5</sup> **Abandoned, Forgotten and Ignored: The impact of the Coronavirus pandemic on Disabled People** (Inclusion London, 2020)

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<sup>8</sup> **Disabled People and their Relationship with Poverty** (Poverty and Social Exclusion in the UK, 2013)

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<sup>9</sup> **Population Profile 2020** (Gloucestershire County Council, 2020)

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<sup>10</sup> *Ibid*

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