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## The impact of the pandemic on disabled people So much more than Covid-19

Over the next minutes I will be talking about the impact of Covid-19 on disabled people through the lens of human rights and social justice. To do this I will look back over the last decade to help our understanding of the present.

I will be referring to Wales, its response to the pandemic and its landscape of social care, but there are limits to doing so outside the wider context of the United Kingdom.

### **Crossing the Rubicon**

Covid -19 was declared a *Public Health Emergency of International Concern* by the World Health Organisation on the 30th January 2020. This, did not galvanise the UK Government to respond to this grave emerging situation, that has become the worst public health emergency for over a century. It was not until the 3rd March that the UK Government in collaboration with Wales and the other devolved governments, published its Coronavirus Plan.<sup>1</sup>

By then it was increasingly apparent that the UK was ill equipped to manage a pandemic. Public Health Services had been decimated by a decade of austerity and organisational changes and the Country did not have stores of essential equipment to manage a respiratory virus. The United Kingdom had a depleted NHS workforce and a fragmented Social Care workforce.

The former UK Secretary of State for Health and Social Care has said in hindsight, *'We prepared for the wrong pandemic'*<sup>2</sup>

From the outbreak of Covid-19, the Welsh Government has been in lockstep with the UK Government. There have since been points of divergence during the course of the pandemic but the nature of the devolution settlement, and the geography of Wales, has made it almost impossible for the Welsh Government to chart a difference course, even when there has been the political will to do so. Consequently, the pandemic has played out in a similar fashion in all the countries of the UK with one of the highest rates of deaths per 100,000 people across the world. Governments of the four nations have robustly defended their strategy and claim to have 'followed the science'.

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<sup>1</sup> DOH&SS, Llywodraeth Cymru, Scottish Government, DOH Northern Ireland (2020) Coronavirus: Action Plan

<sup>2</sup> BMJ 2021;372:n335

The plan of the UK Government and the devolved administrations was to pursue a strategy of containment and delay, rather than suppression of the virus. This strategy, exacerbated by the indecisiveness of Government has shaped our lives and has resulted in the catastrophic loss of life and resultant morbidity of hundreds of thousands of people across the nations of the UK.

The death rates from Covid -19 in South East Asia, New Zealand and Australia tell us that it was **not inevitable**.

### **Legislating for Coronavirus**

The Coronavirus Act 2020 received Royal Assent on the 25th March 2020. It has been described as the most draconian piece of legislation in peace time, and provides for the Governments of the four nations of the UK to suspend a whole raft of legislative duties and powers.<sup>3</sup>

In relation to social care it allowed for the relaxing of duties and powers relating to assessing and meeting needs for care and support.

### **Health vs Economy - a flawed paradigm**

The UK government has set the pace for the devolved nations, and has locked itself into a false dichotomy of health vs economy rather than recognising the symbiotic relationship between the two. The competing philosophies of **Libertarianism** and **Collectivism** have shaped the discourse and the management of the pandemic, and continues to do so.

Whilst the UK Government and devolved governments forged plans for containment and delay, the impact on elderly and disabled people was not identified and thus not mitigated, with the resultant deaths falling hardest upon those living in care homes. Disabled and older people receiving care and support at home were largely absent from considerations, and some of us may argue have continued to be so.

Mary Daly's forensic analysis of policy decisions relating to adult social care in the first months of the pandemic has led her to conclude that the response was *'inadequate, slow, reactive and too late'*.<sup>4</sup>

The death rate from Covid -19 in the UK is by no means the whole story. Long-Covid, a post-viral illness is affecting many and at this stage, it is not possible to know what this will mean for those individuals afflicted or for health care, welfare and social care services in the longer term.

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<sup>3</sup> <http://www.lukeclements.co.uk/the-coronavirus-bill-social-care-sen-2/>

<sup>4</sup> Daly (M) (2020) doi/full/10.1111/spol.12645

## Land of Hope and Glory

The evidence is stacking up that Coronavirus thrives on inequality with disabled, poor, black and minority ethnic people and critically people who share more than one of these characteristics -bearing the brunt .This is indicated by mortality rates, infection rates and morbidity rates. <sup>5</sup>

As a result of perverse and inhumane social welfare policies - there are also the hidden victims of Covid-19.

Food poverty and reliance on food banks, fuel poverty and homelessness have increased significantly during the pandemic.<sup>6</sup>

## Austerity's long tail

The Coalition Government of 2010 set out immediately to reduce public expenditure by curtailing access to social security, re-designing disability benefits and creating a hostile climate for disabled people.<sup>7</sup>

The Marmot Review of 2010 <sup>8</sup> identified the key determinants of a fairer and healthier society.

The follow up review 10 years on<sup>9</sup> confirms a deterioration in the key indicators of poverty and inequality, with the concomitant impact on health and life expectancy.

The 2019 report,<sup>10</sup> by the United Nations Special Rapporteur- Philip Alston, concludes that the British Welfare System has changed radically since 2010. He identifies the litany of cruelty that has followed a failed austerity agenda. Government targeted disabled people together with the unemployed to create a harsh, depersonalised and stigmatising system of social security, and virtually decimated the legal aid system leaving people unable to seek redress.

Alston's searing analysis is that the social contract between people and government, and their social human rights, were significantly altered in these years, with disabled people facing the burden of austerity measures.

He cites Thomas Hobbes' observation, that the fracturing of the social contract leaves the 'least well off to lives that are "*solitary, poor, nasty, brutish and short*".

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<sup>5</sup> <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/coronaviruscovid19relateddeathsbydisabilitystatusenglandandwales/24januaryto20november2020>

<sup>6</sup> BMJ 2021 :372:n376

<sup>7</sup> James, R.F. (2011) Welfare reform bill will punish disabled people and the poor Guardian

<sup>8</sup> Michael Marmot et al (2010) Fair Society Healthy Lives: London: Institute of Health Equity

<sup>9</sup> Michael Marmot et al (2020) Health Equity in England: The Marmot Review ten years on: London: Institute of Health Equity

<sup>10</sup> Philip Alston (2019) Visit to the United Kingdom of Great Britain and Northern Ireland  
Report of the Special Rapporteur on extreme poverty and human rights

## Conditional Dignity

In the fervent early years of the austerity agenda there was a landmark social care case that went up to the Supreme Court and on to the ECtHR.

The case of prima ballerina Elaine McDonald crystallises the State's relationship with disabled people in need of care and support.

When we turn to the Supreme Court decision in McDonald<sup>11</sup>, we are left in little doubt of the extent to which the state is prepared to afford dignity to disabled people and to comply with the Convention on the Rights of Disabled People, to which the United Kingdom has been a signatory since 2009.

The case centered around Elaine McDonald's right to have care services at night, in her home, in order to be able to use her lavatory.

A controversial assessment led to a care plan which required her to use incontinence pads even though she was not incontinent. This, it was argued would offer a significant saving to the local authority and was therefore a legitimate aim to pursue.

The Supreme Court dismissed the appeal by McDonald. It was not considered by the majority on the Supreme Court Bench that the treatment of Elaine McDonald engaged her '*fundamental human rights*'.<sup>12</sup>

The effect of the decision in McDonald means that independent living is subject to what the state believes to be affordable and leaves family carers as the *last possible defence of dignity*.

Covid-19 took seed in this country where '*disabled people continue to face a serious regression of their rights to an adequate standard of living, and social protection, and to live independently and be included in the community*'.<sup>13</sup>

It is within this backdrop that I want to consider the Shielding strategy adopted by the UK Government and the devolved administrations.

## Shielding or Segmenting – a thoroughly British Solution?

It has been argued that the delay and containment plan of March 2020 was rooted in a notion that allowing the virus to spread amongst healthy individuals would lead to '*herd immunity*' - though this objective has been refuted by Government.

Shielding was not in the Covid -19 Plan, but took root as it offered the possibility of minimal state interference in the lives of the majority people and a way of preventing the National Health Service becoming overwhelmed.

A further 1.7 million people have only recently been added to the 2.3 million who have been asked to shield since March of last year. Shielding is proffered as the actions of a benevolent and caring state towards its vulnerable citizens. The act of identifying someone as needing shielding does not bestow protection though we could be excused for thinking it does.

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<sup>11</sup> R (on the application of McDonald) (Appellant) v Royal Borough of Kensington and Chelsea (Respondents)

<sup>12</sup> <http://www.lukeclements.co.uk/resources-index/files/PDF%2001.pdf>

<sup>13</sup> ECHR (2018) Overview of key concerns about social security reform and protecting disability rights in the United Kingdom.

*Herd immunity* was back on the agenda by the Autumn of last year, having been given oxygen by the Great Barrington Declaration<sup>14</sup>. The argument of its three authors was simply that the rights of the healthy and the young were being limited by draconian lockdown policies and having a deleterious impact on the economy, this could be easily remedied by the segmenting of sick, old and disabled people. This, they posited, was a benign and compassionate way of managing the virus.

The proposal gained traction and arguably shaped the UK Government response in the Autumn and powered the second wave of the virus. Embedded in this proposal was the facile view that there could be a simplistic segmenting of society; the healthy from the sick and disabled. This ideological position has underscored the narrative and the execution of the pandemic strategy.

### **Wealth – A shielding strategy?**

It has become apparent that wealth is the best shielding strategy.<sup>15</sup>

Shielding is a blunt instrument that requires the drawing up of a list of people who are identified as Extremely Clinically Vulnerable (ECV) but consequently leaves many people who are very vulnerable for both intrinsic and extrinsic reasons, outside this categorization and without the very limited support offered by the state.

The initial guidance issued on the 24<sup>th</sup> March 2020 marked the beginning of the State's encroachment into the private and domestic lives of some of its citizens, namely the sick and disabled- the Extremely Clinically Vulnerable. Those identified as needing shielding were asked to:

stay at home at all times; not to sleep in the same bed with another person; not eat with other people in one's household; not to share a bathroom or toilet (if possible) and so forth. For those who could work from home, and had the financial, material and personal resources - shielding was possible.

But for the very many 'shielded', who were in jobs where furlough was not viable and would need to rely if at all eligible on Statutory Sick Pay; for disabled parents of school aged children,

for disabled people who lived in shared housing or congregate settings; or for those who were dependent on care provision, **shielding was not benign nor compassionate** and crucially, it was **not possible**.

The high rate of deaths in care homes, and of learning disabled people, in addition to the recent data that confirms that 60% of people who died of Covid -19 were disabled; tells us that the shielding of the '*weak and vulnerable*', is a failed public policy.

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<sup>14</sup> <https://gbdeclaration.org/>

<sup>15</sup> <http://global1hn.ca/2020/05/18/devi-sridhar-wealth-is-the-best-shielding-strategy-for-this-virus-and-from-severe-symptoms/>

Was the shielding strategy an example of the State perversely placing the onus on some of its most disadvantaged citizens, to be responsible for protecting themselves from Covid-19? Over the course of the year there has been further entrenchment of the reductionist perceptions of sick and disabled people as the ‘other’ and separate.

This has legitimised the rider to each announcement of the daily death toll that the majority of the deceased had ‘*underlying health conditions*’ and seems to offer a justification for the death rate in the UK.

Whilst I have used the past tense in talking about shielding, it continues until 1<sup>st</sup> April with the possibility of being re-activated.

Shielding has not been used in countries that have successfully managed the pandemic. With each lockdown in New Zealand, the principle has been – *all down together, all out together*.

### **Social Care in the time of Covid -19**

We know very little to date about what happened in Wales or in the other nations of the UK regarding the provision of social care. A number of reports following the first wave<sup>16 17</sup><sup>18</sup> give us a glimpse into disabled people having their care packages suspended, fewer community services and a greater level of dependence on unpaid carers. A small study by Shakespeare and his colleagues confirms this picture.<sup>19</sup>

Easement provisions introduced by the Coronavirus Act 2020 have not been used in Wales but have in a small number of local authorities in England.

However, Welsh Government noted, following review of the easement provisions, ‘*that the pandemic has resulted in limits to the ‘range and scope of support*’<sup>20</sup> and is having a direct impact on both individuals, and all of the unpaid carers and families across Wales.

As from the 22<sup>nd</sup> March the Welsh Government has suspended the social care provisions of the Coronavirus Act 2020. We must now await to see whether social care provision will be fully reinstated.

The easement provisions remain in place in England.

### **Looking into the Crystal Ball**

The vaccination programme offers the possibility of protecting sick and disabled people from death and severe illness but at this stage we must await the longer-term outcomes. It is easy to imagine a post Covid-19 Wales and UK with the further erosion of the rights of disabled people, as Governments tell us that *the coffers are empty*.

The budget of earlier this month arguably signals a return to a squeeze on public spending and more years of austerity.<sup>21</sup>

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<sup>16</sup> ECHR (2020) Rebuilding a more equal and fairer Wales: Focus on the unequal impact of the coronavirus pandemic

<sup>17</sup> <https://www.carersuk.org/files/section/6609/carers-wales-track-the-act-briefing-final-version-eng.pdf>

<sup>18</sup> Sayce, L ( 2021) The forgotten crisis: exploring the disproportionate impact of the pandemic on disabled people : Health Foundation

<sup>19</sup> Shakespeare, T. Et al Disabled People in Britain and the Impact of Covid-19 Pandemic. Preprints 2021 2021010563

<sup>20</sup> <http://www.lukeclements.co.uk/welsh-government-social-care-announcements/>

<sup>21</sup> Charlesworth, A (2021) The Chancellor’s Squeeze on public spending signals a long deep period of austerity

The British Academy Report published this week identifies the long-term societal impact of Covid -19 and the uncertainty arising out of the pandemic.<sup>22</sup> My dystopian view of course needs to be tempered.

### **A Post Covid-19 Recovery**

Covid -19 exposed the inequality, poverty and racism that is endemic in the countries of the United Kingdom.

A Post-Covid -19 recovery needs to acknowledge embedded inequality and unfairness, and its impact on disabled people and those in need of care and support from the State. This is confirmed by the report from the British Academy on addressing the long-term impacts of Covid-19.<sup>23</sup>

*Build Back Fairer* has to be the ambition and not the mantra of the UK Government and the devolved administrations. Returning to the status quo would be a tragic mistake.<sup>24</sup>

A fairer and equal society requires a radical redesign of economic policy. It would need to bear the hallmarks of the vision that spurred the post-World War II recovery. In this new world, sustainability is intrinsic to the recovery plan, and requires a commitment to a new set of values for our age. The recovery plan must, however, be predicated on the aims of Beveridge and the architects of the welfare state.

The welfare state has been systematically whittled away with accelerated erosion over the last decade and more. The pandemic exposed the harsh and fragmented welfare system in the countries of the UK.

In a post Covid-19 world, **the wrongs need to be righted.**

I end with the words of Amanda Gorman

*“When day comes, we step out of the shade, aflame and unafraid,  
The new dawn blooms as we free it  
For there is always light,  
If only we’re brave enough to see it,  
If only we’re brave enough to be it.”*

‘The Hill We Climb’

Amanda Gorman

Diolch yn fawr : Thank you

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<sup>22</sup> The British Academy (2021) THE COVID DECADE *Understanding the long-term societal impacts of Covid-19*: The British Academy Covid-19 Society

<sup>23</sup> The British Academy (2021) SHAPING THE COVID DECADE *Addressing the long-term societal impacts of Covid-19* :The British Academy Covid -19 and Society

<sup>24</sup> Marmot,M et al (2020) *Build Back Fairer: The Covid-19 Marmot Review. The Pandemic, Socioeconomic and Health Inequalities in England*: London: Institute of Health Equity

