



**Prynhawn da - Good afternoon!**

# The impact of the pandemic on disabled people

So much more than Covid-19

Ann N.James

# Crossing the Rubicon<sup>(1)</sup>

➤ 30th January 2020

WHO declares *Public Health Emergency of International Concern*

➤ 3rd March 2020

*Covid Plan* published by UK Government and Devolved administrations <sup>(1)</sup>

Increasingly apparent - UK Nations are not equipped for a pandemic

➤ Weak Public Health Services

- Decimated by austerity and organisational changes
- Essential Equipment for a Respiratory Virus **not available**
- Depleted NHS workforce
- Fragmented Social Care workforce

# Crossing the Rubicon<sup>(2)</sup>

*“We prepared for the wrong pandemic”<sup>(2)</sup>*

Jeremy Hunt

Former Secretary of State for Health and Social Care, UK.

# Crossing the Rubicon(3)

- ▶ Welsh Government in lockstep with UK Government
- ▶ Divergence limited by devolution settlement and geography
- ▶ Consequently, Covid-19 impact similar across the nations of the UK
- ▶ Highest death rates per 100,000

# Crossing the Rubicon<sup>(4)</sup>

- ▶ UK Strategy one of *containment and delay* not suppression
- ▶ Strategy exacerbated by *indecisiveness*
- ▶ Results in catastrophic *loss of life and illness*
- ▶ Death rates from SE Asia, New Zealand and Australia tell us this was **not inevitable**

# Legislating for Coronavirus

- ▶ Coronavirus Act 2020 receives Royal Assent on the 25th March
- ▶ Four nations suspend a raft of legislative duties and powers
- ▶ Described as the ‘most draconian legislation in peace time’<sup>(3)</sup>
- ▶ In relation to social care, it allows for the relaxing of duties and powers relating to assessment, and meeting needs for care and support

# Health vs Economy - a flawed paradigm(1)

- ▶ UK Government set pace for devolved governments
- ▶ False dichotomy of Health vs Economy
- ▶ Competing philosophies of **Libertarianism and Collectivism**
- ▶ This shapes discourse and management of pandemic



# Health vs Economy - flawed paradigm(2)

- ▶ Plan of containment and delay failed to identify impact on elderly, sick and disabled people
- ▶ Consequently impact not mitigated
- ▶ Deaths fall hardest on those in care homes
- ▶ Plan gives no consideration to people receiving care and support at home

# Health vs Economy - a flawed paradigm(3)

- ▶ Policy decisions in the first months of the pandemic

*“inadequate, slow, reactive and too late” Mary Daly (4)*

- ▶ Post-viral illness - ‘*Long Covid*’ - what will be the impact on individuals, health care, social welfare and social care?

# Land of hope and glory

- ▶ Coronavirus thrives on inequality
- ▶ Disabled, poor, black and minority ethnic people bearing the brunt <sup>(5)</sup>
- ▶ Hidden victims of Covid-19
- ▶ Food poverty and reliance on food banks, fuel poverty, homelessness - all have increased during the pandemic<sup>(6)</sup>

# Austerity's long tail<sup>(1)</sup>

- ▶ The Coalition Government of 2010 set out immediately to reduce public expenditure - 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 identified the key determinants of a fairer society<sup>(8)</sup>
- ▶ The Marmot Review of 2020 <sup>(9)</sup>
  - confirmed a deterioration in the key indicators of poverty and inequality, and the concomitant impact on health and life expectancy

# Austerity's long tail<sub>(2)</sub>

- ▶ UN Special Rapporteur concludes that the British Welfare System has changed **radically** since 2010
- ▶ Government targeted **disabled people and unemployed people**
- ▶ Created a harsh, depersonalised and stigmatising system
- ▶ Virtually decimated the legal aid system - closing the door on redress

# Austerity's longtail<sup>(3)</sup>

## ▶ Alston's searing analysis concludes:

Social contract between Government and its people significantly altered;  
Social human rights altered;  
Disabled people face 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”*** (10)

# Conditional Dignity<sup>(1)</sup>

- ▶ Landmark social care case in the early austerity years
- ▶ The case ‘Elaine McDonald - Prima ballerina’ proceeds to the Supreme Court and finally to the ECtHR
- ▶ The case crystallises the State’s relationship with disabled people in need of care and support
- ▶ The Supreme Court decision<sup>(11)</sup> conveys the extent to which the state is prepared to afford dignity to disabled people, and
- ▶ To comply with the UNCRPD - UK a signatory since 2009

# Conditional Dignity<sup>(2)</sup>

- ▶ The case centred around the right to have care services in her home at nighttime to use the lavatory
- ▶ Controversial assessment leads to plan for incontinence pads even though she was not incontinent
- ▶ It was argued that the use of incontinence pads would offer a significant saving to the local authority  
This it was argued was a legitimate aim to pursue



# Conditional Dignity<sup>(3)</sup>

- ▶ The Supreme Court dismissed the appeal by McDonald  
The majority sitting on the SC bench did not consider that the treatment of McDonald ‘engaged her fundamental human rights’ <sup>(12)</sup>
- ▶ The effect of this decision means that independent living **is conditional on what the state believes to be affordable**
- ▶ It leaves family carers as **the last defence of dignity**

# Conditional Dignity<sup>(4)</sup>

covid-19 took seed in a 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>(18)</sup>*

# Shielding or Segmenting - a thoroughly British solution? <sup>(1)</sup>

- ▶ Herd Immunity at the heart of the delay and the containment plan

This is refuted by the UK Government

- ▶ Shielding was **not** in the Covid-19 Plan
- ▶ It took root as it offered the possibility of minimal state interference in the lives of the majority of people
- ▶ And a way of preventing the National Health Service becoming overwhelmed

# Shielding or Segmenting<sup>(2)</sup>

- ▶ A further 1.7 million have been added to the 2.3 million who have been asked to shield since March 2020
- ▶ Shielding is proffered as the actions of a benevolent and caring State towards its vulnerable citizens
- ▶ Herd Immunity back on the agenda in Autumn 2020
- ▶ Given oxygen by the '*Great Barrington Declaration*'<sup>(14)</sup>

# Shielding or Segmenting<sup>(3)</sup>

- ▶ Argument of the three ‘Barrington’ authors :
  - the healthy and young were being damaged by draconian lockdown
  - an easy remedy - **segment the sick and disabled**
- ▶ The proposal gained traction and shaped the UK response to the pandemic in the Autumn and arguably powered the second wave
- ▶ Embedded in the proposal is the facile view that there could be a simplistic segmenting of society
- ▶ This ideological position has underscored the narrative and execution of the pandemic strategy

# Wealth - A shielding strategy?<sup>(1)</sup>

- ▶ 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 Exceptionally Clinically Vulnerable (ECV)
- ▶ It leaves many people who were very vulnerable, for both intrinsic and extrinsic reasons, outside this categorisation and without the very limited support offered by the state

# Wealth - A shielding strategy?<sup>(2)</sup>

- ▶ The initial guidance of the 24th March marked the beginning of the State's encroachment into the the private and domestic lives of some of its citizens - the sick and disabled - the extremely clinically vulnerable
- ▶ Those identified as needing shielding were, amongst a number of other things, asked to:
  - Stay at home at all times;
  - Do not sleep in the same bed as another person, do not eat with others in your household;
  - Do not share a bathroom or toilet - if possible

And so forth ...

# Wealth - A shielding strategy?<sup>(3)</sup>

- ▶ For those who could work from home, and had the financial, material and personal resources
  - shielding was possible.
- ▶ For the many other shielded ;
  - in jobs where furlough was not viable and would need to rely on SSP if eligible;
  - Disabled parents of school aged children;
  - Disabled people who lived in shared or congregate settings;
  - Disabled people dependent on care provision;

**Shielding was not benign, compassionate and crucially not possible**



# Wealth - A shielding strategy?<sup>(4)</sup>

- ▶ The high rate of deaths in care homes, and of learning disabled people
- ▶ Data confirms that 60% of people who died of Covid-19 were disabled.  
This tells us that shielding of the “*weak and vulnerable*”,  
is a **failed public policy**
- ▶ Was the Shielding strategy an example of the State perversely placing the onus on some of its most disadvantaged people to be responsible for **protecting themselves** from the Covid-19?

# Wealth - A shielding strategy?<sup>(5)</sup>

- ▶ Over the course of the year there has been further entrenchment of 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 offers a justification for the death rate in the UK.
- ▶ 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<sup>(1)</sup>

- ▶ 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 give us a glimpse into disabled people having their care packages suspended, fewer community services and a greater level of dependence on unpaid <sup>(16,17,18)</sup>
- ▶ A small study by Shakespeare and his colleagues confirm this picture<sup>(19)</sup>

# Social Care in the time of Covid-19<sup>(2)</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, *‘that the pandemic has resulted in limits to the ‘range and scope of support’* and is having a direct impact on both individuals, and all of the unpaid carers and families across Wales<sup>(20)</sup>
- ▶ As from the 22<sup>nd</sup> March the Welsh Government has suspended the social care provisions of the Coronavirus Act 2020.
- ▶ The easement provisions remain in place in England

# Looking into the crystal ball

- ▶ 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 UK budget of earlier this month arguably signals a return to a squeeze on public spending and more years of austerity <sup>(21)</sup>
- ▶ The British Academy Report identifies the long -term societal impact of Covid -19 <sup>(22)</sup>
- ▶ My dystopian view of course needs to be tempered

# A Post Covid-19 Recovery <sup>(1)</sup>

- ▶ Covid-19 exposed the inequality, poverty and racism that is endemic in the nations 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 British Academy Report on addressing the impact 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

# A Post-Covid-19 Recovery (2)

- ▶ 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 be predicated on the aims of Beveridge and the architects of the welfare state
- ▶ The welfare state has been systematically whittled with an accelerated erosion over the last decade and more
- ▶ The pandemic exposed the harsh and fragmented welfare system in the nations of the UK
- ▶ In a post Covid-19 world, **the wrongs need to be righted...**

“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.”

from *‘The Hill We Climb’*  
Amanda Gorman





**Diolch yn fawr - Thank you**

## References (1)

1. DOH&SS, Llywodraeth Cymru, Scottish Government, DOH Northern Ireland (2020) Coronavirus : Action Plan
2. BMJ 2021;372:n335
3. <http://www.lukeclements.co.uk/the-coronavirus-bill-social-care-sen-2/>
4. Daly (M) (2020) doi/full/10.1111/spol.12645
5. <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/coronaviruscovid19relateddeathsbydisabilitystatusenglandandwales/24januaryto20november2020>
6. BMJ 2021 :372:n376
7. James, R.F. (2011) Welfare reform bill will punish disabled people and poor, Guardian
8. Michael Marmot et al (2010) Fair Society Healthy Lives: London: Institute of Health Equity
9. Michael Marmot et al (2020) Health Equity in England: The Marmot Review ten years on: London: Institute of Health Equity
10. 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
11. R (on the application of McDonald) (Appellant) v Royal Borough of Kensington and Chelsea(Respondents)
12. <http://www.lukeclements.co.uk/resources-index/files/PDF%2001.pdf>
13. ECHR(2018) Overview of key concerns about social security reform and protecting disability rights in the United Kingdom
14. <https://gbdeclaration.org>

## References (2)

15. <http://global1hn.ca/2020/05/18/devi-sridhar-wealth-is-the-best-shielding-strategy-for-this-virus-and-from-severe-symptoms/> ECHR (2020)
16. ECHR (2020) Rebuilding a more equal and fairer Wales: Focus on the unequal impact of the coronavirus pandemic
17. <https://www.carersuk.org/files/section/6609/carers-wales-track-the-act-briefing-final-version-eng.pdf>
18. Sayce, L. ( 2021) The forgotten crisis: exploring the disproportionate impact of the pandemic on disabled people : Health Foundation
19. Shakespeare, T. et al Disabled people in Britain and the impact of the Covid-19 pandemic. Preprints, 2021 2021010563
20. <http://www.lukeclements.co.uk/welsh-government-social-care-announcements/>
21. Charlesworth, A. (2021) The Chancellor's squeeze on public spending signals a long deep period of austerity; Health Foundation
22. The British Academy (2021) THE COVID DECADE *Understanding the long-term societal impacts of Covid-19*: The British Academy Covid-19 Society
23. The British Academy (2021) SHAPING THE COVID DECADE *Addressing the long-term societal impacts of Covid-19* :The British Academy Covid -19 and Society
24. 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