The Pandemic Coronavirus COVID-19 and Disabled People

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Covid-19 pandemic

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Addressing the three-fold issues facing disabled people of all ages

In recent weeks Disabled people of all ages have voiced their anger and frustration at the apparent disregard of their needs and interests by the Johnson government during the current pandemic. Sadly, the lack of regard for the needs and interests of Disabled people is not new; it needs to be placed within a historical context where disablement is understood as an outcome of capitalist economic and social conditions. The unequal and differential treatment of Disabled people has to be recognised as a systemic issue.

Reclaim Our Futures Alliance in the Forward to the Independent Living for the Future report, ROFA:

"So long as we live under a system that puts profit before people, we will need to struggle to secure the resources required to support Disabled people to access the same rights and opportunities as non-Disabled people. That struggle will take different forms at different times depending upon the attacks we find ourselves facing and the reforms we consider most urgently needed under particular circumstances". [1]

At this particular moment in time the support required by Disabled people to access the same rights and opportunities as non-Disabled people is absent as a direct result of the government's inability and failure to address the medical, socio-economic, and political issues that have arisen due to the COVID-19 pandemic.

Disabled people of all ages who require social care or independent living support for their daily living arrangements and the workforce, families and friends involved providing these arrangements are experiencing growing fear and anxiety due to the complacency of the government. Disabled people of all ages, who as a result of pre-existing medical conditions or the ageing process, are seen as being most at risk during the current pandemic. However, apart from instructing them to self-isolate for three months, national and local government have presented no strategic plan for safeguarding them.

Daniel Kraemer from the BBC Political Research Unit, on 25th March reported that:

"The bill gives the government wide-ranging powers unlike any other recent legislation. Mr Hancock has stressed that the powers in the bill would only be used "when strictly necessary" and would remain in force only for as long as required to respond to the crisis." [2]

Kraemer went on to say:

"Labour's shadow Health Secretary Jonathan Ashworth said no MPs ‘came into this House’ to give powers of this kind to the executive, ‘curtailing some of the basic freedoms our forebears fought for and we take for granted’. While Labour believed unprecedented measures were now needed to 'save lives and protect our communities', he said the measures would ‘chill every Liberal in the House' and only offered its support with a 'heavy heart'.

However, he said the bill required careful scrutiny to ensure the 'quite extraordinary' powers were not abused, particularly in changes to rules on mental health sectioning and the provision of social care."

Whilst recognising the difficult circumstances that the Coronavirus has thrown up, and the need to address the
shortfall in staffing levels, alongside inadequate resources, this piece of legislation is nevertheless extremely draconian. It is an assault on basic Human Rights, especially for those with mental ill health.

Disabled people are also particularly unimpressed by the fact the bill gave councils the power to "downgrade" care and support to Disabled people of all ages, and the fact this should be subject to a review by the Equalities and Human Rights Commission offered no comfort whatsoever.

Perhaps what illustrates quite well the ignorance of MPs around the issue of meeting the needs and interests of Disabled people is the comment by Jonathan Ashworth in relation to the suspension of the Care Act.

He said, "While councils should be able to prioritise those with the greatest needs in the event of staff shortages, 'what no-one of us wants to see is the legal minimum of support become the default'.

Sorry, 'prioritise those with the greatest needs' has nothing to do with meeting 'the legal minimum of support'; it gives a green light to withdraw care altogether for some groups. I was informed by the local Home Care Service that I should stock up with essentials and there may be times when no support would be available, therefore, cope the best you can.

**Health and social care obliteration bill**

Meanwhile, as the bill was going through the House of Lords, Baroness Grey-Thompson said "part" of the legislation was needed, but raised fears over:

* Hard-pressed local authorities no longer assessing whether people require care, once the legal requirement is lifted.

* Disabled children turning 18 and finding their care help will "just stop".

* That it will be possible for a single medical professional to section someone under the Mental Health Act.

* A lack of support for victims of domestic violence, who "will be at greater risk".

* TV advice on the epidemic being broadcast without "a sign language interpreter so that everybody can understand what is going on".

Explaining her presence in the chamber, despite increased personal risk from the virus, she added: "This is a health and social care obliteration bill by a different name." It was also reported that, Baroness Jane Campbell, former head of the Disability Rights Commission, echoed the fears, tweeting: "Disabled people must not be invisible in the survival planning process." [3]

Many disabled activists believe Disabled people are already being made invisible during this pandemic in a variety of ways. We have witnessed distorted stereotyping of our lifestyles and having the dangerous and inappropriate label "vulnerable" attached to them. Disabled people of all ages are at risk during this pandemic, but what creates their vulnerability is not who or what they are; it is the failure to put in place appropriate advice, support and resources.
What this current pandemic shows is there is no infrastructure in place at national, regional or local levels to support groups of people who are potentially at risk. Community based support ought to have been a priority from the first day of recognition that a crisis situation was on its way.

Talking about appropriate advice, over the last few weeks, poor and misleading advice has been issued. Prior to the national 'lock-down', there were guidelines put out on self-isolation which covered Disabled people of all ages, who as a result of pre-existing medical conditions or the ageing process, were considered to be most 'at risk'. By the 22nd March, the public was being told that 'up to 1.5 million people in England identified by the NHS as being at higher risk of severe illness if they contract coronavirus should stay at home to protect themselves'. [4] What people did not realise is that the medical conditions listed for this group were far smaller than were covered previously as it now targets the 'extremely vulnerable'.

As I write, I have seen no evidence that 'a raft of new measures, including a helpline for the most in need of support, have been set out for those considered to be extremely vulnerable due to their medical conditions, so people know exactly how to care for themselves and others in the coming months'. Neither have I been approached about 'a new Local Support System [that] will make sure those individuals self-isolating at home and who are without a support network of friends and family will receive basic groceries'.

As my impairments are not listed, I have little choice other than to go shopping; even though they appeared within the original guidance!

What I am arguing is that the overarching Public Health England advice, for example, on self-isolating has been woefully inadequate because it sidesteps many of the complexities involved in the lifestyles of Disabled people of all ages. There are Disabled people who would find self-isolating both difficult and highly dangerous; many are already isolated or struggle with barriers which could do additional harm if they cannot shop or receive adequate medical or social support.

Low income, stockpiling of food, hygiene products and medicine all have serious implications for Disabled people’s health needs. As the Reclaim Social Care campaign pointed out, little attention has been paid to the implications behind the advice given to care staff or personal assistants that, "a risk assessment should carry out before they visit a person and ascertain if they are symptomatic." [5]

What if they are; stating a face to face visit should not take place, and the person should be left in their room with the door closed, and then a 111 call made does not address what could or should happen next. What is meant to happen while waiting for a COVID-19 test?

It is unrealistic and highly questionable to expect people to be hospitalised; it would violate human rights to abandon people, so how would their support needs be met? There is no indication what would happen to the person if they are found to be positive but not critically ill.

Ideally by now, we should have seen local authorities co-produce with Disabled people’s organisations, contingency plans for safeguarding Disabled people who may be at risk of not receiving the care and support they need as a result of COVID-19 or any future emergency.

This situation has not been assisted by a decade of austerity with a reduction within or the privatisation of services, an acute and largely ignored crisis within social care and the utter contempt successive governments have shown for Disabled people's representative bodies.
I advocate a social approach towards disablement which sees the structures, systems and organisation of society as maintaining the restrictions which exclude or marginalise Disabled people. For many Disabled people, our lifestyles are impacted upon by various forms of disabling barriers at the best of times, however the pandemic is likely to compound the situation.

Adapting our lifestyles is never easy and inadequate information and unrealistic expectations could result in increased isolation. Disabled people of all ages will face uncertainty over the next few months and the advice to limit human contact puts people at greater risk.

Recruiting support is always difficult, but with the possibilities of staff contracting the virus, I am deeply concerned that little or no attention is being paid to Disabled people's lifestyles, be that a disabled child who may have infected parents, through to the older disabled individual without a phone, internet, television, radio or ability to obtain shopping.

If the risk is face-to-face fifteen minute interaction, how could that be mitigated against to ensure Disabled people have adequate support? If the vision within Independent Living for the Future was implemented, an embryonic infrastructure would be in place, a one-stop Centre for Independent Living where information, advice and guidance would be available. A local CIL would co-ordinate emergency cover and community based support.

The Disabled People's Movement raised the slogan, "Nothing About Us, Without Us", because it represented the desire to take control and responsibility of our lives and to collectively work together for betterment, inclusive praxis and for the transformation of society into one that serves humanity and the planet, not wealth creation.

The current crisis however clearly demonstrates how little power and consideration is given to Disabled people of all ages. I feel Disabled people are being made invisible or symbolically placed in a black bin liner with the label "vulnerable" tagged to it.

I have joined those who are voicing anger and frustration because as activists we know the history of Disabled people which is one of abuse, neglect, oppression and murder via euthanasia.

Within the discussions around COVID-19, we have already heard eugenic-sounding rhetoric from medical professionals and others. The alarm bells have been ringing around the NICE rapid COVID-19 Guideline on Critical Care because the first draft read as denying care to many groups of Disabled people. [6]

In case we forget, in 1920 long before the Nazis took power, Binding and Hoche, when speaking of those with impairments, and explicitly advocating involuntary euthanasia, wrote:

"Their life is absolutely pointless, but they do not regard it as being unbearable. They are a terrible, heavy burden upon their relatives and society as a whole. Their death would not create even the smallest gap except perhaps in the feelings of their mothers or loyal nurses." [7]

As a Marxist, I know history does not repeat itself exactly, and we are conscious that the pandemic will result in untimely deaths, but the words spoken by Prime Minister Johnston are being heard differently by Disabled people who already believe they are disregarded by the present government. During this COVID-19 pandemic, Disabled people should be neither silenced nor ignored.
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[7] Karl Binding and Alfred Hoche publish their book Die Freigabe der Vernichtung Lebensunwerten Lebens; the title translates to "Permission to Destroy Life Devoid of Value" or "Permitting the Destruction of Life Unworthy of Life." The book was composed of two parts. Binding’s part addressed the legal relationship between suicide and euthanasia, and then extended it to killing the mentally ill. Hoche’s part addressed the relationship between doctors and patients. He suggested that killing a patient was justifiable when it led to other lives being saved - particularly when the patient in question was, in his view, of no value to themselves or society.