

Written evidence submitted by Sam Margrave (MRS0148)

5 concerning experiences of a disabled person since the outbreak of Covid19

This is submitted as written evidence in a personal capacity by my myself as a disabled person.

My name is Sam Margrave and I was appointed as a member of the West Midlands Office of Disability Issues Regional Board (though that board has not yet met).

I am also a former Councillor and NED at a large housing association, an academic researcher, and member of the General Synod of the Church of England.

My research focus is entrepreneurship, local government, and disability.

I am 37 and have multiple disabilities. I have Myalgic Encephalomyelitis, Fibromyalgia, Autism, ADHD, Ethers Danlos, hemochromatosis, Severe OCD, and other conditions. My life is on hold, my conditions/co-morbidities are meaning things are very hard right now. As they are for many of my friends or contacts who I speak too online.

I have personally suffered from a number of the points I have made and if I had been in a different point in life, may have suffered more.

I have tried to convey my experience/feelings, rather than develop an academic work.

Please note I have written to my MP and Ministers. I am disappointed by the time frame for a response from a Minister, which is 7 weeks. This is relevant as I am not sure how to live my life or to access services or the impact during that period.

I aim to show how disabled people:

- **have not been helped comparatively to their abled peers**
- **been put at risk, and how the Pip criteria is being used to deny treatment**
- **how care has been withdrawn;**
- **how Government or public bodies have acted as if the equality act has been suspended.**

I have highlighted the issues in opening paragraph(s) under a heading and closed with a recommendation for action. While I have chosen not to provide evidence with this document, I do have evidence for all the points I raise, but these involve sensitive data and I didn't want this to result in the document not being considered by the committee.

The main thread of questions you need to ask is, how has the Public Sector Equality Duty or Equality Act 2010 been considered or applied. Is there an Equality Impact Assessment? While I've not listed this as a heading, it's a fundamental expectation which I believed current public policy interventions have fallen short of.

The issues I wish to highlight for the committee are:

- 1. Disabled people are economically active and have not been supported in respect of losses for permitted work or statutory sick pay.**

Many disabled people work part-time or in insecure work because they have no choice, due to other opportunities not being open to them. This can include professionals, including hourly paid lecturers. Hours could have been worked for many years for multiple employers or on a week to week basis, but a knowledge there would be hours regularly coming in. Much work is zero hours contracts, because disabled people are often not allowed to apply for full time posts and employers will not open these opportunities to disabled people who have limited hours they can work.

As such, for many disabled people, their work arrangements are complex. We work either as self-employed (often in new businesses) or in employment, but in permitted work. We are also easily disposed of and often the first to be let go.

Many disabled people in receipt of Employment and Support Allowance (ESA) earn upto £132 per week on top of their benefits.

The disabled person may have a mortgage or other fixed costs due to working.

But the Government has deemed disabled people on benefits as an economically inactive group so given no support in these difficult times. Causing many disabled people (the most vulnerable) more health issues, anxiety, stress and difficulties.

Lots of these people have coped undertaking part-time work, getting shopping online, and having routines and living week to week, hand to mouth.

Those who are in receipt of Universal Credit got £1000 extra per year, but many disabled people remain on ESA or can't claim UC. That means there is an unfairness.

Furthermore, in respect of Statutory Sick Pay (SSP), many disabled people could work upto 16 hours per week but may not be eligible for SSP. As such, disabled people will be worse off in respect of £6000 as a minimum and as much as £8000 compared to someone on UC or the furlough scheme.

This is a stark difference to those in work who have now been asked to be economically inactive, on 80% pay, despite having significant savings, second (or third) homes, and who are not in a vulnerable group.

This group is mainly abled people. As such the decisions and admiration of support for those affected by coronavirus is disproportionately helping abled people. Companies are not offering furlough to disabled people on zero hours contracts or those who haven't yet had hours allocated they normally get or indeed, where hours were promised. The Chancellor said no one should be penalised but some are.

Its this precarious work that disabled people are forced to undertake. As such it is they are who need help most, and they are not being helped.

Indeed support also doesn't support those affected by Covid19 in ways such as mental health, etc (I discuss this below).

The DWP & HMRC is aware of permitted work undertaken, and amounts received. So these figures may be available for the committee to consider or maybe you could ask the Treasury committee to consider this matter.

One further consideration is the future. Disabled people will now for sometime, be stuck at home and with the economy contracting, they will lose access to accessible jobs in the

Labour market. As such opportunities to work from home need to be opened up to disabled people in a way as never before, to ensure we continue to be economically active going forward.

Recommendation:

- a. A payment is made to all disabled people on ESA to keep inline with the Universal Credit Payment.
- b. A payment is made to those on permitted work, based on their last 3 years average of employment income.
- c. Arrangements for disabled people who have lost jobs permanently, and are unlikely to easily find new work, special protection in respect of credit ratings.
- d. Consider how to ensure the Labour Market offers opportunities to disabled people.

2. The use of the PIP/DLA or social services criteria to decide who lives or dies.

The Government has said that being on Enhanced PIP (i.e not managing functional living such as daily or home tasks) doesn't mean someone is at greater risk of Covid-19, and as such isn't eligible to be in the 'extremely vulnerable' group. Causing real hardship for many.

Yet the diagnostic criteria below uses the PIP, DLA or social services criteria to decide who is less likely to survive or who will not get all treatment options. This was first published by the Financial Times and has been disputed. However other such guidance has been issued by NICE and trusts, indicating that certain disabled people are not having access to live saving treatment. Frailty is important, and if as below, autistic people are determined to be frail, despite autism not being physical, they are then denied treatment. Indeed we can see that while there is capacity in the system, and criticism that Nightingale hospitals are under used, they still deny access from frail people. Frail people has become a synonymous term for DISABLED people.

This is alarming and means that disabled people are put to the back of the queue for treatment. This is nothing short of euthanasia. Did Hawking's or Churchills life have no value? They would both score 8-9 on this criteria. That is because Stephen Hawking had MND and its widely thought Churchill had ME/CFS, but he was unable to walk or undertake household chores during the war and is well known for working from bed. As such he would have scored highly on this criteria.

COVID-19 DECISION SUPPORT TOOL



1

AGE	POINTS
<50	0
50-60	1
61-65	2
66-70	3
71-75	4
76-80	5
>80	6

2

Clinical Frailty Scale*

- 1 Very Fit** – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.
- 2 Well** – People who have no active disease symptoms but are less fit than category 1. Often, they exercise or are very active occasionally, e.g. seasonally.
- 3 Managing Well** – People whose medical problems are well controlled, but are not regularly active beyond routine walking.
- 4 Vulnerable** – While not dependent on others for daily help, often symptoms limit activities. A common complaint is being “slowed up”, and/or being tired during the day.
- 5 Mildly Frail** – These people often have more evident slowing, and need help in high order IADLs (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.
- 6 Moderately Frail** – People need help with all outside activities and with keeping house; inside, they often have problems with stairs and need help with bathing and might need minimal assistance (cuing, standby) with dressing.

- 7 Severely Frail** – Completely dependent for personal care, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).
- 8 Very Severely Frail** – Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.
- 9 Terminally Ill** – Approaching the end of life. This category applies to people with a life expectancy <6 months, who are not otherwise evidently frail.

Scoring frailty in people with dementia
The degree of frailty corresponds to the degree of dementia. Confused symptoms in mild dementia include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal. In moderate dementia, recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting. In severe dementia, they cannot do personal care without help.

* 1. Cassel: Studies in Health & Aging, Boston 2008.
2. K. Rockwood et al. A global clinical measure of fitness and frailty in elderly people. CMAJ 2005;173:489-495.

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CO-MORBIDITY	POINTS
In last 3 years, cardiac arrest from any cause	2
Chronic condition causing: • ≥3 hospital admissions in the last year • ≥4 weeks continuous admission for current inpatients	2 2
Congestive heart failure with symptoms at rest or on minimal exertion	1
Chronic lung disease with symptoms at rest or on minimal exertion	1
Hypertension	1
Severe and irreversible neurological condition including dementia	1
Chronic Liver Disease with Child-Pugh score ≥ 7	1
End stage chronic renal failure requiring renal replacement therapy	1
Diabetes mellitus requiring medication	1
Uncontrolled or active malignancy	1

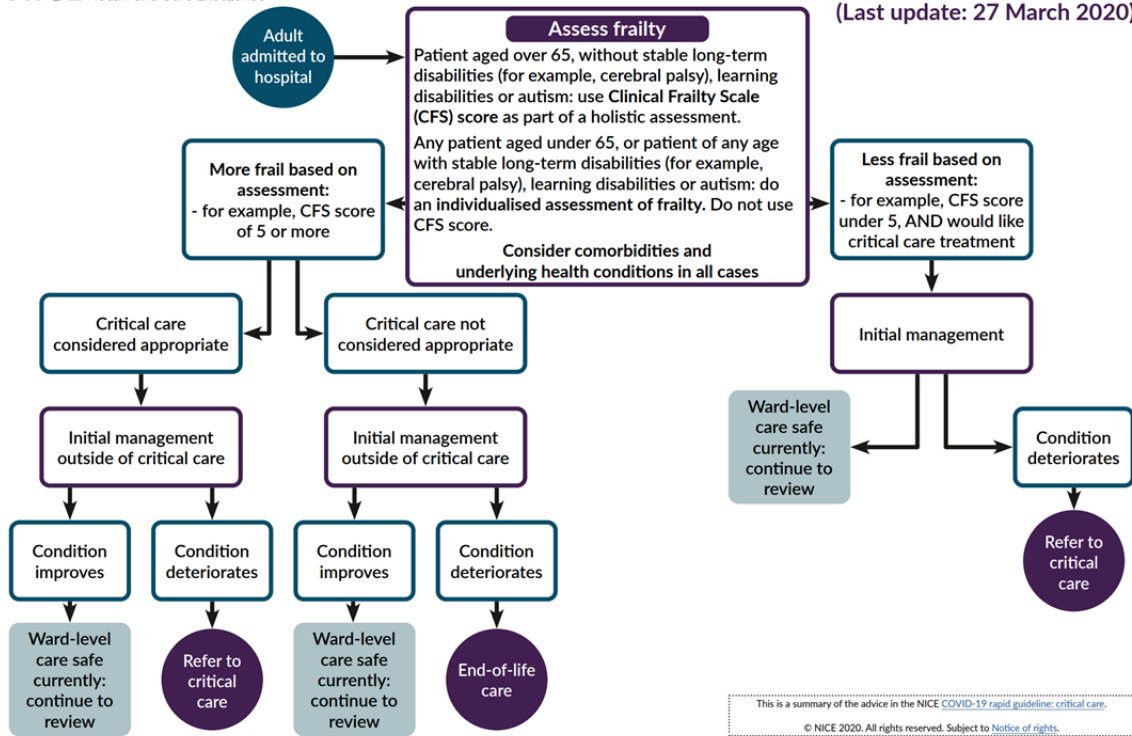
TOTAL = SUM OF THE 3 DOMAINS ABOVE (-1 FOR FEMALE SEX)

! There may be situations arising that are outside the scope of the framework that require special consideration, thus clinical discretion will continue to apply. Frailty scoring is used as a proxy for physiological frailty which leads to reduced chances of recovery in ICU, therefore where conditions pre-exist impact on physical activity but are stable and inappropriately affect the score, then that situation requires special consideration.

POINTS	TREATMENT	FAILURE OF FIRST LINE MANAGEMENT	NOTES
Group 1 ≤ 8	ICU-based care	Palliation or ECMO	Usual criteria for ECMO and <60 years
Group 2 > 8	Ward-based care	Step 3	Consider trial of CPAP
Group 3 Patients not normally for full active management or failed CPAP trial	Facemask oxygen	Palliation	Consider domiciliary care

Deviations from ARDS guideline	Investigations	Support	Treatment
Step 1 ≤ 8	Tracheo-bronchial aspirate for respiratory viruses. Avoid CT & bronchoscopy unless indicated. H score screen blood tests, D-dimers, LDH & troponin (all days). Lung US to reduce X-ray usage	CPAP trial in ICU or with rapid access to intubation (for hours not days) Avoid HFNO	CAP antimicrobials Continue single agent prophylaxis in +ve pts Disease modifying agents as part of RCT
Step 2 > 8	Standard swabs	Ward-based CPAP	CAP antimicrobials Continue single agent prophylaxis in +ve pts
Step 3 Patients not normally for full active management or failed CPAP trial	Standard swabs	Facemask oxygen	CAP antimicrobials Continue single agent prophylaxis in +ve pts

I am also concerned as an Autistic person that my Autism could lead to different treatment to a non-disabled person. This is according to NICE guidelines outlined as below which can be found at: <https://www.nice.org.uk/guidance/ng159/resources/critical-care-admission-algorithm-pdf-8708948893>



Recommendation:

- a. Who gets a ventilator is based only on a physical clinical diagnosis related to respiration or a relevant symptom, not disability as that has no bearing on the success of intubation as a procedure.
- b. The minister for equalities issues a statement about the value of disabled peoples lives and ensure no disabled person is denied treatment due to disabilities.

3. The hardship fund is not what it seems and there is no money reaching the disabled.

The hardship fund is in fact a slight of hand. Covering reduction in business rates.

The money is being used to pay Council tax that otherwise should be paid by Council Tax Benefit.

This means that disabled people don't have access to upfront costs to help them with increased deliver charges, increased food or other costs, or the requirement of a minimum spend or lack of bargains on the shelves.

Disabled people who are house bound can't access foodbanks and have special dietary requirements which are hard to be met.

Cross party groups argued that helicopter money should be given to those groups who are falling through the cracks. There doesn't need to be another system set up. Money could be paid to help individuals on existing benefits.

For example, matching the £1000 above or more to allow a disabled person to buy a freezer to store milk, bread, etc and to pay for food deliveries or the initial costs of stocking up for more than a week or so they have supplies when shielding or stringently distancing, or when carers cant care. This is about access to resources.

Recommendation:

- a. Disabled people as above are given money directly using those on DLA, PIP or in receipt of Access to Work or other benefits that recognise disability.

4. Withdrawing of access to existing strategies, or care services by local authorities and the redefinition of a disabled person.

The Government has created a new two-tiered group of disabled or vulnerable people.

Creating an undeserving and deserving group of disabled people in both the public consciousness and in real terms within key national infrastructure such as supermarkets, pharmacies or local authorities.

I am aware local authorities that before the legislation was given royal assent were instructing staff to stop undertaking assessments under the care act.

Many disabled people have been asked to take stringent self-isolation measures, but this advice isn't clear and fails to take account of those who are already housebound for multiple reasons from physical and mental disabilities.

This has created a new class of the deserving disabled, or the 'extremely vulnerable' class who get access to support and those who 'stringently distance' who do not.

Its hard enough being young, but now I am someone who isn't really disabled according to the Government as they imply to the public, yet I can't get out and if I did get this virus, I would be caused serious harm. It is well known that those with ME/CFS suffer relapse. While I may not die (and we have no evidence I won't, or I am at less risk than someone who is pregnant), I could be incapacitated further.

Supermarkets and pharmacies have used the Governments list to prioritise services/support.

Theses decisions mean for example, if someone is on enhanced care and mobility on PiP, they aren't deemed as being worthy or able to access support despite not being able to leave their homes.

Many with mental health conditions such as OCD are severely affected. These individuals need to be recognised and supported to stay at home.

This is for the benefit of services and service users. Imagine someone in a hospital with a mental health crisis, when they could have had permission/instruction from the Government to stay at home, and stay safe.

Those over 70 and those with pregnancies were included in the extremely vulnerable group, despite no evidence to say they are at risk.

Yet those with many conditions that indicate they are at greater risk (but not the highest risk) through say CFS or EDS or Lupus, are not included. This is alarming because the three tiers means the middle tier has effectively been placed within in the 'not at risk' tier and denied access or not catered for.

In my own case I was recommended to be included on the extremely vulnerable list due to comorbidities, but I am not. My GP couldn't because my conditions aren't listed.

However I was told by my MP there is a way to be included in the extremely vulnerable list based on level of vulnerability. But that isn't the case and there are specific conditions listed.

Its not like say the flu vaccine where the list is candid in saying it doesn't cover every situation. Indeed I've been told by professors and specialists in ME that I am at greater risk.

This may not mean death, but it does mean being bed ridden and a cost for me, and society.

As such why am I not being told to stay at home and stay safe like those in the 'extremely vulnerable group'?

Recommendation:

- a. Councils are given clear guidance that the care act has suspended but Local Authorities should act as if it is still in place apart from by exception. The purpose of the suspension is to act in the best interests of disabled people, and their public sector equality duties have not ended.
- b. That the list of those who are included in the 'extremely vulnerable' list of those who are able to access services such as online shopping or medicines, includes those who are in receipt of DLA or PIP.
- c. Guidance be issued for conditions such as CFS and for these groups to be included in the 'extremely vulnerable group' if frail.
- d. More consideration of those with mental health conditions is given to how we can recognise and support those with mental health conditions.

5. Recognition by Courts and Workplaces

For those in the middle group, even with mental health conditions, who could not leave their homes – the courts and workplaces were not delaying meetings or activity as they haven't recognised those significantly distancing or with mental health issues affected by the current pandemic.

One problem here is that a sick if often not recognised by a Court. While this comes from case law, this means that Judges have been refusing to delay claims or cases or activity.

Much focus has been on the DWP not requiring people affected to attend face to face interviews. But again, disabled people aren't recognised as being economically active and/or having a life that requires meetings. As such provisions aren't being made to put their lives on pause because they don't fit current criteria.

I have a case regarding discrimination. But I am now being told if I don't meet court orders or attend, I will be punished. Fit Notes have no where to recommend a pause such as this or courts have a stay. So there is an anomaly. Fit notes should cover all activity, not just work. No one who is unwell should be undertaking leisure or other activity.

Recommendation:

- a. A sick note given applies to the courts and all activity when someone is sick is accepted as not taking place and that individuals who are unwell should be on bed rest.
- b. All those shielding or in the second-tier group who should stringently social distance, and can't work from home, should be given financial support.
- c. Judges be given guidance by the Lord Chancellor or Government that disabled people should be allowed a stay on their case for reasons such as above or relating to covid19, even if someone doesn't have covid19.

I hope above helps give some information that can be considered by the committee. I am always available to come before you to share either above in more detail, to speak about my experience as a disabled person, researcher or what I am witnessing among friends and those who contact me to share their own stories.

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