To: Women and Equalities Parliamentary Select Committee inquiry

Unequal impact: Coronavirus (Covid-19) and the impact on people with protected characteristics

Submission by WinVisible (women with visible & invisible disabilities) 30 April 2020

WinVisible is a grassroots multi-racial organisation with a UK-wide network, enabling disabled women to have a voice, and providing self-help information, peer support, advocacy, campaigning and other activities. Since 1984, we bring together women who are refugee, asylum-seeking, UK-born and immigrant, with visible and invisible disabilities; older and younger, disabled mums and disabled carers, lgbtq+ and more. We campaign against discrimination, including the impact of benefit and care cuts; of social care charges taken from our disability benefits, and for benefit and healthcare rights regardless of immigration status. In an inaccessible and prejudiced world, coping with disability and ill-health is hard work. We support the international call for a Care Income for care work, which we do for ourselves and other people, and for animals and the natural world.

Summary

The reality for disabled women, the majority of disabled people, is that the measures against Coronavirus are threatening our lives through starvation, denial of medical treatment and lack of social care daily living support.

This crisis came on top of years of cuts which hit disabled women/BAME communities <u>hardest</u>, and after many thousands of women, especially pensioners, had already lost homecare and other vital support services.

Disabled people, family carers and others lobbied against the Coronavirus Act's suspension of **Care Act** duties; and against denial of medical treatment, and told MPs that many people could die as a result of these policies. We fear that after the lockdown, many people will be found dead in their homes from lack of food/water and care.

Instead of prevention, the government chose the "herd immunity" approach. Which people did the government think are expendable? The Prime Minister told the public to "prepare to lose loved ones". Why did they not adopt methods successfully used in other places -- such as Taiwan (near mainland China) where very few people have died and where there was no lockdown?

Access to food and medicine

Many pensioners and thousands of other people with serious health conditions who are self-isolating at home for at least 12 weeks, are <u>not</u> included on the government's "clinically vulnerable" list for help with delivery of food and medicines. Even some who are, are left to <u>fend for themselves</u>. Registration for the list is online, which many people can't access, including visually-impaired pensioners who rely on phone contact. Nationally, at least <u>1.5m</u> people are missing food, and more would starve without the unwaged family carers, volunteers, Muslim and other charities delivering meals.

Disabled women in our network in Brent, Camden, Greenwich, Newham, Southwark and outside London, many of whom are women of colour already suffering discrimination, have told us they are unable to book food deliveries online, and can't stand in queues at supermarkets, also going 8am-9am is not realistic. Some experiences:

- A disabled woman is self-isolating, she couldn't get a supermarket delivery slot for weeks and can't stand in a queue or go during the early time. She cancelled her home help as they didn't have proper PPE and she is worried about infection.
 When she cancelled, Council staff initially told her she would be charged for the cancelled service.
- A woman with severe asthma, and her daughter who has a brain injury, are not on the government's "clinically vulnerable" list to get help, and are reliant on "tagging on" to a friend's food delivery.
- A woman wheelchair user with incontinence had her shopping items restricted and had to choose between buying either food or toiletries.
- A woman who uses a portable breathing machine used to go shopping accompanied by her assistant. Now she can't send her assistant out shopping as she can't be left alone at home, so is reliant on a volunteer scheme for food and prescriptions.

In some cases, donated food parcels have been of unhealthy, low-quality or mouldy food, with instant noodles or chocolate bars not appropriate for diabetics, foods that require long preparation and cooking, or foods which are not familiar to people's culture. Many disabled and older people are unable to cook, so need ready meals. People used to get meals on wheels. With social care cuts the quality declined and they have been largely phased out and replaced by shopping yourself.

Appalling news about National Shielding Helpline

Given the government's terrible <u>track record</u>, we knew that the support offered to people told to "shield" was likely to be poor. But the truth revealed by a <u>whistleblower</u> about the National Shielding Helpline is worse than feared. This helpline should have been staffed by directly-employed DWP or other public sector staff with experience of similar situations and of working accountably. Instead, the helpline is run by the private contractor <u>Arvato</u> with lax systems and call centre staff given hardly any guidance on what situations to refer on. (Our experience of another disability-related helpline is that you are allocated a reference number so that if you call again, the previous information can be matched up.)

The whistleblower told about a woman with a learning disability who confided that she was being abused by a man in the household. She was not offered immediate support, instead afterwards staff laughed at her cutting up crisp packets at home. Other callers with support needs were fobbed off. This is compounded by the reality that when Arvato staff did call adult social care departments, they were often not able to get through.

Social Care

The government's introduction of sweeping powers under the Coronavirus Act, opened us to more discrimination. Rather than making social care a priority alongside the NHS, duties under the Care Act were suspended. (The Labour Party did not vote against this.) This has hit disabled women and men living alone who don't have friends or family helping us, disabled children and their mothers, and other family carers of autistic and other disabled adults where day centres and colleges they attend are closed and no support is offered.

Unwaged carers are working harder than ever and for longer hours, with no respite. Many carer mums are at breaking point, many have ill-health and disabilities themselves. Some are suffering domestic violence because disabled family members are turning their frustration onto them.

Paid carers are not getting protective equipment, some have quit for fear of catching COVID-19 from service users or on public transport to visits. Some disabled women have reported not getting homecare visits which they rely on to get out of bed, or fewer visits than usual. They are restricting their drinks and staying in bed as they don't have assistance for the toilet as needed – leading to kidney infection and pneumonia.

In March, we wrote to Camden adult social care, the local authority where we are based, asking them to consider the people who dropped out of social care services in recent years due to unaffordable charges. The Council replied with the usual channels for emergency referral to the duty social worker. Yet only the Council knows who all those people are and where they live, and could do outreach to people who need support, based on Council Tax and Housing Benefit information they hold.

We want councils to follow Hammersmith & Fulham's <u>example</u>. They are the only Council in England to have free homecare and to have ring-fenced the Independent Living Fund. Their COVID-19 response included contacting disabled people directly by letter and phone, not relying on residents to look online. Council staff told people that there will be no change in service provision, and asked what people need. In other places, many people have been abandoned or lost some of their service. A disabled mum in isolation told us that her disabled teenage son had just been assessed for continuing care and a better wheelchair. Neither has been provided.

Councils are now hiking up care charges but also refusing to do financial assessments, leaving some women impoverished by charges. **We want all care charges suspended, including because people have even more disability-related costs now**, such as having to buy food from corner shops which are more expensive.

Some people get a budget from the Council to employ their own support workers/personal assistants (PAs). This has strict rules and financial controls. During COVID-19, people

should be allowed to spend their Direct Payments as they need, on expenses that arise and to employ family members during the lockdown, which is usually not allowed by Councils. COVID-19 testing for Direct Payments PAs is only just becoming available.

We know from experience, that when we are not getting outside services, some of us have to rely on partners, family, or acquaintances we don't entirely trust or know well. They can often turn exploitative or sexually abusive. Relationship tensions are heightened. Women with disabilities were twice as likely to suffer domestic violence before this crisis. Domestic violence killings have increased since the lockdown. Most refuges are not accessible and if you need daily practical support with washing and dressing, which a refuge doesn't provide, you are not going to leave home. Due to care needs, severely disabled women escaping violence might get placed in a care home – risking a COVID-19 death sentence. Some disabled women don't want to leave home, but just want the family member who is aggressive to get appropriate support. Some women don't want to call the police, especially if they are women of colour, due to racism and consequences of calling the police out. We remember Dalian Atkinson.

One of our members became a wheelchair user after she was stabbed in a homophobic attack and then suffered a stroke. Those of us who are lesbian or trans women suffer additional discrimination and hostility from neighbours, social workers and homecare staff, so struggle to get support.

Disabled mothers who are entitled to childcare help under the Care Act are now even less likely to get it; children are being taken from their mothers with even less legal representation; and those children already in care are being prevented from having much-needed virtual contact with their birth families (see <u>Support Not Separation</u>).

Women with mental distress

- Women are severely distressed, with no in-person support groups and cancellation of self-referral to our usual services.
- A woman told us that a friend was admitted to the local psychiatric unit, but then caught COVID-19, was taken to the COVID-19 ward, and died. People with mental distress often have immune system conditions. Are in-patients protected from COVID-19, or is it like the care homes? Some psychiatric wards are being emptied to make space for COVID-19 patients, with only patchy support in the community.
- Coronavirus Act change to the Mental Health Act: Women are worried about emergency powers where you can be sectioned by one doctor or detained for longer. BAME women, men and young people are disproportionately detained.
- Women discharged from psychiatric hospital are being wrongly charged for social care, when we are exempt from charges under the Mental Health Act s117 free aftercare. Bills of £96/week (based on her disability benefits) arrived at a woman's home before she even left hospital.

Given the horrific scale of <u>deaths</u> of people in care homes, women in our group are worried about neglect of elderly relatives and not being able to visit. One woman told us her mum's care home has prepared one floor for such patients. And care homes are

being contacted to take in COVID-19 patients. A care home owner in Devon has described this as "importing death into care homes, <u>sacrificing the elderly"</u>. Around 45,000 disabled people under pension age live in care homes, including Doug Paulley who is pursuing a <u>critical care</u> legal challenge.

Disability benefits and Section 4 support

Some temporary benefit changes have been made, including continuation of disability benefits, no (usually needless) reassessments and no work conditions and sanctions in Employment and Support Allowance (ESA). Also suspension of face-to-face assessments, which in any case are discredited (see Work and Pensions Committee inquiry into ESA and PIP assessments).

But we are worried by the switch to telephone interviews to assess new claims (such as DLA to PIP), that people will be disadvantaged and scored down. It is very stressful to be put through disability benefit assessments, people should be able to access benefits without stress. With telephone assessments, people get a call while alone, may be asked for important information at a time when they are unprepared and unsupported, and could be assessed without supporting information from GPs and other professionals, so will lose out. Those of us who are survivors of child abuse, domestic violence, rape, war and other trauma find it especially stressful to talk to a stranger about why we need disability benefits where we often have to disclose very personal information.

Universal Credit personal allowance has been increased by £20 a week, but still cuts benefits compared to before, through the five-week wait, loss of severe disability premium, the cut to disabled child element, and many other features. Employment and Support Allowance has not been increased, which was already cut to JSA level for sick and disabled people in the Work-Related Activity Group (£74.35). This is far below even the Statutory Sick Pay (£95.85) which people rightly complained is not enough to live on. Neither has Carers Allowance been increased. The government requires family carers to do 35 hours a week for £67.25 (England rate), while accepting care provided remotely.

Disabled women seeking asylum are barred from getting disability benefits. Global Women Against Deportations (GWAD) highlights that though the government announced Section 4 support for "failed" asylum seekers, offering accommodation and financial support, many fear being at risk of deportation if they come forward. Cristel Amiss from GWAD said: "It is a very genuine worry. . . that if they go to the state for help they can be a target down the line. The virus is very quick at spreading and asylum seekers are in particularly difficult situations, usually in hostels with people from many different countries and backgrounds living close together. Those that are on asylum support get just £37 a week and are often living in overcrowded asylum housing, sharing bathrooms and a kitchen which make it almost impossible to keep yourself safe and follow isolating rules."

Access to medical treatment

Older and disabled people are frightened of going to hospital with COVID-19 as the British Medical Association issued Coronavirus <u>guidance</u> saying ". . . it is both lawful and ethical for a doctor. . . to refuse someone potentially life-saving treatment where someone else has a higher priority"(p.3). This adds to the long-established National Institute for Clinical Excellence (NICE) clinical frailty score. There has been an outcry against refusal of

medical treatment, and an <u>open letter</u> to the NHS from Baronesses Jane Campbell, Tanni Grey-Thompson and many disability organisations calling on the NHS to respect disabled people's right to life and other legal rights. NICE made a small change to its established <u>quidance</u> but disabled, sick and older people are still classed as not worth treating, see <u>Natalie Wolfson</u>. People of colour are "not a priority", see <u>Kayla Williams</u>.

The denial of critical care and pressure to Not Resuscitate remind us of Nazi policies of extermination of disabled people as "useless eaters" and "a life unworthy of life", while pensioners were starved to death in Hungerhäuser. We're #NotExpendable – none of us.

One woman who uses portable breathing equipment says: "I am concerned about restriction on visitors in hospital. If PAs and carers are not allowed to be with me, my life would be at immediate risk as I need experienced and appropriately skilled support with ongoing respiratory physio, operating various prescribed specialist equipment, assistance with personal care, and even to call a nurse as I am unable to press a call button."

Over 40% of NHS workers, 50% of doctors and 20% of social care staff are immigrant, risking their lives – despite the "hostile environment" and the threat of deportation – because the PM, who owes them his life, delayed getting the protective equipment they need. These are the NHS workers who have died from Coronavirus up to 28 April 2020. Women in our group are horrified that NHS staff can be surcharged for NHS treatment based on their immigration status, and that terminally-ill people have been deported.

We are supporting the urgent demand for a <u>Care Income Now!</u> so that caring for people and the natural world – care work we do for ourselves and for others – becomes the priority. Scrapping HS2 (£106 billion) and Trident (£205 billion) would help fund this.

In the meantime we are supporting calls for immediate increases to disability benefits and to Child Benefit and urgent access to food, daily living support and medical treatment for all.

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