



The Impact of COVID 19 on Disabled Women from Sisters of Frida

Voices of Disabled women in the pandemic

Sisters of Frida

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Introduction

About Sisters of Frida

Sisters of Frida (SOF) is a disabled women's collective. We are an unfunded organisation, all contributions are entirely voluntary. We have directors guided and led by a steering group. We focus on disabled women's issues.

At SOF, we are inclusive of self identified women, girls, non-binary, and gender non-conforming disabled persons. We do not claim to speak for all disabled women. We seek to build different networks of disabled women, share experiences and explore intersectional possibilities. We engage with both women's organisations and Disabled People's organisations.

We follow the Social Model of Disability. The Social Model of Disability holds that people with impairments are 'disabled' by the barriers operating in society that exclude and discriminate against them.¹

Who is disabled?

A person is disabled under the Equality Act 2010 if they have a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on their ability to do normal daily activities.

About this paper

This paper started as a brief but we sent the first version in response to the Women and Equalities Unequal impact: Coronavirus (Covid-19) and the impact on people with protected characteristics². We know that the experiences of Disabled women are not visible in the wider response to COVID-19. The need to add the narratives focused on Disabled women is the reason for this paper. We feel that the narrative about Disabled

¹ <https://www.inclusionlondon.org.uk/disability-in-london/social-model/the-social-model-of-disability-and-the-cultural-model-of-deafness/>

² <https://committees.parliament.uk/work/227/unequal-impact-coronavirus-covid19-and-the-impact-on-people-with-protected-characteristics/>

women, when available, is very one dimensional. There is no consideration that Disabled women occupy multiple roles, we are diverse and any considerations have to be viewed through an intersectional lens. We are strongly aware that new measures under the Coronavirus COVID-19 2020 Act threaten rights-based protections and reduce our independent living and in some cases our lives.³

We were asked to join a coalition of women's organisations⁴ calling on the government to take on certain actions, and to contribute evidence from the perspectives from disabled women under the impact of COVID-19. We put out a call for evidence, asking disabled women to share their experiences of COVID-19 and its specific impact for intersecting identities. We want to ensure the voices of Disabled women are visible as they are often omitted as examples of multiple protected characteristics.

We are working with [Inclusion London](#) and [ROFA](#) (Reclaiming Our Future Alliance) on the rights of disabled people under the Care Act 2014 where these are being eroded, the urgency of access to food and services for disabled people, and access to PPE (Personal Protective Equipment) for their Personal Assistants (PAs) and themselves.

Disabled women's needs under COVID-19 measures are no less significant than those of the rest of the disabled community, but disabled women face specific issues.

We are looking in particular at those issues that are impacting rights at the intersection of gender and disability during this crisis.

Statistics on disabled women

Disabled women's concerns are no different from the rest of the disabled community, but there are additional gendered factors in their marginalisation.

³ <https://www.disabilitynewsservice.com/coronavirus-mps-hear-of-disabled-peoples-struggle-to-survive-pandemic/>

⁴ See <https://www.fawcettsociety.org.uk/news/coronavirus-urgent-call-for-uk-government-to-support-women-and-girls>

There are more disabled women than men in the UK (23% compared to 20%).⁵

The most recent Family Resources Survey highlighted that the percentage of adults providing informal care varied by gender:

- Women are more likely to provide informal care than men up to the 65-74 age group⁶
- Women providing informal care are much more likely to be in part-time employment than men: 23% of women providing informal care worked part-time compared to 9% of men.
- Disabled women are twice as likely to experience domestic violence than non-disabled women.⁷

Disaggregated data on disabled women does not always exist, but these statistics highlight women's precarious position in society. Many, if not most, disabled women are in the low socio-economic position in society. The UK Women's Budget Group says that "26% of households with a disabled person are in poverty, compared to 22% in the overall population. This figure is likely to underestimate poverty rates of disabled households" and "50.7% of disabled people were employed but they were more likely to be underemployed and in low-paid jobs. Disabled women earn less (22.1%) than non-disabled men, a gender pay gap four percentage points higher than between all men and women. Disabled women earn 11.8% less than disabled men."⁸

The most immediate concerns of disabled women and the impact of COVID-19 are as follows:

Access to food

⁵ <https://wbg.org.uk/analysis/2018-wbg-briefing-disabled-women-and-austerity/>

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⁷ See <https://www.womensaid.org.uk/the-survivors-handbook/the-survivors-handbook-disabled-women/>

⁸ See <https://wbg.org.uk/wp-content/uploads/2018/10/Disabled-women-October-2018-w-cover-2.pdf>

Panic buying leads to food and household shortages (including essential supplies for disabled people, such as toilet rolls, gloves and sanitisers) which creates particular problems for people who cannot make repeated trips to the shops or travel long distances to find shops that still stock the food and other essential items they need. Some disabled people also require specific food items in order to manage their health conditions and impairments, which become more difficult with shortages.

'Wheelie Mum' wrote to us on the issues she has faced getting groceries, particularly for disabled single mums and those with disabled children:

[S]hopping [is difficult] if you don't have help getting little ones ready and to wait outside at 6am so you don't have to queue for three hours surrounded by a hundred people. Then worrying if some piece of work is going to try it on. It's very stressful. I had people walk in front of me in the queue. They didn't know it was an early access hour shop so that was particularly disgusting. I had my baby with me in the buggy on my scooter and I was stunned. ...No help. I have a toddler. Think about that. I ride tandem with a mobility scooter and buggy, then add a supermarket trolley held on the side. A couple literally cut in front of me in the queue to Waitrose.

Dr. Sarabajaya Kumar told Sisters of Frida more about how the requirement for her to 'shield' has impacted her access to food and increased her informal dependency on others: :

For instance, I was unable to shop online for the initial 4 weeks of lockdown (even though I had shopped online for almost a decade) because the government encouraged everyone to shop online without making provision for those of us who are effectively under house arrest and cannot leave home to shop. The demand for online food shopping went from 7%-30%.

My gender role at home is to organise our shop. Others in my family have their roles, so my partner cooks, my son walks the dog

etc etc. As my entire family comes under the high-risk category, not being able to get the provisions in (including food and cleaning products) for us as a family, made me/us feel very vulnerable. Food is a fundamental physiological need, as is shelter.

I managed to negotiate with several neighbours every day, to get some food in on a daily basis; and we had to get a take away a couple of times, but all my time was taken up with organising and liaising with several people to buy us one or two items, so I didn't burden anyone so much that they would avoid us and not assist us again.

I wrote multiple times to the supermarkets I had shopped with online and even though I implored them not to send me standard responses, I just received standard responses.

I had registered with the central government, as requested by them, but they took a very long time to let the supermarkets where I shopped know I was on the high-risk shielding list. I just received an email a couple of days ago to say one supermarket has received notification from the government and that I should try to log on but may still have to wait in a queue. I had been in queues for several hours on numerous occasions only to be told there were no delivery slots left and was thrown off the site.⁹

The local authority said they couldn't assist to help find someone to do a big shop for me; and that I needed to find volunteers myself through facebook, which I don't do on principle, but it is also inaccessible to me as a severely sight impaired person. They told me I had to. So meantime, I had to locate volunteers myself to shop for me, but my experience of that has been very mixed. Mostly good but also [one] really poor experience and concerns about safeguarding. It would have been much better to have had a vetted volunteer.

This has caused a lot of unnecessary psychological stress.

⁹ <https://www.theguardian.com/money/2020/apr/06/sainsburys-wont-deliver-shopping-if-youre-not-considered-vulnerable-coronavirus>

Supermarkets are now facing mass legal action from disabled people left anxious and distressed because they are unable to buy food and other groceries during the coronavirus crisis.¹⁰

Actions

1. Urgent action: It is vital that the government and local councils work with supermarkets to recognise that disabled people/women's needs for groceries and shopping are prioritised. While volunteers have been offered, the safeguarding needs of disabled women should be realised. The lockdown for disabled people is not expected to be lifted soon. Many disabled people are not listed for priority. This will be exacerbated for women from BAME communities.
2. There should be strategies for future emergencies on the groups that share protected characteristics so that the disabled people impacted will not be deprived of food, similar to that of a crisis zone. It is also important to remember the cumulative intersectional impact.
3. Safeguarding of volunteers should be reviewed to ensure that disabled people are not put at further risk.

Access to Health and Medical Services

Both the health and economic impacts of Covid-19 are gendered. Women, including disabled women, are the majority of those providing care, paid and unpaid, and are the majority of health workers.¹¹ Older people and disabled people with underlying health conditions, including respiratory conditions and diabetes, are the most at risk from

¹⁰ From Disability News Service <https://www.disabilitynewsservice.com/coronavirus-supermarkets-face-mass-legal-action-over-discrimination/>

¹¹ <https://www.weforum.org/agenda/2020/04/women-female-leadership-gender-coronavirus-covid19-response/>

severe health impacts if they contract COVID-19.¹² Older and disabled people who rely on social care delivered by PAs via direct payments or a personal health budget, including informal care from family members, may find it harder to self-isolate.

As hospitals and other health services have to cancel or postpone non-urgent cases, older, sick and disabled people are facing longer waits for treatment, exacerbating existing health problems. At the same time, many women and girls also are skipping important medical check-ups including family planning services for fear of contracting the virus.¹³

Michelle told us how she could not get access to testing after her partner was sent home from hospital with COVID-19, and how it has impacted her in having to care for him.

...[M]y partner was hospitalised and tested positiveI was not tested when he came home still infectious they wouldn't test or check about my health...

He has blood clots on his lungs... it's very bad ...but they would only follow up on [the] phone... he is extremely weak and weighs about 60 kilos. When he arrived home in our small shared flat, I now have to live in the living room while he has [the] bedroom.... I am knackered, cooking food, cleaning etc. There are no guidelines for me to read in a format (as a dyslexic woman) that I could check or have someone to talk to.

Begam, a disabled mother-of-four, is self-isolating with her family inside an overcrowded two bedroom flat. Her 20-year-old daughter, who works as a professional carer as well as providing personal care for Begum, does not even have a bed, and sleeps on the sofa, while Begum sleeps in a bed with her 6-year-old youngest son. She has two other sons, an 18-year-old, who also

¹² <https://www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19#who-is-clinically-extremely-vulnerable>

¹³ <https://news.un.org/en/story/2020/04/1062742>

has health problems, and a 14-year-old, who shares the second bedroom.

A report out this week from the Intensive Care National Audit and Research Centre (ICNARC) suggested that ethnic minority groups are already being impacted more by the novel coronavirus, and one Tower Hamlets councillor has told BuzzFeed News that the Coronavirus pandemic is drawing attention to existing inequalities.

Rabina Khan, a Liberal Democrat councillor, said she can see the “impact on the ground of high infection rates amongst the BAME community who are already struggling on the breadline, overcrowded households, poor health, [and] to bury their loved ones.”¹⁴

‘A’ wrote to us about her difficulties accessing food and medical services in this crisis, as both a disabled woman and a carer of a disabled son, and how this may put her life at risk:

Trying to access food online was impossible for [the] first few weeks till [the] government organised slots for some of us deemed ‘extremely vulnerable’, yet joining that list is so worrying due to data sharing and concern that it means I will be classed as DNR if admitted to hospital...

Nightmares, panic attacks have arisen as each day goes by, tension increasing chronic pain I already have.

...All my hospital treatments have been postponed meaning impairments getting worse, limiting me even further trying to do anything. There will be long term impact on me of delayed treatments. I live one day at a time, knowing for me things can get worse rather than better. For some will not survive, not due to virus, but due to neglect and not understanding the complexity of disabled peoples lives.’

¹⁴ From BuzzFeed https://www.buzzfeed.com/hannahalothman/coronavirus-tower-hamlets-overcrowded?sub=5445125_124585091&fbclid=IwAR39LavF2A0UtZ6q6v4dRQIt1Z-22TVJVL3-GCHJ5iHbvU-DvH5EVm99wZE#124585091

'S', a disabled woman from the BAME community, writes to Sisters of Frida about how institutional racism and attitudes towards her community affect recognition of her situation, and how COVID-19 has affected her health more generally and access to carers:

As disabled women carers especially from the BME community, we are often not recognized, especially if their conditions like mine are hidden. We are told we are too colourful, meaning [we are] lying about our condition. This is institutional racism we have to face as our loved ones also have hidden conditions that [are] not visible. Discriminatory attitudes towards us are very harmful to our dignity and self-esteem, but who cares about the feelings of disabled parents of disabled children? No one.

I can't go to hospital as I am worried of catching it (COVID-19) and I had an appointment cancelled as I have liver disease and ducts swollen could be cancerous, so a scan booked was cancelled. I have the same symptoms I had for my breast cancer on my right side. My carers couldn't [come to support me] as my husband had the virus.

S.'s concerns reflect the reports in the news that "almost 18,000 more people with cancer in England could die after the coronavirus pandemic led hospitals to suspend treatment and deterred patients from seeking NHS care, research has found."¹⁵

N., a disabled woman of Pakistani descent, told us verbally of her struggles to get medical attention for her aged parents.

Particularly concerning is also the plight of disabled people in care homes. While we do not have gender disaggregated data for care home residents, reports are out of "residents dying of any cause has almost tripled in a month, from around 2,500 per week in March to 7,300 in a single week in April - more than 2,000 of the latter were confirmed COVID-19 cases."¹⁶ Women are disproportionately affected by the

¹⁵ <https://www.theguardian.com/society/2020/apr/29/extra-18000-cancer-patients-in-england-could-die-in-next-year-study>

¹⁶ <https://www.dailymail.co.uk/news/article-8268215/COVID-19-deaths-care-homes-EXCEEDED-hospital-fatalities-statistician-claims.html>

dangers of living in a care home. In 2011, 214,000 women aged 65+ lived in care homes, almost 3/4 of the care home population aged over 65 (ONS, 2014). As many as half of Europe's COVID-19 deaths were people in long-term care facilities.¹⁷

Disabled people are also terrified that if they do catch the virus, their survival will not be prioritised when the NHS is under such unprecedented pressures that decisions will be made to ration treatments based on patients' chances of survival or 'quality of life'. 'L' told us she had these worries for her disabled son:

Not knowing whether he'd be allowed treatment or refused an ICU bed is adding to my fears.

While Kate (not her real name) said fears about rationing of treatment made her less willing to register as shielding, which prevented her from getting essential help:

And don't get me started on DNR forms and 'no ventilator for you, missy' guidelines. I've never felt so unsafe to live in the UK - words I never thought I'd say.

'A' was also concerned that registering on the list of 'vulnerable' people would lead to Do Not Resuscitate orders:

I fear admission to hospital as none will know how my impairments and health issues impact me, no one allowed to be with me at a time when I am extremely ill to communicate my needs, means I will be at even more risk.

Sue told us of her panic when she read that anti-bacterial filters used for her personal ventilator might no longer be given to people with muscular dystrophy because they were being reserved for COVID-19 patients by the NHS.¹⁸

¹⁷ <https://www.businessinsider.com/half-europes-covid-19-deaths-in-long-term-care-facilities-2020-4?utmSource=twitter&utmContent=referral&utmTerm=topbar&referrer=twitter&r=US&IR=T>

¹⁸ <https://www.disabilitynewsservice.com/nhs-trust-tells-people-with-muscular-dystrophy-were-keeping-your-ventilator-filters-for-patients-with-coronavirus/>

Fleur Perry says that NHS England's current guidance on visitors during the coronavirus crisis puts her at risk of serious harm, discriminates against her, and breaches her human rights, including her right to life.

The guidance only allows a visitor to accompany a patient into hospital in four situations: if they are in labour; if they are receiving end-of-life care; if they are visiting their child; or if they are experiencing significant mental distress.

Perry said:

I've been in situations where NHS staff were unaware how to safely meet my health needs; but there's always been someone there with me to make sure I'm not dropped on the floor, I'm not injured, I'm not forgotten, and I'm not overdosed on routine medication.

Most NHS staff are not trained in how to use my equipment or how to safely move me.

In an emergency situation, I would not be able to train every nurse I met on how to do my care, and it's not fair to be asking nurses to do a job they're not trained to do safely.

I would not be safe.

She believes the current guidance is a breach of both the Equality Act and the Human Rights Act.¹⁹

The effects of the lockdown on mental health, especially for those with pre-existing mental health problems, also highlights issues with a lack of service provision for disabled women. The organisation WISH (A voice for women's mental health) shared with us some of the concerns that women have expressed about the effects of lockdown on their mental health:

"This reminds me of being locked up in hospital or prison and has heightened my anxiety."

¹⁹ <https://www.disabilitynewsservice.com/coronavirus-nhs-faces-legal-action-over-unsafe-and-discriminatory-visitor-policy/>

“I am now terrified every time someone rings my doorbell but I am unable to go out and shop myself.”

“I am having flashbacks from the past.”

“The voices have come back even though I know I am safe at the moment.” - comment from a prisoner

“I am not eating vegetables because I hear you can catch the virus from them.”

“It is really difficult managing my OCD with all this handwashing I have to do.”

Access to information in accessible formats is essential during this crisis. In a survey by Glasgow Disability Alliance, only 37% of disabled people surveyed had access to home broadband. 23/3% of disabled people have no access to the internet at all.²⁰ This digital divide is likely preventing many disabled women from accessing emergency and alternative services and volunteer networks.²¹

Actions

1. Publish the critical care guidance being used by the NHS to decide who to treat and how to apply Do Not Resuscitate Orders, so that disabled people can be reassured that their right to life under Article 2 of the Human Rights Act will be protected, should they become critically ill.
2. Ensure support is given to BAME communities for access to medical care and services.
3. Ensure supplies of PPE to care home staff, test patients before discharging from hospital to care home. Ensure testing is available to staff and people living in care homes with fair access to treatment and that blanket DNRs are not used.

20

<https://www.ons.gov.uk/peoplepopulationandcommunity/householdcharacteristics/homeinternetandsocialmediausage/articles/exploringtheuksdigitaldivide/2019-03-04#what-is-the-pattern-of-internet-usage-among-disabled-people>

²¹ <http://gda.scot/our-community/news/2020/4/28/covid-19-supercharges-existing-inequalities-faced-by-glasgows-150-000-disabled-people>

4. Ensure that personal assistants or family carers are allowed to accompany a disabled person with other physical or communication support needs at any time they are in hospital

5. Ensure information is available in accessible formats, Easy read, Large print, and in BSL and in the different ethnic languages. Ensure all essential public broadcasts are simultaneously translated into BSL. Ensure people are aware of the alternative services, volunteer programmes, and how to access them including for those not able to access the internet.

Voices of Disabled Mothers

'C', a new disabled mother, tells us how cuts to services due to COVID-19 have impacted access to health support for her and her baby:

The impact of COVID-19 has been so difficult. My new baby was a lovely surprise after thinking I was unable to have a baby due to medical reasons. I was so excited. The birth ended up being traumatic for both of us and due to the pending lockdown I felt as though we were being rushed out of hospital. To be fair it was the last place I wanted to be seeing the nurses doing drills etc. So we arrived home. Services are cut for us. I feel very alone. I am scared he will get sick because I don't believe that we will get proper help. The fact my family haven't met the long awaited baby breaks my heart. The impact has been devastating. I'm just keeping on going and doing my best. I'll give my baby all I can and just keep hoping it will all be over sooner rather than later.

Epilepsy nurse just gave me a quick call to say congrats. She says they normally have an appointment but someone will be in touch after the whole Corona thing. I'm not being monitored at all. I'm not getting my postnatal check up and although his vaccinations are planned to go ahead they said that could change. He isn't registered as being born either.

'L', a disabled mother of a disabled son, tells us about her difficulties finding care for him during the crisis:

My son's 2 main, and preferred, care workers are both unable to get to the UK to work as they are Polish and the country is locked down at the moment. This is very difficult and we have just had to refuse to have someone else to come and work with him as that person is sharing a house with 7 other people (not family members) and lives in Sheffield which has the highest rate of Coronavirus cases outside of London.

I am finding this very stressful as although my son is able to make his own decisions, I know he takes my views into account and if I make a wrong decision he could die as a result. Not knowing whether he'd be allowed treatment or refused an ICU bed is adding to my fears.

As a disabled mother I am also worried that I might not be able to care for him myself even if there was no other alternative.

'A' wrote to us about her difficulties and the stress in this crisis, as both a disabled woman and a carer of a disabled son,

I am a disabled woman who manages my household responsibilities, finances, etc and mum of an adult son with mental health issues who lives with me. I have four adult kids, all who have needed support during this difficult time due to anxiety they have for their families and me.

I am the matriarch of the family, the one to lean on when times are tough.

I have been so emotionally and physically stressed since start of lockdown due to COVID-19.

Fiona Anderson of Enabled2Parent told us that Social Services are not prioritising disabled parents for support, even though parenting has become more difficult due to school closures:

Many disabled parents rely on their child being at school or nursery immensely to allow them to recharge. Not having a rest causes their symptoms of their condition to worsen, frequent falls and feeling like they're failing their child through increased pain and fatigue making them unable to do quality time activities and adequate home schooling. There's more pressure on their partner to assist where PAs aren't turning up but I'm hearing many partners are key workers!

I think disabled parents need to be seen as needing to send their child to the school setting key workers children are being accommodated in as a health need for the parent and if there's no transport, a volunteer allocated to the family for assisting with their children, collecting medication and shopping. Lots of disabled aren't deemed vulnerable enough for govt support like I (finally) am so don't get food parcels and links where they can access support. Social care aren't seeing disabled parents as a priority right now.

Gemma Nash from [Changing the Future of Women in Greater Manchester](#) reminded us that for “disabled children who have a support worker and/or services to help manage violent behavior, Covid-19 is having a massive negative impact upon them and their families. Rules have been relaxed, to some extent, for people with autism etc. But many parents, especially mothers, are struggling to cope with violent outbursts.”

‘B’, an advocate for disabled people at a DPPO, gave us an idea of two of her clients’ problems:

“I am supporting two female clients who have learning difficulties, both of these clients’ children are subject to care proceedings. Their children are currently not living with them. Before the lock down, they were still having contact in a contact centre supervised. Since the lock down, they have not been allowed to have contact due to contact centres being closed.

Advocacy is particularly important for both of these clients. As their advocate, I am able to explain to them as many times that is necessary that this is not their fault or because the social worker is trying to punish them or deliberately take their children away but because the situation currently affects everyone.

One of them told the social worker she would complain to her manager because she was not allowed to see her children. The social worker did not understand why she became so distressed as she had explained the situation many times to her before. Then the client realised that she was not able to put something in writing to the manager due to having difficulties reading and writing so she asked me to help. I explained to her in a way she could understand that this was nothing to do with the social worker but due to the lock down, contact centres were closed. The two mothers I am supporting feel completely side-lined, they do not know what is happening with their children. I am having to tell the social workers that they need to inform them of what is going on with their children like, are they visiting their children etc. In both cases, the current carers of the children are key workers so the children are in school but they cannot see their mothers.

Actions

1. Ensure that disabled parents are prioritised for social care support. Require local councils to assess those disabled parents facing increased need for support as a result of school closures and other effects of lockdown.
2. Ensure that disabled parents receive safe postnatal care despite lockdown conditions.

On access to Support/Paid and Unpaid Care/Independent living

This is an urgent question raised by many disabled people:

Q. I employ personal assistants (PAs) through direct payments. If a PA or the whole team needed to be isolated, how would my care needs be met? And if I contracted COVID-19, could my PAs still assist me? This is a worry for a lot of people.²²

For the estimated 70,000 disabled people who use personal assistants²³, PAs need to be trained for personal care and have a good working knowledge of the work and the individual's care needs. During COVID-19 measures, this poses complications for disabled carers as well as the disabled individuals who need the support for independent living. Disabled people may be left without vital care services if their carers/PAs fall ill or have to self-isolate.

Severe PPE shortages are being reported by users of PA/care services. While virus testing is now being rolled out in care homes, it is not being offered to users of care/PA services who live in their own homes,²⁴ and guidance is limited on how to avoid catching the virus from carers who work with multiple clients.

Fiona Anderson of Enabled2Parent told us that she is having trouble finding enough PA support during the pandemic:

The biggest issue is PAs. Just like disabled people who aren't also parents, PAs are dropping off rotas like flies. Either having to self isolate due to symptoms or a member of their household having symptoms/vulnerable person. Some not turning up due to fear and Mums on DP like myself are having to buy PPE off Amazon with little guidance. PAs not feeling safe with the quality of PPE that we ARE able to obtain e.g plain surgical masks instead of proper filtered ones.

²² From SCIE website <https://www.scie.org.uk/care-providers/coronavirus-covid-19/social-care-questions-and-answers>

²³ Skills for Care estimates that, by 2016, around 70,000 of the 235,000 adults and older people receiving a direct payment directly employed their own staff (creating 145,000 PA jobs between them). <https://www.skillsforcare.org.uk/Documents/NMDS-SC-and-intelligence/NMDS-SC/Analysis-pages/State-of-17/State-of-the-adult-social-care-sector-and-workforce-2017.pdf>

²⁴ <https://www.disabilitynewsservice.com/coronavirus-testing-questions-as-ministers-attention-finally-turns-to-care-homes/>

'A' wrote to us about her difficulties finding enough PAs to support her and her disabled son during the crisis, and how a lack of support has impacted her access to food:

One of my PAs left due to fear of infection, reducing my care by half. The other PA's hours [were] reduced to limit risk of infection to her and me.

The government has ensured access to food items but not considered how people like me would be able to open, cook or use the food. Trying to access ready cooked meals is more often than not impossible due to high demand. Social services not providing either.

Kate (not her real name) told us she is worried that self-isolating with her mother could affect her access to direct payments to pay for her care:

I'm struck by how little trust I have in services and the Government when it's needed most. To avoid being cared for by my PAs (all women with second jobs or caring for large families) I moved to live with my older parents. I know how lucky I am to have that choice and I'm constantly worried how tired my Mum is. I'm scared about being honest with Social Services about where I am in case they make me stop me paying my PAs - for some, they'd be destitute if that happened. I didn't register on the Government website for vulnerability for weeks in case it revealed where I was living. And don't get me started on DNR forms and 'no ventilator for you, missy' guidelines. I've never felt so unsafe to live in the UK - words I never thought I'd say.

One thing that's been very hard is my partner was ill as well and so we had to give complete strangers our personal details and access to knowledge of our medical conditions in order to get our prescriptions picked up. It all ended up being fine and they didn't look or open the prescription bags, but the whole experience was quite invasive to me. I don't have a PA or anything and so it was relying on complete strangers.

It also made me acutely aware of how much my safety is currently based around being in a healthy relationship. I'm lucky in that I don't have anything to worry about (hopefully, for the first time in my life) but also because my partner knows my history and is completely happy with me taking any steps, I need to make myself feel safe.

'E' told us how her informal, unpaid care support has been reduced by, and the effect of this on her health:

I am a PhD student with moderately severe CFS/ME. My impairment entails that I have significantly reduced mobility, require a powerchair for daily use and am partially housebound. Although I do not currently receive social care, I have previously been assessed as borderline eligible for social care and have consequently come to rely on informal support from friends, family and loved ones with daily tasks such as shopping and cleaning to enable me to function relatively independently. Given that I live alone, the lockdown has effectively entailed that I have been deprived of the informal support I generally receive, which has meant that my living conditions as well as physical and mental health have deteriorated. I sought an interruption of my studies due to my deteriorating mental and physical health.

People in BAME communities might be more reliant on community and family support, especially with disabled family members.²⁵

Actions

1. Urgent action: PPE must be made available to all disabled people who have PAs/carers working in their homes.
2. COVID-19 testing should be made available to all carers/PAs of disabled people, so that they are not at increased risk of catching the virus from carers who work for multiple clients.

²⁵ <https://www.childrenssociety.org.uk/sites/default/files/young-carers-of-bame-families.pdf>

3. Comprehensive guidance should be released advising people on how to prevent the spread of COVID-19 while using care/PA services, whether the care is funded by direct payments or provided by volunteers such as family members, including those from BAME communities.

COVID-19 and the Rights of Disabled People/Women

The Coronavirus Act raises many concerns in regards to the rights of disabled people as a whole, and this includes disabled women. At least 10 disabled MPs and peers have signed a letter calling on the prime minister to ensure that the government improves its support for disabled people in its response to the coronavirus pandemic, saying that disabled people's rights are at risk, including the right to healthcare, the right to social care and support, and the right to information.²⁶

Dr. Sarabajaya Kumar writes that COVID-19 measures are impacting disabled people's rights:

Last year I became a Women's Equality Party candidate for the now-postponed London Assembly elections because I want to advance equality for everyone. But as I stay indoors, shielding, trying to deliver my UCL teaching from home, while also navigating my own daily health needs without the carer I usually depend on, I am becoming increasingly concerned that disabled people's hard-won rights are going backwards.²⁷

[T]here is research which finds that women, and people from BAME backgrounds, are often not listened to, understood, believed, or are dismissed when they present with symptoms which results in differential and inequitable health outcomes for us; and being of intersectional identity - a disabled, woman of colour - means that there is recognition that I experience

²⁶ <https://www.disabilitynewsservice.com/coronavirus-mps-and-peers-ask-pm-for-a-disability-inclusive-response-to-pandemic/?fbclid=IwAR3xMcwQbIf3xloqdUuush2U0mLm64S14-RuWK1MN3LnAHvtgIhufTbU0ek>

²⁷ <https://bit.ly/39HWT7T>

oppression/discrimination compared to that of a non disabled, white person. I'm not sure how much discrimination a white man may face - maybe class, sexuality?

That said, in the time of COVID-19, and identified as being in the 'extremely high risk' category of people, who should not only be shielding for the next eight weeks (at least), but also self isolating from family members, eating and sleeping and being alone, or at the very least 6 metres apart, not being in the kitchen at the same time etc etc., I have felt that much of the independence I had previously had (pre-COVID-19), has been much reduced. I have lost my carer due to lack of PPE and my concerns about her being a vector for the disease; and this has meant that my daily living is very strenuous and difficult.

We all feel uncomfortable with the lack of certainty - disabled and non-disabled alike - but as a disabled woman I have felt Covid-19, has meant I have also lost what little control/agency I had, because of the strict, albeit necessary, requirements of ensuring I and my family and the NHS are safe. In other words, my dependence on others seems to have increased; and that has put strain on me and other family members.

Eleanor writes of her worries of the rise in hate crime against East Asians as a result of COVID-19 lockdown:

As a disabled East Asian woman, I am worried about the rise of hate crime against East Asians here in the UK. I've had disability hate crime before and now I am also worrying about race hate.²⁸

Particularly concerning, are the measures which weaken the safeguarding against abuse within mental health settings. For instance, time limits have been extended on psychiatric detention, so that now it only requires one doctor to authorise someone's sectioning, and no

28

<https://www.independent.co.uk/news/uk/home-news/coronavirus-uk-hate-crimes-chinese-people-china-a9499991.html>

second medical opinion is necessary before forcing psychiatric medicine upon someone against their will. These measures will disproportionately affect members of the BAME community, who are already over-represented in detention, stay in psychiatric hospitals for longer, and are eight times more likely to be subjected to forced outpatient treatment, according to a 2019 independent review.

“These are unprecedented times, but weakening the safeguards in an already coercive Mental Health Act, and extending its powers, is a grave step and risks the rights of people with disabilities,” said Akiko Hart, CEO of NSUN. “Given the serious implications of the Coronavirus Act for some of the people it seeks to protect, it’s vital that the government ensure that the new law doesn’t undermine rights and do lasting harm.”²⁹

The Coronavirus Act also essentially, for up to two years, suspends the 2014 Care Act duties of local authorities in England to provide social care services to all who are eligible, leaving disabled adults at risk of neglect in their homes. It will also mean a relaxation of the standards of educational support for disabled children³⁰ which will disproportionately affect women as they are more likely to be primary carers.³¹

Given that the social care system has been undermined by the ten years of austerity and the demise of the Independent Living Fund, this Act is very worrying for disabled people seeing it as rolling back disability rights and putting many lives at risk.³²

“Support for thousands of people with disabilities and older people does not need to be sacrificed to fight the current COVID-19 crisis,” said Shantha Rau Barriga, director of Disability Rights at Human Rights Watch. “These are the groups among the most at risk in this pandemic; they should not also be at risk because of the response.”³³

²⁹ <https://www.hrw.org/news/2020/03/26/uk-covid-19-law-puts-rights-people-disabilities-risk>

³⁰ <https://www.theguardian.com/society/2020/apr/15/pandemic-isolates-families-disabled-children>

³¹ <https://www.theguardian.com/society/2019/mar/15/older-female-workers-twice-as-likely-to-be-informal-carers-ons-report>

³² <https://www.theguardian.com/society/2020/mar/23/uks-emergency-coronavirus-bill-will-put-vulnerable-at-risk>

³³ <https://www.hrw.org/news/2020/03/26/uk-covid-19-law-puts-rights-people-disabilities-risk>

We have received comments from a number of disabled people whose rights have been particularly affected by lockdown. Kirsten H. is incensed by the ableism inherent in all of the COVID-19 emergency action:

I'm beginning to feel that in order to survive I am forced by other people's failure to make reasonable adjustments and act to include disabled people, to have special services. I can't join in the mainstream. I should [...] off to my segregated services, and not inconvenience non-disabled people. That's making me feel even more isolated. This is the ableism of emergency action. No adjustments can be made, because it's an emergency. How does that leave disabled people? Lonely, isolated, left out, excluded.

E. reflected on how lockdown has reduced the rights of people with invisible impairments, and how this has gone unacknowledged in public discussions of COVID-19:

During the lockdown, there has been some acknowledgement at state level that prolonged periods of social isolation may have a negative impact on the mental health of the general public. Yet, the negative repercussions of social isolation and exclusion on disabled people (which is often a consequence of structural and social barriers as much as impairment) is seldom acknowledged in public discourse. This is perhaps particularly the case for people with ME/CFS and other invisible illnesses who often face public scrutiny regarding their impairments and frequently have their experiences of distress minimised or delegitimised altogether. Witnessing the social response to the enforced lockdown and non disabled people openly share their distress about their curtailed life experiences has underscored the extent to which the social expectation for disabled people to be uncomplaining about experiences of social exclusion and isolation is disciplinary.

Actions

1. Require any councils enacting Care Act easements to release a document showing how they are continuing to deliver their duty of care to Disabled people in light of the easement and how they made the decision to take that option and when they will review that decision.
2. The government should review the suspension of Care Act duties no less than every three months, reviewing its impact for disabled people who receive care funded by social services. This should also assess how the suspension is impacting those who have multiple protected characteristics, such as Disabled BAME women.

Disabled Women and Domestic Violence/Abuse

It is likely that disabled women in particular are between three and four times more likely to experience domestic abuse than non-disabled women, and are more likely to experience multiple forms of abuse in their lifetime.³⁴ There has been a dramatic increase in calls to domestic violence helplines and support services during the coronavirus crisis.³⁵ And as End Violence Against Women has noted, the crisis, particularly the lockdown, provides a frighteningly ‘conducive context’ for abuse. Isolation means that abuse can occur without detection much more easily with connections to friends, neighbours, family, colleagues and other services (for instance school teachers who may be able to spot signs of child abuse) severed. It also means that many will find it much harder to flee dangerous situations, or to find the refuges and services they need to make that decision. This will affect most those who have already struggled to access support and justice, including disabled women, BAME women, migrant women, those with ‘no recourse to public funds’, women with ‘complex needs’ and sex workers. As EVAW argues, these women will “have an even stronger sense that they are not

³⁴ <http://www.sisofrida.org/resources/stay-safe-east-da-bill-briefing-and-amendments-disabled-survivors/>

³⁵ <https://www.theguardian.com/society/2020/apr/12/domestic-violence-surges-seven-hundred-per-cent-uk-coronavirus>

the priority and that their abusers can control them without interruption, unless there is proactive work to counter this".³⁶

StaySafe East, a user-led London-based organisation which supports Deaf and Disabled survivors of domestic and sexual violence, have been working on amendments to the Domestic Abuse Bill. SOF, along with other organisations have been on their advisory board. They have been exchanging some stories of their clients and the extra problems caused by COVID-19 restrictions. Women with learning difficulties no longer have the one to one access to their advocates as before and might not be able to communicate, deaf women are having communication issues, not just because of BSL access but also because of the social distancing and communication to be handled by phone. Advocates working from home are not able to be effective in advocating for their disabled clients.

Here is an example of a case study given by StaySafe East as evidence:

A safeguarding meeting was held in relation to a disabled woman experiencing domestic abuse; on arrival at the meeting, she and her advocate found that the perpetrator had been invited. He was asked in front of the victim whether he was abusing her; he denied it. Exasperated by his lies, she spoke out, and in spite of efforts by her advocate, the social worker asked the disabled woman specific questions about the abuse and advised her to find a refuge space. The advocate eventually managed to stop the meeting so that she could support the disabled woman to be safe (a refuge was not an option due to her support needs). Had the advocate not been present, the disabled woman would have returned to her home and faced further abuse.

Tracy asked for advice in her struggle with her husband in a divorce:

I've spent days searching the net, an acrimonious divorce [and] house now on the market, he's angry that I've had to suspend viewings for 12 weeks, if the distancing continues after this he will

³⁶ <https://www.endviolenceagainstwomen.org.uk/wp-content/uploads/EVAW-Coalition-Briefing-on-COVID19-Pandemic-and-Duty-to-Prevent-VAWG-April-2020-FINAL.pdf>

be chomping at the bit for court. I want out of this house and was hoping to be moved by September, but with my lungs I'm at risk. I'm trying to find out if he can force me into a court or to move house if social distancing continues?

Actions

1. Alert women's frontline VAWG organisations and refuges to the needs of disabled women in danger of Domestic Abuse as to the communication and access needs of disabled women, more than reasonable adjustments.
2. Ask LAs to be more flexible about care packages for disabled women trapped in social isolation and in danger from Domestic abuse.
3. Support Staysafe East's amendments to the Domestic Abuse Bill.

Disabled Women in Prisons/Detention

Epidemiologists have estimated that up to 1% of people in prison could die if the coronavirus spreads across the estate, resulting in 800 deaths.³⁷ Many prisoners already have other pre-existing and severe health conditions making them especially vulnerable to COVID-19. Chantal Edge, from the UCL's Epidemiology department, has said that "A lot of people in prison are from deprived backgrounds, and have a history of drug use" arguing that the death rate within prisons may well be significantly higher than among the general population.³⁸ As disabled people are overrepresented in the prison system this will mean they will be disproportionately represented (see below). A study of newly sentenced prisoners (Ministry of Justice, 2012) showed that a greater

³⁷ <https://www.theguardian.com/uk-news/2020/mar/21/prisons-could-see-800-deaths-from-coronavirus-without-protective-measures>

³⁸ <https://www.theguardian.com/uk-news/2020/mar/21/prisons-could-see-800-deaths-from-coronavirus-without-protective-measures>

proportion of female prisoners (55%) were considered disabled than male prisoners (34%).³⁹

Around 2% of the general population has a learning disability compared to around 7% of people in contact with the criminal justice system (NHS England 2016); women prisoners are slightly more likely than male prisoners to have a learning disability (Mottram 2007).⁴⁰

The Prison Reform Trust describes high rates of mental health problems among women prisoners, and show that women in prison are more likely to self-harm and attempt suicide than women in the community.⁴¹

Women whose mental health is already at risk in prisons are likely to experience more impacts of COVID-19, including on their mental health.

Actions

1. Monitor police actions taken towards disabled people, people from BAME backgrounds, and other marginalised groups, under the powers of the Health Protection (Coronavirus) Regulations 2020.
2. Review the impact of COVID-19 on disabled prisoners, including women.

Disabled Women and Employment

In a letter to the Prime Minister, signed by the All Party Parliamentary Group on Disability and one hundred parliamentarians, calls are made for disabled people to be part of coronavirus strategies.⁴²

³⁹

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/278827/estimating-prevalence-disability-amongst-prisoners.pdf

⁴⁰ <http://www.prisonreformtrust.org.uk/Portals/0/Documents/Out%20of%20the%20shadows.pdf>

⁴¹ <http://www.prisonreformtrust.org.uk/Portals/0/Documents/Women/PRI-Women-in-prison-and-mental-well-being.pdf>

⁴²

<https://www.disabilityrightsuk.org/sites/default/files/word/100%20signatures%20disability%20covid.docx>

This call includes:

The Government cannot allow the disability-employment gap or the treatment of disabled people in the workplace to worsen as a result of this pandemic, and the Government must address this issue by undertaking an impact assessment of the recovery plan based upon equalities principles.”

However, Disabled people have found that they have been disadvantaged by the pandemic and the lockdown restrictions.

N. asked why is it that those who are shielding have been advised not to leave the house, and yet Access to Work still requires forms to be signed and posted? ⁴³

From Emma Vogelmann:

Under the current rules I am unable to support the charity in any capacity which I have been finding extremely difficult. I am an important figure in the disabled community and I have been effectively silenced. I cannot write blogs to support my community out of worry that this will be seen as work. I cannot share our urgent fundraising appeal or Retweet a message from our CEO. I feel these restrictions go too far when it comes to the charity sector as for many of us this is not just a job. I myself have a muscle-wasting condition and to be prevented from helping others like me has been extremely difficult.

From other Disabled women:

I've been furloughed from my job with a charity that supports disabled people. I'm heartbroken at not being able to support my community because it can be seen as work. I'd never jeopardise my employer by working but it's so hard.

⁴³ <https://sites.google.com/site/natalyadell/home/accesstowork#TOC-Covid-19-Coronavirus-information>

As an employee, it's been hard to transition to working from home and having good ergonomics that mean I won't hurt. As a wife I feel like I'm failing when I can't even go for a walk to get space without falling and getting injured. A lot of space is no longer safe for me.

It feels as though the narrative about disabled women is very one dimensional. There is no consideration that disabled women occupy multiple roles. As a disabled woman who is a key worker, student, an employer of PAs, a family member and friend; being told to remain housebound for a minimum of twelve weeks is not straight forward. The label that persists and is consistently applied to me is that of a "vulnerable" person. The multi dimensional lives we live are made invisible. The overwhelming feeling for me is that of invisibility - we are expected to survive at home with little to no additional statutory support whilst our rights are eroded. The threat to me living an independent life on the other side of this feels massive. Juggling the demands of my job and course whilst managing the additional stress that disabled people are facing during this crisis has been a real challenge.

As a self-employed Disabled woman, I have not been able to get any paid work. I'm not sure if Access to Work will penalise me for that. I've kept on my support worker because he helps me with zoom meetings but they are not often paid. I cannot furlough him because he is self-employed too. I do not want to lose a good worker. There are no instructions, I am really being stressed out.

Conclusion

There is a common thread running through all the disabled women's stories shared with us, that social isolation during this pandemic is causing psychological distress. Although DDPOs and informal groups of disabled people have been coming together to support each other, online support groups and information are not available to everybody, especially to those who do not use the internet or lack access to home broadband. Online services are not always accessible for Disabled people either.

A suggested action post COVID 19 to start now to build networks of disabled people which are inclusive which will help with giving peer support and information locally as well as online. Grassroots DDPOs need to be capacity built so that they can then work co productively with their councils and MPs to prepare for emergencies. There is much unpaid work being undertaken by disabled people/women during this pandemic in campaigning and championing disabled people's rights. There should be more planning to work out strategies and funding to prepare for future crises. A UN Disability Inclusive Policy Brief on COVID-19 states that Disabled people "have the right to participate fully and effectively in decisions that affect their lives. They are a diverse, non-homogenous population who possess unique knowledge and lived experience of disability that others do not".⁴⁴

We call on the government to seek the input of disabled people's organisations, including disabled women's organisations, in all policies that impact disabled people. Looking to a post-COVID-19 future, grassroots disabled people's organisations DDPOs need to be funded and capacity built so that they can work co-productively with their councils and MPs to prepare for emergencies.

Final Recommendations

- Co-production with disabled people and our organisations should be central to government policy-making on COVID-19, both during lockdown conditions and as we leave lockdown.
- The government should carry out Equality Impact Assessments on all its COVID-19 policies, including the Coronavirus Act 2020, the amendments to the Care Act 2014, and the Health Protection (Coronavirus) Regulations 2020.

⁴⁴ https://www.un.org/sites/un2.un.org/files/sg_policy_brief_on_persons_with_disabilities_final.pdf

We thank Magda Szarota for this insight about the need for society not to go back to the 'old normal':

As a disability and human rights activist and researcher I have been constantly monitoring briefs, reports, open letters regarding strategies on how to deal with COVID-19 that are issued by national and transnational think tanks, agencies, institutions, influential civil society organizations etc. More often than not even those documents which were meant to specifically focus on 'vulnerable' marginalized populations and were promoted as intersectional in their approach overlooked disabled women and their situation. As much as this negligence is disappointing and cruel because it might and does cost lives... it is far from being the 'new normal' caused by the pandemic. It is the old, so-called, normal ways of discriminating and disposing of disabled women. That is why I am alarmed every time I hear that "we should go back to normal asap" because this innocently sounding 'normality' from the perspective of disabled women is underpinned by systemic and daily violations of human rights. Do not resuscitate...this version of the world.

Fleur Perry says she has hope for a post-COVID-19 future for disabled people:

There have been many negative impacts from COVID-19, and I can't say I'm not scared too. Yet there have also been a few positive impacts. As the world shifts to open access to as many things as possible digitally, suddenly there's new things in my world. Travel is exhausting for me, so video calls and webinars being the norm means I can participate in more events without draining my energy so far. Museums, theatre performances and courses that are usually geographically fixed are suddenly available to us all, with reduced associated logistical and cost barriers. There's less pollution, and less social pressure to have

the energy to be somewhere and do something on a particular day at a particular time. There's a need for us all to find different routines and different ways to solve problems. We have to support each other more than ever; learn the skills we need to do different tasks because no one else can and pass them on. I can definitely say my overall health has improved since the start of lockdown. It seems strange to say that during a pandemic, but it's measurably true. I know a few others who I've seen grow so much in such a short time. We need that access to stay. We need those new support networks to stay. We need that sense of autonomy and understanding of our own and each other's needs to stay. If we can do that, the post-COVID-19 world will be better than the one we remember. Let's do it!