



WinVisible

women with visible & invisible disabilities

WinVisible's submission to MPs on the Health and Social Care Select Committee Social care: funding and workforce



Protest at Greenwich Town Hall against
higher care charges

1. ABOUT WinVisible

We are a grassroots multi-racial organisation with a UK-wide network, enabling disabled women to have a voice, providing self-help information, peer support, campaigning and other activities since 1984. We bring together UK-born, immigrant refugee and asylum-seeking women with visible and invisible disabilities; disabled mums and disabled carers; older and younger; LGBTQ+ and more (www.winvisible.org).

In an inaccessible and prejudiced world, being disabled is hard work, which is barely acknowledged. Many of us look after children, partners, family, friends -- while coping with our own disability or ill-health. We campaign against cuts to benefits and services and other discrimination, for benefit and healthcare rights regardless of immigration status.

We have always promoted high-quality independent living -- and opposed care charges, rationing and privatisation. We supported Hammersmith and Fulham Coalition Against Cuts ([HAFCAC](#)) in their eight-year campaign which won abolition of homecare charges by Hammersmith & Fulham, the only council in England which does not charge.

2. SUMMARY

- **COVID-19** has been the occasion for a **cull of older and disabled people, mainly women/people of colour, especially in care homes**. Tens of thousands have died as a result of the callous and/or negligent government response ([Public Accounts Committee](#)) which promoted care homes taking people discharged from hospital untested, and allowed care workers (who have to take multiple jobs to earn enough) to go from care home to care home without testing. At the same time, relatives were prevented from visiting, thus isolating older and

disabled people in institutions, walled away from scrutiny and protection by their loved ones. We support Dr Cathy Gardner's [legal challenge](#) on avoidable deaths. Care staff, NHS workers and other low-waged key workers of colour have also died disproportionately.



- Instead of prioritising social care as a key service alongside the NHS, the **Coronavirus Act suspended Care Act duties**, abandoning disabled people. Government decisions ([delayed](#) response to COVID-19; NHS deprioritising of disabled people, cancer patients) still threaten our lives. Disability benefit claims have plummeted while DWP staff were [transferred](#) off disability benefits onto Universal Credit.



A woman stuck in bed with no homecare visits posted this photo on Twitter.

- **A valued and well-paid workforce** is central to high-quality support across different situations. COVID-19 has made people suddenly recognise the value of care work, both at home and in institutions, and of other essential jobs previously considered menial. But for all the clapping for carers, higher pay is not on the table. This is outrageous and must be reversed. Continued low pay reflects that older and disabled people don't matter.
- Before COVID-19, **the lack of support services, cuts in hours and care charges** for decades already had a terrible impact. Meanwhile social services spend huge sums taking children away, including from disabled mothers who are entitled to, but denied, Care Act support for [caring responsibilities for children](#). This has caused huge trauma among children and mothers in the most targeted low-income communities.
- **We oppose the integration of health and social care into one huge monolith** which will make institutional life-and-death decisions over our heads.
- **We want flexible quality support of our choice**, not institutional "care".
- **Support services should be free** like the NHS, funded from taxation of wealthy companies and individuals and by transferring military spending.
- **Homecare charges from our disability benefits should be abolished.**

- **We oppose a social care tax from age 40**, “cost-sharing” once older, and **robot-care** (Japan system).
- **We oppose private insurance.** A class-biased, two-tier system.
- **The “lifetime cap” on care charges is a con.** It does not cover expensive general living costs in residential homes, only hands-on personal care.
- **People needing support are not commodities. Social care must no longer be a profit-making market** with [insecure workers](#).
- **Unwaged family carers** save the government £132 billion a year (2015) but Carer’s Allowance is a pittance at £67.25 for minimum 35 hours. We **demand a living wage** for all carers, in the family and outside. Proper payment would enable friends and family carers to **continue, go part-time or opt out**, as others would come in. This would work together with a free [National Independent Living Service](#), and principles of the [UN Convention on the Rights of Persons with Disabilities](#).
- **We oppose “professionalisation”** and institutional **“collectivised modes of care”** (Women’s Budget Group) which take away our power of decision.
- **Zero-hour contract carers also demand the real living wage.**
- We support a [Care Income for people and planet](#) to revalue care work of all kinds as a priority for people and against climate change, and remove its patronising associations.

3. WHAT IMPACT IS THE CURRENT SOCIAL CARE FUNDING SITUATION HAVING ON THE NHS AND ON PEOPLE WHO NEED SOCIAL CARE?

We are stopped from living at home.

Thousands of older and younger disabled people are placed in care homes against our wishes. Under COVID-19, CQC inspections were [suspended](#) and family visits banned, so abuse is even more hidden. Many COVID-19 [deaths](#) are unreported and people have died in place as a result of being denied treatment for other illnesses.

At home people suffered due to lack of Personal Protective Equipment (PPE) and testing of care workers; denial of supplies such as home ventilator filters diverted to COVID-19 instead; loss of homecare. Most self-isolating sick and disabled people are not on the government’s “extremely vulnerable” register to get food and medicine, some have [died](#). See our [evidence](#) on food supply to EFRA (COV0106), and to Women and Equalities on the [Unequal Impact](#) of COVID-19 (MRS0284).

Food parcels, where provided, often did not meet dietary needs.

Before COVID-19, deaths have been hastened by lack of support, living in squalid conditions, being stressed and impoverished by homecare charges, which make us ill and miserable. Women with high needs have lost care hours. Some lost 24-hour Independent Living Fund (ILF) support. The ILF was

abolished in England and the funds transferred to councils, but mostly not ringfenced. (Schemes continue in Scotland, Wales and North of Ireland.)

1.5 million older people, mostly women, are not getting homecare, or less than we need ([Age UK](#)). Generally, if you can microwave a frozen ready meal, you are judged not to need homecare. Under-assessment of needs is compounded by sexism, racism, homophobia and other prejudice. Access to services is also limited by language barriers, including for Deaf people. An Asian woman was told she should bring over a relative from India for her care. Estranged from family, those of us who are lgbtqi depend more on services, but fear being out to [support workers](#). We are [over-represented](#) in care homes.

Disabled mothers are denied Care Act entitlements for caring responsibilities for a child. Instead councils spend huge sums taking children away from loving mothers in unwarranted, discriminatory and traumatic separation. A mother with learning disabilities won this support via her advocate. She was promptly hit with increased care charges. State reliance on child carers is an indicator of parents being deprived of support and of the need to recognise the caring work which families, including children, provide and need to be financially rewarded for.

4. WHAT LEVEL OF FUNDING IS REQUIRED TO ADDRESS THIS?

For a start, the recommended £8 billion and the increase of Carer's Allowance to a living wage. Due to central

government cuts to local Councils, spending on social care is [below the 2010-11 level](#) by nearly £0.4 billion. On 14 July, Lord Forsyth, Chair of the House of Lords Economic Affairs Committee (EAC), [conveyed](#) to Jeremy Hunt MP and this Committee that needing to reach all-party consensus is an excuse. No policy change is needed to put more funding into social care -- it needs to happen immediately, he said. Their 2019 [report](#) called for £8 billion to restore social care to an acceptable level, and the introduction of free personal care. In June 2020, the EAC [protested](#) about the government's lack of response.

By contrast, [£220m](#) was immediately spent on setting up COVID-19 Nightingale Hospitals. Some were left empty. These could have been used for people denied COVID-19 treatment, and cancer patients could have had planned treatment.

5. NEW: WHAT FURTHER REFORMS ARE NEEDED TO THE SOCIAL CARE FUNDING SYSTEM IN THE LONG TERM?



Hammersmith & Fulham is the only council in England to abolish homecare charges – usually taken from our disability benefits.

Support services should be free. Daily living support should be free like the NHS, funded from taxation of wealthy individuals and companies, tackling tax avoidance, and instead of wasteful spending on HS2 and road schemes which destroy communities, the environment and wildlife, and by transferring spending on military weapons -- which kill, disable and traumatise.

The cost of replacing Trident nuclear submarines (£205 billion) is 10 times what is currently spent on social care yearly. £140.4 billion a year is spent on health but only £22.2bn on social care. Making support for daily living free would also mean fewer people needing hospital. Free does not mean low-quality – free can be quality tailored support, with choice and proper payment and conditions of people involved.

Hammersmith & Fulham Council -- a model to follow. Since April 2015, H&F abolished homecare charges and increased social care spending despite overall reduction in their government grant. The council keeping disabled people connected with services and accountably working with them, has put disabled and older people in a better position to get through the pandemic. H&F abolished use of bailiffs and has piloted universal free primary school meals, paid for by property developers written into their contract with the council.

We oppose charges from our disability benefits. The charges systems for

residential and homecare are different. Unlike charges for going into residential homes, which depend on savings, disabled people with no savings can be charged for homecare from our benefits. Homecare charges are discriminatory and cause poverty, debt, misery and worsening health. Charges disproportionately affect women, severely disabled people and people of colour, especially if we are all three. Bills start to accumulate when services start, often before the financial assessment is done on our disability costs and what we can actually afford. To be paid under threat of being taken to court for debt, followed by deductions from benefit authorised by the magistrate.

Some women have stopped services due to unaffordable homecare charges. Women with learning disabilities or visually impaired have no statutory support to deal with letters, bills. Many are forced to depend on unscrupulous, even abusive people. See our open letter to Greenwich Council against increased charges.

We supported Sue Ferguson's 2001 legal action against Liverpool City Council which resulted in excluding her husband's income from the financial assessment, helping to protect disabled women against financial dependence on partners and relationship pressures, to this day.

Testifying to this inquiry, Kevin Caulfield described how newly-disabled people face harsh assessment of their needs and income, and are made to feel 'other', a burden and expensive: "It comes at a point [where you] need support and peace and tranquillity, instead what happens is

you move further and further away from that.”

People on disability benefits with high needs get charged more, as we need more hours of support. Wages of disabled people are excluded from the financial assessment but unwaged people have most of our benefits taken into account. When benefits increase annually, so do charges. One woman’s weekly charges went up to £99.61 for music and art therapy sessions she needed to stay out of psychiatric hospital -- more than her entire benefit for care needs.

Getting proof of disability-related expenses to offset charges is stressful. Most councils require all disability-related expenses to be evidenced with receipts and weekly averages or otherwise offer flat-rate mitigation which is unfair as it is not enough. People cannot cope with fighting everything each time we are discriminated against, and continue to be charged wrongly.

The Care Act expanded charging regulations, allowing councils to take benefit for night care into account for daytime needs. But charging remains discretionary – councils do NOT have to increase charges to comply with the Care Act. We also get Council Tax bills with a ‘social care precept’ – so we are paying twice.

In 2018, more than 160,000 people had [social care debts](#) and 78,000 were under debt management by their council.



Robots are used in care homes in Japan to replace human contact. This is studied for use by the NHS and must be stopped.

We oppose a social care tax from age 40 and robot-care – Japan’s system since 2000. Low income people can’t afford more tax, and how do we know that social care taxes will be spent on us? In Japan everyone aged over 40 pays £40-£50 per month social care tax. And from age 65, people are charged at least 10% of the cost of services, which are anyway limited. Japanese people demonstrated against charges being extended to disabled people under 65. Terrifyingly, [robots](#) are used in care homes to replace human relationships, especially for people with dementia. This is being studied for the NHS, and must be stopped now.



In Japan, disabled and non-disabled people demonstrated in 2006 against extending the charging system, and won free support for most people under pension age.

We oppose private insurance – a two-tier system. We are against private insurance to pay for services: a class-biased two-tier system, whereby low-income people continue to get poor-quality

care, while those who can pay, or can buy private insurance, get better care ([Damian Green](#)).

The “lifetime cap” on care charges is a con to rip off older people.

Home-owners were promised the lifetime cap on care charges in the Care Act 2014 so they would not have to sell their house to pay residential care home fees. The cap has not been implemented. But the costs of living in a care home are mostly general: accommodation, heating, meals, laundry. These are not counted towards care costs. Prof Luke Clements [calculated](#) that it would take 3.5 years to reach the cap, by which time the person would have paid over £150,000. Even then they would continue to pay £230 a week for accommodation (and lose their disability benefit which stops after 28 days). Most people placed in residential homes don't survive long enough to benefit from the cap. In one study, only [a third](#) of care home residents survived for more than three years. And the lifetime cap does nothing to stop charges for care at home (domiciliary services).

Abuse must be tackled. All government proposals bypass the reality that abuse is embedded in the care home sector, as exposed by [Compassion in Care](#) and others. It is a scandal that people are spending their pensions and life savings to be abused and neglected. Abuse is rife in many types of institutions.

6. WHAT IS THE EXTENT OF THE CURRENT WORKFORCE SHORTAGES IN SOCIAL CARE,

HOW DO THEY NEED TO BE ADDRESSED?

A disabled woman former home help points out, as many others have done, that care work is shamefully undervalued but suddenly got more social recognition with the COVID-19 crisis. But there has been no official move to raise pay, abolish zero-hour contracts or improve conditions.

Disabled and older people's support needs are grossly underestimated. People are without company for long hours and days. People have the right to be integrated in society, not left alone in the name of independence.

Unwaged carers must be paid a living wage. Unwaged carers save the government £132 billion a year ([2015](#) figure) but Carer's Allowance is a pittance for a minimum 35 hours a week. Most family carers aren't eligible. Other carer [benefits](#) are also insufficient. Carer benefits are tied to the disabled person's benefits, threatening the household income when claims are disrupted, e.g. teens moving from DLA to PIP.

Many older and disabled people want family members, not strangers, to look after us -- or trusted close friends if we don't have family or they don't respect our wishes. Or strangers only some of the time. We are deprived of choice mainly by financial limits. Friends and family should get a living wage and support services themselves and have choice on how much they are involved. A disabled carer said: "You want someone you trust to support you, how are they going to keep being there? You need to think about that!"

Unwaged family carers are **demanding a living wage** to give us a choice of doing caring work full-time, part-time or not at all. If this work was treated as the valuable skilled job it is and paid accordingly, more people would be willing to do it instead. This would complement a **National Independent Living Service** and principles of the **UN Convention on the Rights of Persons with Disabilities** against institutionalisation.

Carers who have to stay in waged work to survive financially, are penalised as they have to take low-paid part-time work to fit in with caring responsibilities. They lose out on income for caring, pitiful as it is. **“Flexible working”** deals with being double-booked and is proposed to be expanded -- so women can get even more exhausted doing two jobs.

Many older and disabled people live alone with no-one visiting. Some get limited homecare visits. Most people providing support are unwaged. At least **600 people** a day, majority **women**, give up waged work to look after an older or disabled person. The workload and impoverishment taken on by family and friends multiplied under COVID-19 when paid carers were unable or unwilling to put their own health or the disabled person's health at risk.

We oppose the imposition of professional/institutional care. The Women's Budget Group (WBG) produces telling statistics on women's caring responsibilities, **women of colour**, and the impact of social care and benefit cuts on **disabled women**. But it favours increased institutionalising of children and older people to “free” more women to go out to

work, starting by joining the care industry. Across several reports, WBG considers women's home-based unpaid caring responsibilities for children and disabled people as bad for the economy, as this keeps women out of the labour market; and objects that care by relatives in the home is not as productive and efficient as when carried out by professionals or in institutions:

*“The provision of collectivised care services, child and elder care, not only directly creates jobs in the care industry, it also frees others to take on other jobs. This is because **collectivised modes of care provision** [our emphasis], either in nurseries or elder care homes, and even organised services provided in individual homes, are generally **more productive** than individualised care within the family. In particular, collective care provision enables a greater labour market participation of women, who in its absence are likely to be the ones caring at home.” **Investing in the Care Economy to boost employment and gender equality** (p.12)*

We are not objects to be placed wherever professionals dictate. We are continually fighting against institutions and uncaring professionals. The assumption that professionals know what's best for us is patronising and discriminatory. We want to decide what support we need and from whom. We want to be able to do some things ourselves and be supported at other times.

Waged carers. Caring is hard and skilled work whether done in the family or outside. Care workers, many women of

colour, are treated badly. In social care, 7 in 10 key workers are paid under £10/hour; a quarter are on zero-hour contracts (TUC). Care workers often get less than half the hourly rate paid to profiteer companies by councils. These companies get around the living wage by only paying visit time as short as 15 minutes – not travel time between houses. Travel is badly managed, and women are overstretched, so arrive tired. Zero-hour contract carers are demanding the real living wage and decent staffing. These would remove the tensions fuelling abuse of older and disabled people.

Many disabled people have chosen **direct payments** instead of council services, so becoming the employer. While this brings flexibility, it is **widely acknowledged** that direct payments have cut budgets and official responsibility. Disabled people are often bogged down by accounts, employer paperwork and day-to-day problems. There should be, but isn't, support. Family carers who keep an eye, co-ordinate and support the paid workers, are not recognised. Being the employer has not eliminated abuse. But bad experiences seem a price worth paying for living in our own home.

We support Stay Safe East's amendments to the Domestic Abuse Bill, including defining paid carers who abuse their position, as domestic abusers alongside family.

WinVisible supports a Care Income for people and planet, which prioritises care work for society and the natural world, against poverty, climate change and environmental devastation. This takes care work out of its patronising and

demeaning association with disability and old age. It redefines caring as the essential relationship for the kind of world we want to live in. Everyone needs and deserves respectful care at different times throughout life. It's in all our interests to ensure we can draw on and provide it.

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