

Local Government Association
Green paper for adult social care and wellbeing
The lives we want to lead

Response by WinVisible (women with visible and invisible disabilities)

Who we are

Started in 1984, WinVisible is a grassroots multi-racial self-help group of women with visible and invisible disabilities, with a UK-wide network. We bring together women who are refugee and asylum-seeking, older and younger, UK-born and from different countries. We enable disabled women who face multiple discrimination (disability, sex, race, age, motherhood, class, sexual identity...) to have a voice, and we provide self-help information, peer support, advocacy, campaigning and more, including supporting legal challenges upholding human rights.

We highlight that, in an inaccessible society, coping with disability and ill-health is hard unwaged work. Many of us look after children, partners, friends, family members in our communities, on top of coping with our own disability or ill-health. Women are faced with the terrifying insecurity of losing disability benefits under Personal Independence Payments (PIP), the Work Capability Assessment of Employment and Support Allowance (ESA) and Universal Credit (UC) – so losing entitlement to Housing Benefit, and facing eviction for rent arrears¹; or simply being cut off when not coping with the relentless benefit reassessments and forms; plus Council charges taken from disability benefits for inadequate support services; plus Council Tax and increased disability expenses.

We have always opposed charging, rationing and for-profit privatisation of statutory services. We are against the marketisation of care where people are treated as commodities. We want a return to non-profit provision of care/support of our choice for all of us who need it.

We support disabled asylum-seeking, refugee and immigrant women and secure legal representation to challenge unlawful refusal of provision by Councils, including the Freedom Pass (Lambeth, 2008) and accommodation of a vulnerable wheelchair user (case of GS vs Camden, 2016).² We remember Lillian Oluk and Lynne Matumba, an HIV+ mother and her daughter aged two, found dead of thirst and starvation in Gillingham in 2016 after Medway Council stopped their food vouchers when the Home Office refused Ms Oluk's asylum claim fleeing HIV+ status persecution in Uganda.³

We support a living wage for mothers and other carers (unwaged and waged, not only disability-related), and are part of the Support Not Separation coalition to stop children being taken into care from mothers with disabilities, denied the financial and other support they are entitled to. In 2015, we were among the organisations and individuals giving evidence to the UN Committee on the Rights of Persons with Disabilities, which concluded that UK government policies had caused a "human catastrophe" for disabled people⁴.

The LGA Green Paper approach

The LGA Green Paper spells out the underfunding of social care and resulting under-provision but does so in a sanitised way. It looks at models of how to finance care, but does not make the case for free social care or independent living support. Labour plans for a funding boost and National Care Service to be funded by revenue changes ⁵, which is supported by pensioner organisations, is not mentioned. ⁶ Inclusion London says: “Currently Local Authorities could improve health and wellbeing in local areas by ensuring that social care/personal assistance fulfils Disabled people’s rights under the Care Act 2014, the Human Rights Act 1998 and rights under Article 19 of the UN Convention on the Rights of Person with Disabilities, (UNCRPD).”

The LGA Green Paper lists various options for funding social care⁷:

- *Means-testing winter fuel payments and free TV licences for pensioners.* But after a lifetime of work, pensioners are entitled to universal benefits like this -- and much more, not less. Means-testing would deter people from applying, hit people just above the threshold, and is likely to increase preventable winter deaths, especially of women pensioners who are most at risk.
- *A Social Care Premium* paid by over-40s earning above a minimum level, similar to a social insurance model. However, the Green Paper description does not really match the social insurance model applied on the Continent, which in Germany is *Körperschaft des öffentlichen Rechts* (run by a public corporation). What is described is more like private insurance. We oppose private insurance or added taxation of people not high earners or super-rich.
- *1 per cent on Income Tax*
- *1 per cent on National Insurance Contributions*
- *1 per cent increase in Council Tax* (including for low-income residents). Bristol Mayor Marvin Rees pointed out that central government is cutting its support grant to his Council, an ongoing policy of targeting Labour Councils with low-income areas.⁸ Relying on Council Tax revenue is problematic because Councils with mainly low-income communities raise less revenue from Council Tax while at the same time having greater need. And since 2013, low-income people have had to pay Council Tax contributions, and associated court costs due to abolition of Council Tax Benefit. Hammersmith & Fulham recently announced a positive policy of not using bailiffs for debt recovery, as this increases evictions leading to emergency housing costs.
- *Charging for accommodation costs in Continuing Health Care.* Continuing Care is the equivalent of NHS free care, provided outside of hospital. This would be a massive increase in care charges discriminating against those with the very highest needs. Some Councils are already ducking their responsibility to cover “enablement” following discharge from hospital.⁹

We are concerned that this approach feeds the government agenda of individual responsibility and personal insurance, rather than collective responsibility and taxation from those who can afford it, including corporations (which benefit from lower corporation tax), though the uncollected taxes from avoidance are alluded to.¹⁰

Tax from multi-national companies and super-rich individuals¹¹, the military budget such as Trident costed at £205 billion, and other redirection of resources, could easily pay for free high-quality care and independent living for all who need it, for a living wage for mothers and other carers, accessible housing and transport, the NHS, benefits and other social provision.

The social care crisis is caused by funding cuts by central government and implementation of cuts, rationing and charges by local government, not by the absence of the right “strategy”.¹² Jeremy Corbyn recently said that local authorities are not to be the conveyor belt for austerity.¹³

Charging for statutory services

People are given the impression that only people with savings get charged for care, therefore the system must be fair. The opposite is true. Those with least, and the highest needs, get charged the most. For example, wages are excluded from the financial assessment for care “contributions”, but unwaged people (both working age and pensioners) have most of our benefits taken into account as assessable income. Charges can increase, the more hours of support we need.

Here is one example from Camden’s 2017 consultation document on increased charges, which we and others campaigned against.¹⁴

Mr and Mrs A live in extra care sheltered housing, which costs £560 per week. This is due to the fact that Mr A is in need of care at night, at unpredictable times, which his partner is unable to provide for him.			
Current financial assessment – assessed as a couple		Under the proposed change – assessed using Mr A's income	
Income	£	Income	£
Pension & Pension Credit	230.85	Retirement pension	133.96
Attendance Allowance	82.30	Attendance Allowance	82.30
Total Income	£313.15	Total income	£216.26
Less:		Less:	
Living Expense Allowances	£	Living Expense Allowances	£
Minimum income guarantee	288.57	Minimum income guarantee	144.30
Disability and housing expenses	25.00	Disability and housing expenses	25.00
Weekly contribution	NIL	Weekly contribution	£46.96

Mr A is charged £46.96 per week out of his Attendance Allowance (AA). Pensioners do not get any mobility benefit, so have to find transport costs as well as other disability costs, out of AA.

Opposing charging

WinVisible has always opposed care charges, rationing and privatisation. Services should be free, like the NHS.¹⁵ We supported Sue Ferguson's 2001 legal action against Liverpool City Council which resulted in excluding her husband's income from the assessment of her homecare charges, helping to protect disabled women against financial dependence on partners and relationship pressures, to this day.¹⁶

While the Green Paper refers to the cuts in central government funding, it does not mention political opposition, nor how pursuing an "efficiency agenda" impacts on those of us who are reliant on support services.¹⁷ Many Councils have increased charges for care, clawing back money from people rather than pressing for funding. The living wage has been cited as a reason for higher charges to older and younger disabled people. Some Councils have not ring-fenced the money from national government for recipients of the closed Independent Living Fund and slashed care packages of former ILF recipients severely.¹⁸

We were part of a community campaign against care charges increases in Camden.¹⁹ We told them care charges are leaving us short of money to live on, causing us to stop the services we need, increasing unwaged carers' overwork and disproportionately hitting families of colour (least likely to afford private care or alternatives to Council services, due to low earnings and other discrimination).

Charging also inherently discriminates according to level of need, as someone who happens to be more severely disabled, needs more and is charged more than someone who needs fewer hours, as they receive higher disability benefits which are "assessable income".

We supported Carers and Parents Enfield (CAPE) who defeated a proposal by the Council to increase charges for many severely disabled adults by taking day and night care benefits into account when only providing day services.²⁰

Impact of charging

The impact of charging has been known at least since the publication of 'Charging into Poverty' in 2008.²¹ How Councils implement care charges has a huge and often distressing impact.²² Women have contacted us who dropped out of care services or reduced their hours due to unaffordable charges. Some women are in thousands of pounds of debt and threatened with court, when the Council has not even followed the basic procedure of assessing actual disability-related expenses. Councils are allowed to start charging a presumed amount immediately, before any financial assessment. Charges create impoverishment which drives disabled women into dependence on others who can often become exploitative and abusive, leaving women reliant for "care" on violent men.

Some Councils charge more than the person's entire care benefit amount, driving their income down to a minimum, and discounting disability-related expenses which can be very substantial, instead allowing a low fixed amount which bears no relation

to reality. A Scope report found that on average disabled people face disability-related costs of £570 per month (an average of £492 a month for disabled people in work, an average of £640 a month for those not in work), 20% of disabled people have extra costs of more than £1,000 per month.²³

Their demands for proof of disability-related expenses are so bureaucratic and onerous that people cannot cope with this, so continue to be charged wrongly.

Charging is hastening deaths as we cut down on heating and food or drop out to save money. If disability benefits are needed towards rent arrears caused by the bedroom tax, we have even less money for our disability-related needs.

Free homecare – the example of Hammersmith & Fulham

Hammersmith & Fulham Coalition Against Cuts (HAFCAC)'s eight-year campaign, combined with a fresh incoming Labour Council, won free homecare in Hammersmith & Fulham from April 2015, the only Council in England which has policy not to charge for homecare.²⁴

Council Leader Stephen Cowan said:²⁵ “We recognise that independent living support is critically important for Disabled people to be able to participate as equal citizens. That’s why we guaranteed to continue our funding after the Independent Living Fund was cut by the Government. Without this funding, our residents – who are often the most excluded from everyday life – could have been left facing severe and adverse consequences. We have also abolished home care charges and invested an extra £3.4m per year into adult social care.” Cllr Cowan has also made clear that this is despite cuts in central government funding. This leading example is not mentioned in the LGA Green Paper.

Scotland

Personal care is free in Scotland to those over 65. The Green Paper mentions free personal care as an option under discussion, but without lending LGA backing.²⁶ Free personal care has been criticised, as personal care means hands-on care, it does not include housework, food shopping, day centre attendance or residential home accommodation. Scotland Against the Care Tax²⁷ costed the benefits of abolishing charging, these include more people getting support. Assessment and collection of individual charges cost an enormous amount in administration, as well as being carelessly done and causing misery.

Direct payments

Direct payments, far from being one of “world leading initiatives”²⁸ have not brought the liberation from institutional treatment promised, as implied by the jargon “choice” and “control”. There is an enormous amount of Council scrutiny, intrusion into people’s lives, and bureaucracy. People are required to set up a dedicated account for payments which is monitored; unspent money is repossessed instead of being reserved for periods of high need or emergencies; charges are deducted at source from monthly instalments, leaving people no choice but to pay from our disability

benefits or cut back on hours. Direct payments are cheaper than services, so represent a cut in spending. The “personalisation” policy has made disabled people and unwaged carers into managers, employers and accountants, we deal with paid carer arrangements 24/7 (finding a replacement when paid carers are sick) and are burdened with quarterly accounts. Many of us feel that instead of the budget freeing us to live our lives, we are as beholden to the Council as before.

Many disabled women we know on direct payments, have suffered neglect, abuse, theft, exploitation, while being the employer, or the paying customer of a private care company. This shows that in itself, being the employer does not overcome disabled people’s low status in society, does not create an equal, respectful relationship, does not solve pay, conditions and job security for paid carers or personal assistants, who may be on minimum wage or zero-hour contracts. Oversight, supervision and protection of both the disabled person and employee is absent. Council Adult Social Care staff have virtually no accountability when things go wrong.

Needs assessment

Councils use needs assessment and the goal of “independence” to minimise the time needed from a person in a support role. For example, recommending equipment, buying in services or to be reminded to take medication by a reminder on their phone, instead of a person being present. Social workers largely do not listen to women but only respond to issues in a way which meets their agenda. Sometimes people deemed difficult are dropped from care services altogether.²⁹

While people need other services for wellbeing (going to sports centres, parks...) this must not be used as a substitute or an excuse to continue underproviding and underfunding social care.³⁰

As part of cost-cutting, social workers assessing disabled women may pressure them to be “self-managing” and “self-financing” completely outside of Council provision, for example, to make their own arrangement with a care agency and pay the agency out of their disability benefits.

After the Carers (Recognition and Services) Act 1995, carers said that the assessment of their own needs was used to find out and exploit their unwaged work. (This testimony is not recorded in Council consultations of carers as Councils aim to show they are complying with the law on assessment.) Successive legislation says that carers should be supported but the overwork goes on and is relied on to make cuts that impoverish carers even further.³¹

The Care Act 2014

The promised “lifetime cap” on charges

Many charities and disability organisations backed the Care Act “lifetime cap on charges” which puts a limit on how much a person needing support services would have to pay, as preferable to the current situation.³² The cap doesn’t help people on low/modest incomes forced to pay homecare charges from our Attendance

Allowance or DLA/PIP care/daily living component. Together with Hammersmith and Fulham Campaign Against Cuts (HAFCAC), we lobbied certain organisations not to give up the principle of free care. The Dilnot Commission proposal was to cap at £35,000. The threshold was doubled by George Osborne to £72,000. This was dropped by Theresa May in 2017.³³

The Care Act 2014, always a mix of different agendas, is positively regarded by the LGA³⁴, yet it deepens the regime of charging for care, treating care needs almost like a commercial transaction, being based on a market for care where older and younger disabled people are commodified and depersonalised.³⁵ Councils have also cited compliance with the Care Act to justify taking a disabled person's 24-hour care benefit into account for charges, when only providing daytime services. By comparison, previous Department of Health guidance began by stating there is no obligation to charge and did not limit what could be accepted as disability-related expenses to offset charges. The Care Act promotes near-total privatisation of Council services and abdication of responsibilities, which is a disaster.

However, the Care Act "outcomes"³⁶, such as support for caring responsibilities for a child, have the potential to be used effectively.

Unwaged family carers

Proposals on social care or for a national independent living service often do not adequately address the situation of unwaged (usually family) carers, whose number is increasing, among pensioners over 80, for example³⁷. Many disabled people, older and younger, do not want strangers involved, at least not all the time, neither do their family members want to entrust their loved ones to strangers. But the lack of remuneration, respite or support for family carers creates the conditions for domestic abuse. The State should fund carers without taking over care, and easily could increase Carers Allowance and widen its eligibility. (For more discussion on caring as central to the whole of society, not ghettoised as a disability issue, see: *The Perspective of Caring* by Nina Lopez, Global Women's Strike.³⁸)

There are many forms of relationships, we do not want all relationships to be changed to statutory services or an employer/employee hierarchy. Together with other women, we are calling for a living wage for mothers and other carers (not specific to disability) so that both the carers, and the babies, children and adults who receive that care, are valued.³⁹

"Improving financial support for carers" is a main demand from Carers UK, alongside the priority of relieving women's overwhelming workload via funding for services.⁴⁰ One way to acknowledge the £132b saving by unwaged carers is remunerating them. It is not clear whether this valuation includes child carers who are not registered in the ways adults are. Instead of providing disabled mothers and fathers with services, children are grossly exploited.⁴¹

Carers Allowance is a pittance, many women are excluded by eligibility rules so claim Income Support as well or instead. But carers on Income Support/Universal

Credit are subject to benefit sanction for not attending work-focussed interviews and are therefore discriminated against. Their work is not counted as work, even though the government counts on it and intends to increase it.

Paid carers

The move from direct employment by local Councils to privatisation and zero-hour contracts has exploited paid carers, who are often immigrant women and women of colour, as well as resulting in neglect. Some of us were formerly home helps. When we worked as a home help or had home helps who were directly employed by the Council, the difference in quality of care was due to having status as a supported respected employee, not only full-time but also paid for unsocial hours and time off to attend the funerals of people you had cared for, with the time and breathing space to do not only what is needed but what is wished, to improve quality of life.

Disabled mothers – lack of Care Act support

Mothers with physical or learning disabilities, mental health problems, are targeted when we should be receiving extra support services to care for our children according to the Care Act 2014 outcomes. If we contact Social Services for simple help with children, such as escorting to school, we are threatened with fostering. Those of us who are pregnant have infants adopted instead of being given a chance to look after our baby. See Legal Action for Women's dossier *Suffer the Little Children and Their Mothers*.⁴²

Mothers are being denied ESA and found fit for work by reason of caring for children.⁴³ At the same time, disability is being used to take children away from their mothers. The families targeted for child removal are working class and low income; they come to the attention of the authorities because they receive or lose their benefits.⁴⁴

Pensioners demeaned and neglected

Pensioners are wrongly demeaned as a “drain on society” and for causing relatives to give up productive waged work, but living longer is not a problem, and why isn't caring counted as productive? We don't agree with the working age/pensioner split in social care. Those of us who are pensioners are entitled to everything after a lifetime of work, and also want to live full lives, just as younger disabled people do. Day centre closures (whatever their faults) mean staring at four walls all day.

Under austerity policies, the number of older and disabled people receiving homecare has plummeted. Around 1.4 million pensioners in need of support get no homecare.⁴⁵ Concurrently, the number of carers aged 85 and over in England has risen by 128% in ten years to over 87,000.⁴⁶

We believe that the preventable winter deaths, 33,464 from the beginning of December 2017 to February 2018, the highest figure for 18 years, 3,200 of which are linked directly to people experiencing fuel poverty, is connected with lack of

homecare, as thousands of pensioners and younger sick people have no one visiting who can intervene and make sure they are warm.⁴⁷

“Integrating” the NHS and social care

Support services should enable us to live independently and help prevent neglect where our health deteriorates to the point where we have to call in the NHS.

Obviously there should be homecare in place when we are ready to leave hospital; we should not be blamed and insulted as “bedblockers” for shortages in social care which we are the first victims of.⁴⁸ There should also be pleasant intermediate places, not like hospitals, to convalesce if we are not quite ready to go home, as there used to be. But disabled women worry that integration of NHS and social care will be used to increase institutionalised care and undermine staying in our own home. At the moment both social care and the NHS are like massive bureaucracies that do not respond to our needs and wishes but which impose their solutions on us according to their own criteria.

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WinVisible (women with visible and invisible disabilities)
Crossroads Women's Centre
25 Wolsey Mews
London NW5 2DX
Email: win@winvisible.org [Web](#)
Tel: 020 7482 2496

¹ https://www.runcornandwidnesworld.co.uk/news/15646247.HEART-RENDING_Mum_who_died_alone_in_the_cold_with_her_hat_and_scarf_on/

² <https://winvisibleblog.wordpress.com/2017/11/22/disabled-woman-won-housing-under-human-rights/>

³ <https://www.kentonline.co.uk/medway/news/inquest-into-deaths-of-mum-102094/>

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<https://labour.org.uk/manifesto/healthcare-for-all/>

⁶ <https://www.theguardian.com/politics/ng-interactive/2017/may/16/what-would-labours-manifesto-cost-pledges-money-guide-details>

⁷ See p. 57

⁸ <http://www.itv.com/news/westcountry/update/2016-12-15/like-a-sticking-plaster-for-a-broken-leg-brisol-mayor-reacts-to-social-care-funding-announcement/>

⁹ <https://www.bristolpost.co.uk/news/bristol-news/north-somerset-Council-renamed-care-1472158>

¹⁰ LGA Green Paper, p. 57

¹¹ <https://labour.org.uk/press/tory-austerity-hand-110-billion-corporate-giveaways-new-figures-reveal/>

¹² LGA green paper p. 8

¹³ <https://www.bbc.co.uk/programmes/p06lycc1>

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¹⁷ LGA Green Paper p. 40

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- ²¹ http://www.cosla.gov.uk/sites/default/files/images/charging_into_poverty.pdf
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- ²⁴ <https://winvisibleblog.wordpress.com/2018/06/26/disabled-people-transforming-hammersmith-fulham-policy/>
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- ²⁶ LGA Green Paper, p. 54
- ²⁷ <http://www.scotlandagainstthecaretax.com/>
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- ³⁵ LGA Green Paper, p. 38
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