

Professor Shirin Rai and Associate Professor Juanita Elias
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Dear Shirin Rai and Juanita Elias,

Crisis of Care in Austerity Britain

WinVisible submission to the Political Studies Association Research Commission



Since 1984, WinVisible (women with visible and invisible disabilities), a multi-racial organisation of older and younger women, has enabled women from many backgrounds and situations to have a voice and get together to tackle the problems we face.

In an inaccessible world, all people with disabilities have to work hard just to survive, but women with disabilities work even harder. So much of the disability work we have to do, is not necessary – it shouldn't take so much effort to move around, communicate, or get things done. Many of us look after children, partners, friends, families and others in our communities, on top of coping with our own disability or ill-health. As women, we are harder hit by austerity and face sexism, racism, ageism and disability discrimination. Those of us who are mothers are frequently threatened with fostering if we contact Social Services for help, those of us who are pregnant threatened with adoption of infants.

Together with other women, we are calling for a living wage for mothers and other carers so that both the carers, and the babies, children and adults who receive that care, are valued (see [The Cost of Caring](#), Fawcett Society blog, 10 November 2015). Disabled people are often demeaned as a “drain on society” and an obstacle to carers who would otherwise go out to work. We want recognition for our own unwaged work and contribution to society – we are carers and workers too, for ourselves and other people, even when we don't have a waged job. And the jobs disabled women can get are mostly low-waged with bad conditions, so we are exhausted but no better off financially when we do them.

WinVisible has always opposed homecare charges, rationing and privatisation. We have joined with other groups of disabled and older service users such as Hammersmith & Fulham Coalition Against Cuts (HAFCAC), whose eight-year campaign won free homecare in the borough from April 2015. Many large and small organisations backed the problematic Care Act 2014 on the misleading promise that it brought in a “lifetime cap” on how much someone is made to pay towards their care (see p.6). In contrast, we and other grassroots groups opposed this acceptance of charging people in need of assistance. Charging also inherently discriminates according to level of need, as someone who happens to be more severely disabled, needs more hours and is therefore charged more than someone who needs fewer hours.

Following our participation in the “Valuing Care” seminar in May, we are submitting:

1. **Articles** and leaflets about the experiences and issues facing women pensioners and younger women reliant on care services.
2. **Six personal testimonies** from women in different situations, including a former home help who now gets homecare, others caring for family members on top of coping with their own health problems or disabilities, and an experience of going from hospital to home (community mental health team) and back again.
3. Some **facts** and comments to update the other material.

1. Articles and leaflets

- [‘Crippling’ bill for pensioner’s baths](#) (2008) – press report of meeting held by the Campaign Against Care Charges, WinVisible was part of.
- [Jennyfer Spencer vigil](#) (April 2010) – community campaign for a neglected disabled Black woman found dead in her flat.
- [Uncaring officials](#) (June 2010) – problems of homecare.
- [Defend Elaine McDonald and disability rights](#) (2011) – protest at Kensington & Chelsea Town Hall by disability groups. Elaine McDonald lost a human rights legal challenge at the Supreme Court against being forced to use incontinence pads at night when Kensington & Chelsea cut her overnight carer. Lady Hale dissented from the majority judgement, see [here](#) p.24.
- [Winning free homecare in Hammersmith & Fulham](#) (from April 2015)
- [Victory for woman told to repay £800](#) for care – problems with direct payments (2015)
- WinVisible at a Camden lobby for a [living wage for privatised residential care home staff](#) (2015)
- [Woman loses 48 hours of support](#) after abolition of Independent Living Fund (August 2015).
- [Yes to free quality care](#) – WinVisible leaflet
- [No change five years after](#) Winterbourne View. [Simone Blake](#), whose torture was featured in the Panorama exposé of Winterbourne View in 2011, has [continued to suffer](#) in institutions and been placed [far away](#) from her parents (2016).
- [Death of Gloria Foster](#) from dehydration and starvation after Home Office immigration raid shuts down care agency (2013)

2. Personal testimonies

Ms A compares home help in the 70s and now:

“During the early 1970s I worked as a home help in Derbyshire. On average the visits were for three hours, travel time payment was included. Supervisors regularly called by while I was working to check everything was OK. As a worker I felt valued, supported and knew the work I did mattered. I cleaned, cooked, shopped and occasionally helped with personal care, took people shopping, cleaned windows, etc. I had the time to get to know people, so I had a good understanding of how they were coping and the difficulties they were experiencing.

“I am now a user of homecare services and I have had many issues with the services provided by private care companies. Carers have arrived not knowing my name and have not properly introduced themselves. Some seemed to lack basic common sense, and

some said they usually 'didn't do cleaning just personal care'. One carer arrived who was experiencing her own mental health problems. "Communication has at times been difficult, because of some differences in language. I am articulate and able to express any concerns, however those who cannot for whatever reason (illness, fear of complaining, reprisals, etc.) are in an extremely vulnerable position. If the quality of care does not improve, many vulnerable people in need of support will experience even more suffering."

Ms B:

"The privatised carers we get are on zero-hour contracts and many have become callous about our welfare. Because our lives are not valued, neither is the caring work they do. (An [undercover documentary](#) about Sevacare in April 2016, showed an 87-year-old blind woman given cheese and crackers every mealtime, which was quickest, not hot balanced meals. Another pensioner with diabetes missed eating and medication at the right time due to late visits, so his health was deteriorating.) Instead of being supported to do their job well, helpful staff are punished for spending too much time, and disciplined for giving out their mobile number to their people so we can know if they are running late. Staff don't get paid for travel time, and are harassed by managers calling them on their mobile to cut visits short and be in two places at once. Generally, immigrant women and women of colour are the lowest paid by employers.

"When carers and service users are pitted against each other like this, it's no surprise that racism and other discrimination happens. With privatised homecare, the Council is not directly involved, there is bureaucracy (timesheets signed while blank and satisfaction surveys which are pointless) but no sense that anyone is watching day-to-day or cares when problems arise – it's just the two of you alone in your home. A profiteer company is not like the Council which has a responsibility to protect its staff from discrimination and a direct public sector duty of care to service users.

"Some people prefer direct payments where you employ someone of your choice, or agency staff. But there is a lot of stress and paperwork involved, including when the arrangement breaks down. Lots of women have suffered neglect, stealing, bullying. Yes, you can get employer's insurance but what about feeling crushed by bad experiences? Being the employer doesn't stop us being taken advantage of because we are basically dependent on that person and discriminated against in society."

Ms C:

"My mother and I moved to Scotland in 2008, hoping my cousins would help out with her care. They visited once and didn't want a bar of her, suggesting she was ready for a care home. She was reaching a point in the illness where she did not want to be left alone, as she could sense her decision-making skills diminishing. I was unable to leave her unsupervised as I went to a job interview and returned to find she had used the stove but had singed her clothing. I applied to Social Services and we were given four hours respite care. The rest had to be funded by our own budget.

"As mum moved into her 90s, her body began to deteriorate. Four hours was increased to six. Then Social Services tried to build a case to remove her from my care by force. She had been brought into a care home under false pretences of respite and they had no intention to release her. I fought hard to build a case to have her returned home. The day

before her release she was raped by a service user who mistook mum's friendliness for a romantic invitation.

“When mum was released back into my care, we had 12 hours respite and two day centre days. I worked and we were able to afford additional private care. Around six months before mum's death, we were suddenly charged for the 12 hours social care we were getting for free. Mum developed a bladder infection and was admitted to hospital. At this point the excuse given was austerity measures, but it turned out we should not have been charged in the first instance.* All our money was refunded.

“Sadly, mum was never returned to my care. She was moved to an NHS care unit and died there, one month short of turning 95. This decision was made almost exclusively on what was judged as my inability to cope as a disabled carer.”

**Since 2002, there has been free personal care in Scotland for pensioners over 65. This does not include shopping and housework, only hands-on care. In residential homes, it does not include accommodation costs. Disabled people under 65 are charged for personal care.*

Ms D:

“My brother lives in a supportive care home in West Hampstead with two other residents. He has severe learning disabilities and needs 24-hour care. He contributes between £455 - £569 per month from his benefit to pay for attending New Shoots day centre for three days per week plus supported living. This includes shopping and cooking. Without this supported living, my brother and the other residents could not survive. His activities are mainly based at New Shoots, which has been threatened with closure.

“Outside of these allocated days, my brother rarely leaves the house, because the support isn't catered for. This leaves him sitting in the front room of the house doing nothing. I support my brother by taking him out some evenings and shopping for clothes, but there isn't anyone else to help. Westminster Society whose staff support the house, are paid some money by Camden Council, but there are few staff and they are stretched with their work already.”

Ms E's experience with Adult Social Services in South East London:

“Early in February 2016, I approached Occupational Therapy to enquire if there was any further support available to assist me with access to my bath and general support around completing domestic tasks. I was assessed a few months prior but the intervention implemented was no longer working. I expressed the extent in which my health had been inhibiting me from completing such tasks and that things were generally in a state of decline. *I was not asked what support I needed.*

“Subsequently, I was contacted by the Adult Reablement Team who arranged an assessment with me in my home. Reablement is a six week process in which a carer is employed to ‘enable’ a person to live more independently with the view to that person not needing any more support. In some cases it is also used to ascertain what additional and/or long term support is required after six weeks.

“The assessment was conducted by an Occupational Therapist (OT). It was largely focused on my ability to carry out tasks such as making tea, transferring (bed, chair and toilet), and my ability to carry out personal care. It was recommended at assessment that additional equipment/aids should be ordered and that a carer would be arranged to assist me with personal care. I got to choose which days of the week I wanted this worker to

attend and nothing else. *At no point in the process was I asked what support I was seeking when I originally made the enquiry. Furthermore, there was a reluctance to recognise and report that my accommodation is unsuitable and disabling me.* When I expressed these sentiments, the OT unequivocally said that there were limited resources and Reablement does not have the capacity to look into my wider issues.

“I later received a copy of My Reablement Goal Plan/Review from the assessment conducted -- I had to request this. I was unhappy and disappointed with various aspects of the report. The report did not accurately mirror the reality of my circumstances and the way in which the physical features inside and outside of my dwelling are disabling, not promoting my wellbeing and inhibiting me from living a more independent life. Moreover, aspects of the report identified discrepancies between what was said on the day of the assessment, what was heard and what was subsequently reported, thus not illustrating an apt holistic overview. I was horrified. I could not believe that a professional could produce an inaccurate report, and fabricate and present a misleading impression about me. This was my first time asking for support from social services and this experience has left an unsavoury taste. Consequently, I complained about the OT and rejected aspects of the Reablement plan. I am still waiting to be reassessed by another team.

“I appreciate that the current climate has put a strain on resources, and that this has impacted and dictated care teams’ capacity to meet people’s needs. *I do not think this should be an excuse to view and assess people through a narrow lens to fit budget criteria and objectives not derived mutually with the person. To allow people to dialogue with professionals to ascertain what care they would like and how it should be implemented should be at the heart of the working practices of adult social services.*

Ms F:

[My experience of the psychiatric system](#) -- from hospital to home (under the Community Mental Health Team) and back again (click on link for statement).

3. Some facts and comments

- Tax from multi-national companies and super-rich individuals, the military budget such as [Trident costed at £205 billion](#), and other sources 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.
- Personal care is free in [Scotland](#) to those over 65. This does not include housework, shopping and day centre attendance. Under-65s are charged. Scotland Against the Care Tax has done [costings of the benefits of abolishing charging](#), including more people getting support. Assessment and collection of individual charges cost an enormous amount in administration.
- Under austerity policies, the number of older and disabled people receiving homecare has [plummeted](#). More than one million pensioners in need of support get no homecare. We believe that the 40,000 [winter death toll](#) from 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.
- With understaffing, standards of NHS care have also plummeted. A woman in our group says she was told off for helping patients other than her mother to eat and drink,

whom no one was helping. An “integrated health and social care service” could be against us or for us – it depends whether people’s welfare or cost-cutting is the priority.


- As part of cost-cutting, social workers assessing women pressure them to be “self-managing” and “self-financing”, to make their own arrangement with a care agency and pay the agency out of their disability benefits, so Social Services is hardly involved. Adult Social Care professionals and Occupational Therapists largely do not listen to women but ask set questions and only respond to issues which meet their agenda. Women should have the opportunity to give information in whatever ways suit them, instead of being under pressure to present everything during a stressful home visit.
- Despite running the “Don’t Cut Care” petition, Age UK contributed to care cuts by backing the introduction of rationing in the government’s Fair Access to Care Services policy (2003), saying this would benefit pensioners by redressing a supposed bias towards younger users. While part of the now-defunct [Coalition on Charging](#) (alongside the [Care & Support Alliance](#)), they never opposed charging outright, though charging drove thousands of pensioners out of homecare and off the books of Social Services. Age UK is compromised because it is not an independent voice, more a service contractor charging for its [services](#). It was exposed for being [involved in Eon overcharging pensioners for fuel](#).
- The Care Act promotes near-total privatisation of Council services and abdication of responsibilities, which is a disaster as we know from what has happened already. Older and disabled people were misled into lobbying for the Care Act on the basis that it introduces a “lifetime cap” on charges for care, so that older people going into residential care would not have to sell the family home to pay for it. The cap starting at £25,000 was proposed by the [Dilnot Commission](#). But once passed, the cap was immediately increased by the Conservative government to £72,000 – and then postponed because of “austerity”. In reality, only 7-15% of pensioners entering residential care would live long enough to benefit from this lifetime cap, as residential home costs include accommodation and service charges not counted as care costs (see [Privatisation and outsourcing in social care](#), p.7 para 2).
- The lifetime limit doesn’t help people on low/modest incomes forced to pay homecare charges from our Attendance Allowance, DLA/PIP care/daily living component. For us, [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.
- The government sold the majority share in Remploy to the notorious multi-national Maximus. Remploy got the contract for “Experts by Experience” tasked by the Care Quality Commission with asking residents in care homes, what their care is actually like. The fees for these important interviews [were promptly cut](#).

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