

Written evidence submitted by Disability Rights UK, Greater Manchester Coalition of Disabled People, Inclusion London (ASC0086)

INTRODUCTION

Disability Rights UK (DR UK) is a national organisation led by Disabled people. Our vision is a world where Disabled people have equal rights, opportunities, and access to power. Our work is rooted in the lived experience of Disabled people. We are a membership organisation and work closely with organisations led by Disabled people across the UK.

Greater Manchester Coalition of Disabled People (GMCDP) is a Disabled People's Organisation, which means it is controlled and run by Disabled people only. All Executive Council members and staff positions are only available to Disabled people. This is because, as an organisation, we feel it is essential for Disabled people to have our own voice and our own control of our organisation.

Inclusion London supports over 70 Deaf and Disabled Organisations working across every London borough. Through these organisations, our reach extends to over 70,000 Disabled Londoners. Our organisations strongly encourage the Inquiry to take steps to ensure it can receive evidence directly from social care users, Disabled people and Disabled People's Organisations.

What is the cost of inaction to individuals and how might people's lives change with action on adult social care reform?

The system of social care in England is utterly broken. It fails millions of Disabled people of all ages by denying us support, providing us with inadequate levels of support, and providing us with harmful and oppressive support in closed settings. Many Disabled people die before they receive social care. The current system doesn't enable us to develop, flourish, and lead full lives. Rather, it rations help, puts in place minimum levels of care and charges people with scant resources.

Failure to progress anything akin to meaningful reform means the current social care system is based on flawed principles and outdated service methods. Disabled people are treated as passive

recipients of care, not equal and valued citizens, who require support to live full lives. Just 13% of people are satisfied with the social care system, according to last year's [annual British Social Attitudes](#) survey – the lowest level of satisfaction recorded since the survey began in 1983.

The current social care system is based on flawed principles and outdated methods of service. Disabled people are treated as passive recipients of care, not equal and valued citizens who require support to live full lives. It's been nearly 30 years since the findings of the last Royal Commission on Care, which argued for "The costs of long-term care should be split between living costs, housing costs and personal care. Personal care should be available after assessment, according to need and paid for from general taxation: the rest should be subject to a co-payment according to means." We are no closer to this stepping stone on the route to the system we need.

The situation is only likely to worsen in years to come. According to a BBC investigation, the average UK council faces a £33m deficit by 2025-26, a rise of 60% from £20m two years ago. Unison, has warned that local authorities might not be able to offer Disabled people the "legal minimum of care."

The Homecare Association [reported that](#) half of the 225 homecare agencies it surveyed experienced a 25% fall in the hours of care that councils commissioned them to provide. This is despite the growing demand for care, with the latest census showing that 1.2 million people aged 10 to 24 in England and Wales now declare themselves Disabled – more than double the number a decade earlier. A third of Homecare's respondents said the decrease in commissioned hours was due to councils' squeezed budgets. This will only worsen with the County Councils Network research finding that the care costs for working-age adults could reach £17 billion by 2030.

Social care support is vital for Disabled people to get on with their day-to-day lives. No matter who we are, we all want to live safely in our local community, connected to our friends and family support networks.

Disabled People's led organisations witness every day the significant negative impact on Disabled care users' physical health and well-being. As the situation gets worse there have been substantial rises in the rates of mental distress created by trying to survive in poverty caused in large part by disproportionate and increasing Councils' social care charges. In fact, reporting by the BBC has shown that more than 60,000 Disabled adults and those with long-term illnesses in England were chased for debt by councils after failing to pay charges for their social care support at home.

Our organisations are certain that the current trajectory will lead to an escalation of health and social care needs, and therefore costs, in the medium to long term. Missing out on the support we

need leads to increased social exclusion, disempowerment and isolation, significantly limiting our ability to live independently. This is particularly acute for Disabled people with high support needs who are unable to work and supplement their income. Cutting us off means Disabled people are virtually becoming institutionalised in our own homes. The damage and pain to individuals is enormous, with many of us not being able to wash, eat, move, when needed.

As colleagues from ROFA have made clear: *“Decreasing packages of support restrict access to aspects of life that non-disabled people take for granted such as daily washing, being able to leave the house and having fresh cooked rather than microwave meals. People are now commonly left for hours at a time without access to food or drink and at risk in case of emergency. In person support is replaced with technology such as care alarms wherever possible.”*

More must be done in the short-term to stabilise this broken system. First and foremost, ministers should end care charges and introduce an amnesty on care debt, which would support thousands of us. Funding must be increased, with at least 8 billion funding for social care needing to be unlocked, and focused on prioritising community-based support.

Where in the system is the cost of inaction on adult social care reform being borne the most?

The cost of inaction is most clearly visible in the complete lack of vision from subsequent governments for how the system needs to change to actually provide the care and support Disabled people need. Care and support should enable Disabled people to live with choice and control over our lives, as Article 19 of the UNCRPD lays out clearly. Continued inaction means that social care is not about connecting us with the communities around us. Instead, it is a list of ‘care tasks’, which gives us the absolute minimum to survive.

A system that has experienced nothing but cuts and crises in the last decades means we are currently devoid of the sort of transformational vision we need, and Disabled people have a right to. It is clear that the greatest cost has been the failure to end care charges and introduce an amnesty on care debt, which would support thousands of us. The NHS and Social Care should be on equal footing – it is a scandal that so many believe social care to be free when, in fact, thousands of us are plunged into debt as a result of extortionate care charges, which are little more than a tax on our impairments. A punishment for the inaccessible world non-Disabled policymakers has built.

The failure to address the current situation means that all those who draw on the social care system are missing out on the benefits that a nationwide service underpinned by a new legal right to independent living could bring. There needs to be more action on enshrining our universal right to Independent Living as set out in the UNCRPD in a new act of parliament. The system is completely

un-equipped to tackle the multifaceted nature of the current crisis, whether it be in transport, education, employment, housing, or social security.

The system we have now is fragmented, uneconomical and structured around anything but Disabled people's well-being. The imperative at its heart is a denial of need, tied to short-term priorities to achieve budget savings. Within a climate of major funding shortfalls and rising demand, Disabled people's needs are eclipsed until crisis point. This leads to blockages in the system and increased demand for acute services, with the needs leading NHS left to pick up additional costs.

If looked at as a whole, the disability support system is economically inefficient. But more than that, Disabled people, our families and society as a whole are suffering from failing services. Poor treatment of Disabled people within service provision will not change without fundamentally reshaping the design of a system that relies on the dehumanisation of service users in order to function.

We remain concerned that as this crisis deepens more and more councils will go bankrupt, cutting our support in last-ditch attempts to preserve solvency. This has manifested in the rights-removal approach of council such as Bristol City Council: who last year tried to prop up their social care provision by moving older and disabled people who currently live at home with care and support packages above a certain cost, into residential settings. This local authority preference for residential settings demonstrated a clear ignorance of the 2014 Care Act and established a worrying trend amongst councils.

This situation has come at a clear cost—the lack of a bold new vision to fix it. We need to co-create a new system with Disabled people, led by Disabled people, and delivered by local Disabled People-led Organisations (DPOs). The DPO Forum England, of which our organisations are part, believes that this new vision should be of a National Independent Living Service (NILS).

This new system would be needs-led. Not only is this what many of the British public assume we have now and believe the welfare state should provide, but a need-led system will provide support when needs first appear, preventing crises and expensive blockages in the system and substantially reducing demand for high-cost acute provision.

It would be free at the point of delivery so the poorest and most acutely disabled are no longer pushed out of support because they cannot afford it. Costs currently spent implementing charging will be saved. The model upholds equality and human rights, enabling Disabled people to live as equal citizens.

It is based on the principles of choice and control, nothing about us without us and the right to independent living. Disabled people lead, shape, and deliver NILS at every level.

NILS will recognise and address other forms of discrimination experienced by Disabled people, including racism, ageism, sexism, homophobia, and transphobia. It would exist alongside the NHS but separate from it as the NHS follows a medical model approach for treating and curing biological pain, distress and illness. A fundamentally different approach underpinned by the social model of disability is required to support Disabled people to live equal lives and participate in society.

This change would also reform where and how social care support is delivered. Delivering it locally would provide the much-needed space for local responsiveness, which is currently dominated by cost-cutting and profiteering. Independent living support services will be commissioned and delivered locally, as for too long, local services such as Deaf and Disabled People's Organisations have been pushed out of contracts by non-user-led national services able to offer lower unit costs through economies of scale and by private companies willing to reduce costs by compromising on quality.

NILS would mark a crucial shift away from the private sector, locating service provision in the public sector via Public Commons Partnerships and excluding the private sector to stop the diversion of public money into shareholders' profits. Public money would go directly towards meeting needs through high-quality services provided by a valued workforce. NILS would create a unified, democratic service led by Disabled people and will ensure that Disabled people's voices and lived experiences shape policy and services.

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