**Fixing a broken system: a bold new vision for disability support fit for the 21st century**

**Introduction**

It is no secret that the social care system and mental health services are in crisis.

Alongside chronic under-funding, there are structural problems with the delivery of both.

These systems are the direct successor of the asylums and long stay hospitals of the nineteenth and twentieth centuries.

The founding of the welfare state did not interrupt the incarceration of Disabled people and second-class citizenship, rather leaving disability services under local authority control.

The approach to disability underpinning disability support provision continues to be at odds with human rights treaties and the social model of disability.

What we need is a bold new vision of independent living support fit for the twenty first century.

**Part 1. Presenting the Case for Change**

**The Mess at the Moment**

**Chronic underfunding and unmet need**

Services essential to the lives and well-being of Disabled people are broken, struggling with funding shortfalls set against rising demand.

The systems responsible for delivering social care and mental health services are at breaking point, unable to meet need and causing serious safety issues.

Cuts and under-funding have dashed hopes that the personalisation agenda would extend personal budgets and support to live in the community to more groups of Deaf and Disabled people.

**Government measures do not go far enough**

Recent government measures do not go far enough to address the fundamental issues at the root of failing support services.

The new Health and Social Care Levy will not raise sufficient funds to fill the social care shortfall and the majority of the money will go into health.

The draft Mental Health bill (2022) is non-compliant with the United Nations Convention on the Rights of Disabled People.

**The Case for Fundamental Change: why local authority administration has failed**

The disability support system we have now is fragmented and uneconomical.

Significant duplication occurs between Local Authorities (LAs).

Disabled people continue to experience a post-code lottery of provision.

Privatisation of social care support increases fragmentation and diverts public funds away from the purpose of directly meeting need.

Considerable bureaucratic effort and expense goes into denying support to those who need it as LAs focus all their efforts on achieving annual budget savings.

The situation has become much worse since 2010.

However, it is the design of the social care system that meant cuts could be passed directly on from LAs to Disabled people.

Whereas the NHS was established on a needs-led basis, the adult social care system was set up to be resource-led.

The Care Act 2014 re-established this.

Poor treatment of Disabled people within service provision will not change without fundamentally reshaping the design of a system that relies on dehumanisation of service users in order to function.

**Why this is urgent**

Poor quality services are seriously detrimental to the Disabled people to whom they provide support.

They cause neglect, human rights abuses and avoidable loss of life.

The intersection of disability with other equalities issues creates multiple layers of oppression.

Disability is everywhere and it is a growing issue. Rising prevalence creates growing demand for services.

Society does care about what happens to Deaf and Disabled people.

Whilst the wider public may only have a limited understand of disability, there is common consensus that there should be a social safety net that protects those most in need.

Investing in a bold new solution to the issue of disability support will pay off in the longer term by supporting Deaf and Disabled people to contribute to society, through a valued disability support workforce and through services that are effective, efficient and well-managed.

**Part 2. FOR DISCUSSION: A Bold New Vision Fit For The 21st Century**

**Introduction**

The crisis in social care has become a prominent topic in both public and political debate. There is cross party consensus that something needs to be done.

However, the majority of civil society and think tank reports, government measures and opposition party attention has focused on the question of funding for social care while leaving aside bigger issues relating to the design of the system we have now.

For this reason, Disabled people who use social care support, Deaf and Disabled People’s Organisations (DDPOs), and Deaf and Disabled people led campaign groups worked collaboratively to create a vision for a radically different support system – one designed with the reality of who Deaf and Disabled people are and a holistic picture of our lives in mind, and one capable of upholding our basic human rights.

This vision was outlined in a document “Independent Living for the Future: Our Vision for a National Independent Living Support System” launched in Parliament on 25 April 2019.

Since then, support for a National Independent Living Service (NILS) has been voted in favour of by the TUC Disabled Workers’ Conference, Unite the Union policy conference, Trades Union Congress and Labour Party conference. Introducing NILS is a Green Party manifesto commitment.

Part 2 of this paper opens discussion on the next level of detail for the NILS vision.

**Co-producing the future**

Any proposals for the future of any elements of disability support must be designed in co-production with people with lived experience of using relevant support services and DDPOs.

High levels of involvement of Deaf and Disabled people in policies and services that affect us are particularly important given widespread lack of disability awareness and misperceptions about many aspects of our lives.

**Capitalising on success**

Designing NILS will not need to start from scratch. There are a number of previous initiatives, and one current one, whose success could be built on to inform the development of a new streamlined, national, needs-led system.

**Disabled Peoples User Led Organisations (DPULO) Programme**

The Department for Health and Office for Disability Issues ran a number of programmes from 2005 – 2015 to support the development of new “DPULOs” in areas where they did not previously exist, to strengthen existing organisations run and controlled by Deaf and Disabled people and to evaluate good practice in commissioning and delivery of peer led services.

The Department for Health developed a set of “User Led Organisation (ULO) Design Criteria”.

The full design criteria list was experienced as overly onerous by many DDPOs but still provides a useful guide to the general criteria that DDPOs work to.

**Independent Living Fund**

The Independent Living Fund (ILF) was set up in 1988 to fund support for Disabled people with high support needs in the UK, enabling them to live in the community rather than move into residential care.

The ILF had very high satisfaction ratings among its service users as well as very low overheads. According to its final annual report and accounts, it had a user satisfaction score of 98%, while just 2% was spent on administration.

**Right to Control Trailblazer Pilots**

The programme was designed to enable Disabled people to pool resources from up to six funding streams.

The intended benefits were to enable Disabled people to plan the support we needed for work and home life together, heavily reduce the bureaucracy of accessing support, and improve our control over the support we use.

The Right to Control pilot programme was fully co-produced with Disabled people and our organisations.

**Social Prescribing**

Social Prescribing is an initiative introduced by NHS England.

Emerging evidence shows that Social Prescribing can lead to a range of positive health and wellbeing outcomes.

The support provided through Social Prescribing replicates the type of support formerly provided through LA commissioning to Disabled people. It is an example of the NHS stepping in to fill gaps left by LA cuts and to ease the resulting cost burden.

**A National Independent Living Support Service**

The vision in brief:

*A new universal right to independent living, enshrined in law and delivered through a new national independent living service co-created between government, people with lived experience and workers, funded through general taxation, managed by central government, led by Disabled people, and delivered locally in coproduction with Disabled people.*

A National Independent Living Service will be:

* Needs led
* Free at the point of delivery
* Funded out of general progressive taxation
* Alongside the NHS but separate from
* Managed centrally by a newly created NILS
* Co-produced with Disabled people
* Providing independent living support
* Delivered locally
* Located in the public/not for profit sector

**What it will look like**

* NILS will be a national service. The government will be accountable to Parliament for its operation.
* NILS will replace the separate funding streams we have now.
* People with relevant lived experience will be meaningfully involved at every level of NILS operation and governance.
* Local partnerships between NILS, LAs and DDPOs will work together to ensure the availability of a range of high quality, intersectionally-sensitive, sustainable and user led service provision appropriate to the needs of the local population.
* The development of NILS will be informed by and compliant with the UN CRDP, CRDP de-institutionalisation guidelines, and CRDP General Comment number 5 as well as the principles of independent living.

**QUESTIONS FOR DISCUSSION**

1. What different functions and support would local independent living services need to provide and what role would DDPOs, LAs and local third sector have in delivering these services?
2. What would the national functions of a NILS include and how would a national NILS work with local DDPOs and LAs?
3. How could we ensure a right to independent living delivers support free at the point of need?
4. How do we need tackle staff/Personal Assistant recruitment, pay and conditions?