

Campaign for a National Care, Support & Independent Living Service (NaCSILS) : An Overview

Who is involved : Keep Our NHS Public (KONP), Reclaim Our Futures Alliance of Disabled People's Organisations (ROFA), the Socialist Health Association (SHA), Act4Inclusion (was Reclaim Social Care), the National Pensioners Convention, the Women's Budget Group, Health Campaigns Together, Doctors in Unite, Greater Manchester TUC, PCS Associate and Retired Members and others.

The campaign for a NaCSILS is based upon seven demands which lay a principled foundation for a radical transformation of the current social care system.

Our Seven Demands

- 1. The Government shall have responsibility for and duty to provide a National Care, Support and Independent Living Service (NaCSILS),** adopting into English Law Articles from the United Nations Convention on the rights of disabled people that establish choice and control, dignity and respect at the heart of person-centred planning. The rights as understood within the UNCRPD transfer across to older people as well.
- 2. This will be fully funded through government investment and progressive taxation, free at the point of need and fully available to everyone living in this country.**
- 3. Publicly provided and publicly accountable**
The NaCSILS will have overall responsibility for publicly provided residential homes and service providers and, where appropriate, for the supervision of not-for-profit organisations and user- led cooperatives funded through grants allocated by the NaCSILS. A long-term strategy would place an emphasis on de-institutionalisation and community- based independent living. All provision will deliver to NaCSILS national standards.
There will be no place for profiteering and the market in social care will be brought to an end.
- 4. Mandated nationally, locally delivered**
The Government will be responsible for developing within the principles of co-production, a nationally mandated set of services that will be democratically run, designed and delivered locally. Local partnerships would be led by stakeholders who are delivering, monitoring, referring to or receiving supported services or budgets, eg. organisations representing disabled people, older people, people who use other services and care and support workers, in partnership with Local Authorities and the NHS.
- 5. Identify and address needs of informal carers, family and friends providing personal support**
The NaCSILS will ensure that there is a comprehensive level of support freeing up family members from personal and/or social support tasks so that the needs of those offering informal support, eg. family and friends, are acknowledged in ways which value each person's lifestyles, interests, and contributions.
- 6. National NaCSILS employee strategy fit for purpose**
The NaCSILS' standards for independent and supported living will be underpinned by care and support staff or personal assistants who have appropriate training, qualifications, career structure, pay and conditions to reflect the skills required to provide support services worthy of a decent society.
- 7. Support the formation of a taskforce on independent and supported living** with a meaningful influence, led by user controlled groups of people who require independent living support, from all demographic backgrounds and regions. This would also make recommendations to address wider changes in public policy.

Why we need a National Care, Support and Independent Living Service

England's Social Care system is not fit for purpose.

- People face isolation, indignity, maltreatment, neglect and barriers to inclusion and independent living which breach the UN Convention on the Rights of Disabled People
- Ten years of vicious austerity politics including 60% cuts to Local Government budgets have drastically cut services, reduced the number of people able to access any support at all, despite increasing demand, and started to reverse de-institutionalisation
- The almost wholesale privatisation of care and support services has left them unstable and fragmented. Large hedge funds have taken over an increasing share of the market. Profit comes before quality of care and there is no accountability to the public over how our money is spent
- Care and support doesn't reflect users' needs, wishes and diversity. It gives them little say in designing, planning and running services and side-lines their expertise
- Disabled and older people needing support face high charges, leaving thousands in poverty
- Staff wages, training and conditions are at rock bottom, particularly in the private sector. Vacancies have reached 112,000 and are rising rapidly as care and support workers are forced to seek a living wage elsewhere and the Government ramps up immigration restrictions.
- 8 million unpaid, overworked family carers, including children and elderly relatives, provide vital support with little or no assistance

Why a NaCSILS needs to be separate from the NHS

- We accept that people with impairments –and that includes many of us as we become older - are disabled by the barriers they face in negotiating a social world which is not inclusive (the social model of disability). Support for disabled and older people has to be about building inclusive societies, working with Housing, Transport, Town and Community Planning, Education, Employment, Leisure etc. not just, or even primarily with health.
- We are concerned that looking at disability through a medical lens shapes individual not social responses and encourages a view of people as bundles of largely physical needs eg. for food, toileting etc. which can be timed and ticked off on a task sheet.
- It also reinforces the historically pervasive notion that medical and managerial “experts” know what is best for people and should provide **for** them, rather than seeing people who use support, as well as families and local neighbourhoods, as not just experts in what is needed but also potential providers.
- On a more practical level, given the size of the NHS and the government's determination to shrink expensive hospital care, organisational integration would mean that Social Care and Support are sucked into largely unaccountable, “Integrated (Health) Care Systems” to act as handmaidens to health and vehicle to hasten hospital cuts and closures.

Why social care and support should be universal and free

- When we are ill we expect the NHS to give us the best care available. When you have impairments at a younger or older age there is no reason it should be different. If you have cancer the NHS will give you free care but if you get dementia, for example, and need substantial care and support, you will be means tested. In most areas of England you will have to pay full costs of any care provided if you have assets worth more than £23,500. If you own your home, charges can be recouped long after your death.

- Funding the NHS and Social Care and Support through progressive taxation and providing services free at the point of use is the fairest and simplest way to guarantee support for everyone who needs it, when they need it, and peace of mind for all of us.
- It is also an efficient use of resources as money will be saved by getting rid of wasteful and demeaning means testing and by investing in community based solutions rather than high cost, segregated institutions.
- Ensuring that everyone can access the support they need to participate equally in community life and paying care and support workers decent wages is an economic investment not just a cost. Disabled people and their families providing peer support and other services create net input into the economy; while 1.6 million workers in the adult care sector alone, particularly if paid decent wages, contribute a huge amount of taxes and spending power.
- Currently the UK spends just over 1% of GDP on social care and support, which is half the amount spent on defence. It is also around half the amount spent in Norway and the Netherlands and two thirds of Switzerland's spend. Clearly substantial money is needed; about £40 billion a year would bring spending up to 2% of GDP. (1) However it is not just a question of more cash to deliver a bigger and better version of what we have already; NaCSILS is about a total, bottom up rethink of what we all need to have equal access to a fulfilling life.

Why care, support and independent living should be publicly provided

- The almost wholesale privatisation of social care and support services since the 1990s has left us with a totally fragmented, unstable and highly vulnerable hotchpotch of provision. There are about 5,000 separate providers of care homes but the five largest private providers own about 20% of the total beds. Home care has around 9,000 constantly churning providers. All these private firms have no accountability to local people and can hide behind 'commercial confidentiality'. If they cannot turn a profit they just walk away.
- When Local Authorities commission private providers they are ensuring that a percentage of public money is siphoned straight into the pockets of private owners and shareholders. Many of the 26 big care home providers use complex company structures to maximise leakage and hide profit extraction going to owners, investors, and related companies, some of which are off-shore tax avoiders.
- Private providers generally pay staff less as cutting pay, offering staff inferior terms and conditions, juggling them between jobs and providing little or no training, all helps increase profit margins. It has also contributed to increasing risk during the pandemic.

Why there needs to be a national framework but local provision

- A national framework of support is essential to ensure universal and fair access to support and avoid postcode lotteries.
- However services need to be locally designed, managed and run to ensure that they are accountable to local people, that they involve partnerships with service users, relatives and local communities in all stages of visioning planning, developing and managing provision and ensure that what is provided is what people want and need. This **genuine co-production** should implement the demand of disabled people that there must be "nothing about us without us". It requires a significant shift in the mind set and practices of Local Authorities, patient work on building trust and a powerful, consistent push from organisations of disabled people, older people, relatives and campaigners in local communities.
- With co-production as the broomstick we think there needs to be fresh, 'out of the box', thinking about provision and a strong focus on de-institutionalisation and independent living, where

independence means having real choices, access and control not necessarily living on one's own.

- Although Local Authorities have a key role to play, we would like to see more scope for co-operatives and peer support services, all within the context of building more inclusive societies.

Why informal carers must be given proper recognition and support

- Most informal carers want to look after someone they love, but in doing so they should not have to damage their physical or mental health or live in poverty. Even before the pandemic, Carers UK (2) found that 2 in 5 carers were 'struggling to make ends meet' and a study by the Children's Society found that of the 800,000 children between 5-17 acting as carers, over a third were having mental health problems and 27% were missing or having problems at school. (3) As a result of the pandemic Carers UK estimated in June 2020 (4) the number of unpaid carers has risen by nearly 50%, from 9.1 million to 13.6 million, often juggling paid work alongside caring responsibilities, putting them under extra pressure.
- Without the army of informal carers the fragile Social Care system would have collapsed years ago. Little financial, emotional, or other support, such as respite assistance is provided. The support that family and friends provide, unpaid, must be valued and respected alongside paid professional support.

Why care work needs totally revaluing

- The gross undervaluing of support staff is the other side of the coin from the undervaluing of older and disabled people in society. Both flow from a value system distorted by marketisation, which measures people in terms of profitability, pits them against each other and commodifies relationships as well as things. It also reflects the undervaluing and stereotyping of what is seen as women's work. 83% of care and support workers are women and 18% of workers are from overseas. These values are at odds with the way most of us want to live as part of extended networks of family, friends, neighbours and colleagues working with, not against, each other. The pandemic has shown just how powerful and important is the undercurrent of mutual support that has been flattened but not crushed and provides us with an opening to insist on a re-evaluation of what is essential.
- The Women's Budget Group has flagged up how investment in care is not only needed to transform our broken social care system, it is an excellent way to stimulate employment, reduce the gender employment gap, counter the inevitable economic recession as the UK comes out of lockdown and generate green jobs. (5)
- We support all care and support workers and their trade unions struggling for pay justice and better conditions of service.

Why we need a task force on independent and supported living.

'Fit-for-purpose' support for independent living will need the active involvement of disabled people in the development and planning of the service. The formation of an Independent Living Taskforce with a meaningful influence, led by groups of people from all demographic backgrounds who need/use independent living support, would provide the initial steps towards the co-production of the new service. The taskforce would be charged with developing proposals for framing the independent living support service element of the national service.

1. [Fully Funded Social Care \(myftpupload.com\)](https://myftpupload.com)
2. <https://www.carersuk.org/news-and-campaigns>
3. <https://www.childrenssociety.org.uk/what-we-do/our-work/supporting-young-carers/facts-about-young-carers>
4. <https://www.carersweek.org/media-and-updates/item/493439-covid-19-pandemic-4-5-million-become-unpaid-carers-in-a-matter-of-weeks>
5. <https://wbg.org.uk/wp-content/uploads/2020/06/Care-led-recovery-final.pdf>