END SOCIAL CARE DISGRACE CAMPAIGN FOR A NATIONAL CARE SUPPORT AND INDEPENDENT LIVING SERVICE - RESPONSE TO THE FABIANS REQUEST FOR EVIDENCE ON A ROADMAP TO A NATIONAL CARE SERVICE

The National Care, Support and Independent Living Service (NaCSILS) campaign www.nacsils.co.uk is a non-party political alliance calling for radical change to social care. We brought together a wide range of groups and organisations committed to a radical transformation of Social Care based on seven core demands.

Our steering group includes representatives from Doctors in UNITE, Greater Manchester Association of Trade Union Councils, Health Campaigns Together, Keep Our NHS Public, National Pensioners Convention, Reclaim Our Futures Alliance, Socialist Health Association, Women's Budget Group, Public and Commercial Services Union Associate and Retired Members, Save Lewisham Hospital Campaign, the Green Party.

We are delighted that the Labour Party is exploring options for improving social care and support. The situation is desperate and we were glad to hear Wes Streeting saying: "I would love to see a national care service delivered exactly on the same terms as the NHS, publicly owned, publicly funded, free at the point of use …"

WHAT VALUES SHOULD INFORM ADULT SOCIAL CARE?

Independent Living

This is a key concept: that the right to independent living as outlined in Article 19 of the United Nations Convention on the Rights of Persons with Disabilities becomes reality:

"All Disabled people to have equal rights to live in the community, with choices equal to others, and be fully included and able to participate in the community, through:

- the opportunity to choose their place of residence and where and with whom they live on an equal basis with others, without being obliged to live in a particular living arrangement
- access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community
- community services and facilities, for the general population are available on an equal basis to Disabled people and are responsive to their needs." Independent Living for the Future - (rofa.org.uk)

To provide more context, the twelve pillars of Independent Living were developed by Hampshire Coalition of Disabled People building on seven action points, originally devised by the Derbyshire Coalition of Disabled People, which identified the barriers to independent living and how they can be removed

These are:

- Appropriate and accessible information
- An adequate income
- Appropriate and accessible health and social care provision
- A fully accessible transport system
- Full access to the environment
- Adequate provision of technical aids and equipment
- Availability of accessible and adapted housing
- Adequate provision of personal assistance

- Availability of inclusive education and training
- Equal opportunities for employment
- Availability of independent advocacy and self-advocacy
- Availability of peer counselling

Democracy, coproduction and accountability to those drawing on Adult Social Care

Coproduction means delivering public services in an equal and reciprocal relationship between professionals, people using services, their families and their neighbours (New Economics Foundation). Key principles include:

- Equality – everyone has assets and no one group is more important than another
- Diversity – as with equality, all groups have assets and it is important in co-produced work to include a diverse mix of people who use services as well as those who may be excluded from such services.
- Accessibility – the process must be accessible to all involved in co-produced work to ensure everyone is taking part on an equal basis.
- Reciprocity – all involved in co-produced work must get something out for what they put in.

The Labour Party has had a lot to say about these principles. Consultation Paper, *Democratic Public Ownership*, published in September 2018 [i], says:

> "An organisation, and indeed sector, should be run by the people who have the experience, skills, knowledge, and competence to do this. However, this is always a collective learning process and is done best where the considerable diverse knowledges of the workforce and citizenry are brought together to inform the decision-making process."

The Labour Party developed the policy of participation further in the report *From Paternalism to Participation: Putting civil society at the heart of national renewal*.

> "Labour wants people to have a bigger say over the public decisions and the public services that affect them, with more direct accountability to service users where possible.
>
> We will promote collaborative decision making, encouraging public service providers to involve their service users in taking decisions about how those services are run, the outcomes they are working towards, and the support they offer. This cannot be limited to consultation alone – people need the power to assert their voice when those in power refuse to listen, and civil society has an important role in acting as their advocates and champions."

Community involvement and power

Our social networks, our social capital, helps to keep all of us healthy. The key element is the ability of people to collectively take more control of their lives and their environments. This applies as much to users of social care as anyone else. We want to see social care take account of local communities, supporting them to support each other and enable individuals and groups to take more control. This requires future social care and support provision to include community development workers.

Community Development (CD) is an approach that enables local people to identify the issues that matter to them and then be supported to negotiate responses and solutions to those issues, harnessing the assets and insights of the communities themselves. It thus enables local people to help set the agenda for planning, working with the statutory sector which may in addition include education, police. This is a key approach to participatory democracy.

Community Development has been shown to improve health, help tackle health inequalities, encourage positive health behaviours and be good value for money.

Every council, in conjunction with its local NHS, perhaps through its Health and Wellbeing Board, should produce a Community Development (CD) strategy. This should deliver a CD presence in every ward. At the same time, there needs to be significant change in the governance of the Local Authority and the NHS to ensure that the system is responsive to the drive to democracy at local level.

The social model of disability

The social model of disability states that people have impairments but that the oppression, exclusion and discrimination people with impairments face is *not* an inevitable consequence of having an impairment but is caused instead by the way society is run and organised.

The Social Model of Disability holds that people with impairments are 'disabled' by the barriers operating in society that exclude and discriminate against them.

Here is a diagram of the Social Model of Disability that shows some of the thinking and assumptions of this Model.

The Social Model not only identifies society as the cause of disability but, equally importantly, it provides a way of explaining *how* society goes about disabling people with impairments. Sometimes referred to as a "barriers-approach", the Social Model provides a "route map" that identifies both the barriers that disable people with impairments and how these barriers can be removed, minimised or countered by other forms of support.

The Social Model of Disability - Inclusion London

Value for money – social care and support is an investment rather than a cost

We would expect that all provision would offer value for money.

Going further, we expect that an underlying value of the new care and support system would be that it is regarded as an investment rather than a cost. Most health-related funding has about a 1:4 return on investment. In social care and support, that includes better health for users, better jobs for workers, with concomitant tax to the Exchequer, for instance.

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. https://wbg.org.uk/wp-content/uploads/2020/06/Care-led-recovery-final.pdf

Also, the APPG on ASC has a lot to say on this issue. Inquiry — APPG on Adult Social Care (adultsocialcareappg.com)

Move from care to support

In the same way as we see a new system underpinned by the principle of Independent Living, we want to move away from the idea of social care, implying a user requires care, as a supplicant or a dependent person. NaCSILS wants one of the underlying principles to be "support" enabling people to live the lives they want to lead.

End the market in social care

There is now clear evidence that privatisation has resulted in poor care, significant overheads and rampant profiteering[ii] [iii]. Funding social care and support on the same basis as the NHS would be fairer and cheaper, overall.

We offer suggestions for how this could be done later in this document.

WHAT SHOULD ADULT SOCIAL CARE ACHIEVE?

NaCSILS has a clear seven point plan for transforming social care and support. These have been built with cross-sector support.

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. Our Seven Demands | NaCSILS

WHAT SHOULD CARE AND SUPPORT FOR ADULTS IN ENGLAND LOOK LIKE IN 10 TO 15 YEARS' TIME?

Social care and support will be free at the point of use

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. The Tory redesign is inadequate (Resources | NaCSILS final document on the page from

the IFS) and is unlikely to make a great deal of difference for most people, even if the money stays available.

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.

Social care and support will 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 [iv] [v]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.

Social care will remain independent, not merged with 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 handmaiden to health and vehicle to hasten hospital cuts and closures.

For more detail, see Resources | NaCSILS

We will have a different kind of care and support, based on the principles of Independent Living and coproduction

The system will be geared to listen to, understand and respond to the needs of those who draw on ASC and support. Standards will be mandated nationally, but services will be different in different areas, flexing to respond to different requirements.

Services will 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, steady work on building trust and a powerful, consistent push from organisations of disabled people, older people, relatives and campaigners in local communities.

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.

People will be able to stay at home if that is where they and their families want them to be

This is current LP policy. It will require the sort of care outlined above. It may be more expensive to offer creative, flexible, person-centred care designed with the user in their own home than current residential care.

All needs identified by users will be funded

This is essential if coproduction and democracy are to be key principles.

Every local authority will fund a local Disabled People's Organisation to help run adult social care and provide support for users and advocacy. This would include help with assessments, managing care and similar requirements.

Workers in the care and support service will be properly funded and supported

See NaCSILS Charter for Care and Support Workers here Resources | NaCSILS

Unison has made the following recommendations Fragmented and fragile: it's time to fix social care | Article | News | UNISON National :

➢ Training, occupational registration, concern for safeguarding, terms and conditions of work and funding are intricately connected and improvements must be made on all fronts to recognise and reward the skills and professionalism of care workers.

➢ Better learning outcomes for care workers and professionalisation of the sector cannot materialise in the absence of security of income, security of hours of work and protection of workers' wellbeing and health.

➢ The extensive skills involved in care work and support make it wholly inappropriate for care workers' wages to be pegged at or around the applicable statutory minimum wage rates. Recognition of the professionalism of care workers means wages must be put on a professional footing.

➢ Action is needed to reach agreements about minimum standards across the sector so that all workers are included. There is a need for sector-wide agreements on training and learning to be reached by negotiation between employers' and workers' representative organisations. Agreements on core terms and conditions of work should sit around this.

➢ The fragmentation of the care industry (with approximately 25,000 registered providers in over 50,000 locations) presents a difficulty for enforcing higher training and qualification standards within regulatory structures that enable considerable employer discretion.

➢ The basic skills (literacy, numeracy and I.T.) needs of the care workforce must be addressed with sensitivity and urgency in order to support training requirements set out in regulations and to overcome a big potential barrier to successful registration.

➢ Care workers need to be recognised for their skills in engaging and negotiating with unpaid carers as well as with professionals in other health and support roles.

➢ More information about the self-funded care and support market is needed.

➢ An absence of registration (and, to a large extent regulation) is characteristic of the PA sector and there is a need for more research and greater understanding of the interrelationships between the PA sector and other sectors of the care market.

➢ Body work is an under-recognised skill component of care work practices. To value care work properly there must be stronger regard and recognition of the skills and knowledge of body work. It should also be explicitly included as a requirement in regulation about training.

➢ The skills of care workers in respect of end-of-life care are often overlooked in accounts of their professionalism.

➢ Training in the promotion of personalisation in policy and care workers' knowledge, understanding and ability to put these concepts into practice.

➢ All care workers need training in health and medically related skills and knowledge about complex conditions like dementia and diabetes for hands-on care work.

➢ There is a substantial need for care workers to develop skills in conflict management, motivating others, team-working and organisation.

➢ There is very little information and research about on-the-job training, such as shadowing or observation shifts. This form of training is routinely used in the sector but is rarely mentioned in academic or policy literature.

➢ Regulation, or regulatory guidance, should ensure that time required to be set aside for training is paid time.

➢ Care workers who are shadowed should be recognised as trainers in key practices and as peer-to-peer communicators of essential knowledge.

➢ There is a marked difference in the regulation of training and workforce standards in England, and elsewhere in the UK. It seems timely to review the decision to reject registration in England on cost grounds.

➢ The initiative taken by devolved nations to introduce and advance registration would be supported and assisted if England were also to develop a registration scheme for care workers because the vast majority of the U.K. care workforce are based in England.

➢ There is evidence that regulatory initiatives for the occupational registration of care workers and workforce matters are aligned with recognition of the importance of job quality to care quality (for example on zero hours contracts in Wales, on staff wellbeing considerations in Scotland, and the density of temporary workers in Northern Ireland). However, devolved nations are not able to make legislation or regulate directly on matters of employment.

➢ Professionalisation via worker registration and prescribed training standards is most advanced in N. Ireland. Sanctions on providers for engaging workers who are not fit to work in care and for breaching staffing standards appear strongest in Northern Ireland.

➢ Sanctions on employers for failing to appropriately train, supervise or appraise care workers are inconsistent across the UK and need to be made consistent. It is hard to understand why it is a prosecutable offence in Scotland for providers to engage workers who are not fit to practice, but not so in England without proving avoidable harm or significant risk.

➢ A significant marker of professional status in Wales is that an unregistered person commits a criminal offence if they take or use the title 'social care worker'.

There will be a taskforce on Independent 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.

There will be a fully-fledged NaCSILS which is:

- Publicly funded, free at the point of use
- Publicly provided, not for profit
- Nationally mandated but designed and delivered locally
- Co- produced with service users and democratically accountable
- Underpinned by staff whose pay & conditions reflects true value and skills
- Designed to meet the needs of informal carers
- And which sets up a taskforce on independent living

Our Seven Demands | NaCSILS

HOW SHOULD IT BE RUN?

A national framework of support is essential to ensure universal and fair access to support and avoid postcode lotteries. As we have said above, standards need to be mandated nationally.

The role of Local Authorities

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.

Many disabled people feel that LAs have let them down for so long on so many occasions and have offered an oppressive approach to care, that they want LAs to have no influence at all. They, and all social care users, want more accountability, but have not necessarily found Councillors or Council staff provide an adequate mechanism for such oversight.

The evidence is that most people prefer small-scale provision and personalised care. A good example might be enhanced care homes, which allow for both care and independence, in a supportive and personalised environment. This modernised model of care delivery, small scale and personalised, could be provided by small council-owned care homes and council-owned supported living provider organisations, or if the council did not have the capacity, by alternative non-profit forms of ownership in line with the Labour Party consultation report *Alternative Models of Ownership*[vi], published in 2017. It advocates, as well as nationalisation and municipal ownership, various forms of community-owned and worker-owned non-profit social enterprises, including co-operatives.

Accountability, democracy and Local Authorities

There are a number of recommendations for how LAs could improve accountability. Many can be found in the Paper "Democracy in Social Care" here Resources | NaCSILS They are summarised here

- For Council Committees with participation by the users and providers of services
- For participation by the users and providers of services in each Scrutiny Committee
- For Citizen Forums
- For Community Development and a community development strategy.
- For inclusive digital participation in policy-making

The Voluntary Sector:

The voluntary sector and not-for-profit organisations have made a major contribution in developing innovative and specialised services that are highly valued by service users. We want to see this role continued. There is scope for this through the grant-funding powers of local government (which was the norm for many years prior to the huge expansion of the market in social care).

The move in the past two-to-three decades from grant-funding to commercial contracts for services has been hugely detrimental to the ability of voluntary sector organisations to explore new innovative approaches and develop responsive services. We want to see this role restored, with voluntary and not for profit agencies grant-funded to provide ongoing action research in partnership with service users, family carers and local authorities, leading to developments that are also used to inform mainstream services. We envisage an expanded and ongoing role for such action-research.

The fact that Councils are compelled to look at the economics of competitive tendering by different care providers, means that they often do not give proper weight to the social value that different forms of care provision offer. Thus, for example, co-operative models that offer proper pay scales, good training, innovative individualised forms of care are 'priced out' of the market".

WHAT LEVEL OF DEMAND WILL THERE BE FOR CARE AND SUPPORT IN ENGLAND OVER THE COMING YEARS?

We do not know. This is largely because there is no measurement by councils of unmet need. Whilst the law does not require it, policy in England, as in other parts of the UK, prohibits exposure of unmet need.

The first inescapable requirement must be real time information about the scale of unmet need at any point in time. That will require the wholesale transformation of the way needs are assessed, support planned and resources allocated.

An entirely new system of assessing need and allocating resources will be required. Assessments must start from the vision of what each person needs for independent living. Practitioners must identify and cost all such needs for every older and disabled person in need of care and support. Budget holders must control spending not by controlling the local eligibility threshold, but by making decisions about what they can afford. They must learn to secure the greatest degree of independent living for the greatest number of people their budgets allow. IT systems must capture information about needs met and unmet for strategic reporting.

Whatever the current restrictions in determining demand, Within 5 years, the people who need LA funded care will probably double if free and, because of Implementation of a cap of £86,000 on personal care costs, setting this as the maximum amount any individual can spend on their personal care over a lifetime.

WHAT WILL BE THE COSTS AND BENEFITS OF ADEQUATELY MEETING THIS NEED?

Costs

It is perfectly possible for the UK to fully fund social care; in fact, the failure to invest in social care creates multiple problems, which have significant social and economic costs. Most importantly the failure to fully fund social care is a failure to recognise the human rights of the people who need support, and are formal or informal users, carers, or clients etc. under the current system, and people in need who have been refused.

We need a new way of thinking about what we mean by a fully funded social care system. Instead of treating social care as some kind of necessary evil, whose costs must be controlled whatever the human price, we must develop an ecological model that seeks to find the right balance of investment in social care to ensure all of the following objectives:

- Maximise the contribution by people with long term health conditions, disabled people to community life, with full protection for independent living as appropriate.
- Support the integrity and value of family life, enabling mutual support and a good life for people who are disabled and for family members (‘carers’)
- Foster accessible and inclusive communities that can welcome and support each other and where every citizen can find role of value

- Pay Social Care staff decent wages, acknowledging their value and the value of those they support
- Rebalance social care so that a priority is given to services that support citizen and community development.
- Guarantee parity and cooperation between social care and other public services, ensure all public services are as accessible as possible to the whole community.
- Ensure Social Care is valued and understood by the whole community and there is widespread support for ensuring sustainable investment in it.

There have been a number of comprehensive reports on options for funding social care:

Social care funding: Debate on the Economic Affairs Committee report - House of Lords Library (parliament.uk)

Prof Prem Sikka: Why we must resist the Elderly Social Care (Insurance) Bill - Left Foot Forward: Leading the UK's progressive debate

https://www.bing.com/ck/a?!&&p=fed56ee9c17d8be0JmltdHM9MTY1OTc5OTcxNiZpZ3VpZD1lNTBjYjcxNC1mNzkwLTQ3OTAtYjg0NC00Mzc2NTg1ZDkyMjYmaW5zaWQ9NTE5MQ&ptn=3&hsh=3&fclid=6fea6648-159c-11ed-9b01-298f1db0bee7&u=a1aHR0cHM6Ly93d3cudHVjLm9yZy51ay9zaXRlcy9kZWZhdWx0L2ZpbGVzL1ByZW0lMjBTaWtrYSUyMEJyaWVmaW5nJTIwTm90ZSUyMCVFMiU4MCU5MyUyMEVsZGVybHklMjBTb2NpYWwlMjBDYXJlJTIwLSUyMEluc3VyYW5jZSUyMEJpbGwlMjAyMDIxLnBkZg&ntb=1 from para 51 onwards

https://www.centreforwelfarereform.org/uploads/attachment/660/fully-funded-social-care.pdf

Benefits

- People's health is likely to improve as the support they receive will meet their needs.
- Demand on the NHS is likely to reduce. One of the current strains on the NHS is the inability to discharge people to social care and support
- People drawing on the service will be more productive, able to contribute to civil society and be more independent.
- This transformation would set a global precedent for a caring state and a massive boost for a civilized society.
- People using the service will be happier. Anxiety about having to pay and lose their savings and capital will disappear. Compare and contrast the experience of medical care before and after the creation of the NHS.
- Staff will be more productive, happier and offer a better service to users
- If we implement a social care which engages and supports health creation and community development, we can expect an impact on health inequalities and health protection
- There is likely to be a 1:4 social return on investment [vii] [viii] [ix]

There is a good summary of the benefits in the document "The value of investing in social care" by the Health Foundation and the Kings Fund Resources | NaCSILS

WHAT WILL HAPPEN IF IT ISN'T MET?

If recession continues and this investment is not made into civil society's infrastructure, fear of old age and disability will increase. Health inequalities will be even wider and more entrenched. Disabled people of working age will experience even more discrimination. The NHS will be under increasing pressure. Companies are likely to continue making unreasonable profits and, if recession hits too hard, will abandon the social care market and those who draw on their services.

Already disabled people are being charged for care and being pursued by debt services if they cannot pay. These kind of aggressive approaches will increase and spread.

WHAT ARE THE IMPLICATIONS FOR EQUALITY, DIVERSITY AND INCLUSION?

If the 7 Demands are met, then these values will be massively enhanced. If they are not met, then discrimination, as outlined above, will continue.

WHAT REFORMS TO CARE AND SUPPORT IN ENGLAND SHOULD BE INITIATED IN THE FIRST YEAR OF A NEW GOVERNMENT ELECTED IN 2024?

Approaches to bringing contracts into the public sector (see NaCSILS resources). May need legislation e-voice.org.uk.docx (live.com)

Increasing Local Authority capacity to take on these added responsibilities

Start the process of boosting pay and conditions for care workers. This must include

Make personal care free. Harness the Scottish example. Also work with Hammersmith and Fulham Council to see how they have achieved this.

Every Local Authority to fund a local Disabled People's Organisation to help run adult social care dept and provide support for users and advocacy – assessments, managing care

Stop the practice of reassessing people with long term health conditions that cannot improve, to see if they still qualify for benefits

Increase care benefits by the rate of inflation each year.

Produce a funding plan for a NaCSILS, using the suggestions earlier in this document.

Legislative and treaty change – suggestions from ROFA

- Legislate for a free-standing right to independent living that includes an adequately resourced right to inclusive education.
- Implement the appeals process under the Care Act 2014.
- Bring into force Section 1 of the Equality Act 2010 to introduce a socio-economic duty on public sector bodies and dual discrimination provisions.
- Reverse the changes to legal aid that have restricted eligibility for Disabled people.
- Remove UK reservations and interpretative declaration on Articles 24 of the United Nations Convention on the Rights of Persons with Disabilities15.
- Amend the Mental Capacity Act 2005 to give full human rights to Disabled people and their families and to ensure that 'best interest' decisions made reflect the will and preferences of Disabled people and introduce an accessible system for people to challenge decisions made about them.
- Bring detention, substitute decision-making and compulsory treatment to an end for all Disabled people.

WHAT FURTHER REFORMS SHOULD BE INITIATED OR PLANNED OVER THE COURSE OF ONE PARLIAMENT?

We have to be ambitious like the government that introduced the NHS. There had indeed been debates for decades about an NHS, but Labour brought it in in one parliament. The same applies here. There has been debate for decades, now is the time for well-evidenced policy that transforms a near derelict system into something that offers civic pride, social justice, improved health and better outcomes for users and staff.

SPECIFICALLY, WHAT CHANGES SHOULD AN INCOMING GOVERNMENT CONSIDER WITH RESPECT TO:

Rights, control and personalisation for service users, carers and families
I hope that we have made the essential elements of this clear earlier in this paper. We want a service where those using it and their carers can have real involvement in the type of care, support and independent living choices they want

Workforce reform
I hope that we have made the essential elements of this clear earlier in this paper. Unison has done a lot of thinking in this area – we have listed them above. NaCSILS Charter also sets out the key requirements. We know that Labour intends to start in this area, and we welcome that.

Bring in a visa for carers to come from any part of the world, not just the EU.

Financial allocations and funding mechanisms
As mentioned above, there have been a number of comprehensive reports on options for funding social care:

Social care funding: Debate on the Economic Affairs Committee report - House of Lords Library (parliament.uk)

Prof Prem Sikka: Why we must resist the Elderly Social Care (Insurance) Bill - Left Foot Forward: Leading the UK's progressive debate

https://www.bing.com/ck/a?!&&p=fed56ee9c17d8be0JmltdHM9MTY1OTc5OTcxNiZpZ3VpZD1lNTBjYjcxNC1mNzkwLTQ3OTAtYjg0NC00Mzc2NTg1ZDkyMjYmaW5zaWQ9NTE5MQ&ptn=3&hsh=3&fclid=6fea6648-159c-11ed-9b01-298f1db0bee7&u=a1aHR0cHM6Ly93d3cudHVjLm9yZy51ay9zaXRlcy9kZWZhdWx0L2ZpbGVzL1ByZW0lMjBTaWtrYSUyMEJyaWVmaW5nJTIwTm90ZSUyMCVFMiU4MCU5MyUyMEVsZGVybHklMjBTb2NpYWwlMjBDYXJlJTIwLSUyMEluc3VyYW5jZSUyMEJpbGwlMjAyMDIxLnBkZg&ntb=1 from para 51 onwards

https://www.centreforwelfarereform.org/uploads/attachment/660/fully-funded-social-care.pdf

Organisational structures for commissioning and delivery
NaCSILS is clear that we need to move towards a service fully publicly funded by progressive taxation. We have also made clear that we are in principle in favour of co-ops and innovations from the voluntary sector, so there will need to be small amounts of commissioning. The expertise for setting up contracts and monitoring them must be enhanced in Local Authorities.

Please see the document on the NaCSILS website on ending private sector contracts and bringing them into the public realm. Resources | NaCSILS

Every LA funds a local DPO to help run adult social care dept - commissioning and delivery - and provide support for users and advocacy – assessments, managing care

National and local leadership and accountability
NaCSILS wants to see a democratic service, accountable to the people it serves. Please see NaCSILS Resources | NaCSILS section on Coproduction.

Boundaries, interactions and integration with other parts of government, and with the rest of society

We see social care and support separate from the NHS, but services closely coordinated and wrapped around those who draw on services. Indeed, we expect that, so far as possible, the those who draw on services would be running or helping to control the development of the services.

Clearly there needs to be coordination between Local Authorities, the NHS, the voluntary sector and co-ops. ICSs, so long as their democratic processes are effective (about which we are very concerned) could be essential and effective here.

There need to be links with Public Health, Levelling Up (if Labour continues that department) and the Treasury. Cabinet overview would be essential.

If we develop a community development infrastructure for social care, then local people will become increasingly involved with designing and supporting social care.

We are talking about a significant enlargement and transformation of civil society – how local communities respond to the changes will be an exciting and optimistic aspect of the process. There needs to be thought given to whether and how Local Authorities and ICSs might be able to create the conditions where this kind of community development and health creation can thrive.

CONTACTS: Dr Brian Fisher brianfisher87@googlemail.com 07949595349

Gilda Peterson NACSILS secretary nacsilservice@gmail.com 07419295754

[i] LABOUR PARTY CONSULTATION PAPER: DEMOCRATIC PUBLIC OWNERSHIP - The Labour Party (readkong.com)
[ii] Private provision in children's social care | Children's Commissioner for England (childrenscommissioner.gov.uk)
[iii] Quality of care in for-profit and not-for-profit nursing homes: systematic review and meta-analysis | The BMJ
[iv] Private provision in children's social care | Children's Commissioner for England (childrenscommissioner.gov.uk)
[v] Health Management and Policy Alert: Plugging the leaks in the UK care home industry: strategies for solving the financial crisis in the residential and nursing home sector (blogs.com)
[vi] Labour's Alternative Models of Ownership Report // New Socialist
[vii] IMPACTAgewell: an integrated community development approach to improving the health and well-being of older people: sharing our learning: year 4 evaluation update MID AND EAST ANTRIM AGEWELL PARTNERSHIP Mid and East Antrim Agewell Partnership 2021
[viii] Return on investment of public health interventions: a systematic review | Journal of Epidemiology & Community Health (bmj.com)
[ix] Making the case for public health interventions | The King's Fund (kingsfund.org.uk)