End Social Care Disgrace

Campaign for a National Care, Support and Independent Living Service

www.endsocialcaredisgrace.org
endsocialcaredisgrace@gmail.com
X @EndSCDisgrace Tel. 07419295754
https://www.facebook.com/EndSocialCareDisgrace

Submission to the Casey Commission

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1. Our Vision

The End Social care Disgrace Campaign (ESCaD) is a non-party political coalition which brings together disabled and older people, unpaid carers, care and support workers in common cause, in the firm belief that what works well for disabled and older people provides job satisfaction and improves retention of staff and frees up unpaid carers to pursue more life of their own choosing. We are all in it together!

We are calling for the setting up of a freestanding National Care, Support, Independent Living Service which

1. **Is funded through Government investment and progressive taxation**
2. **Free at the point of use**
3. **Publicly provided and accountable**
4. **Nationally mandated but locally provided**
5. **Radically re-imagined and co-produced with disabled people, carers, sector workers, and local communities**
6. **Offers choice, control, dignity and independence**
7. **Provides a range of practical and financial support to carers, gives them rights and values their expertise**
8. **Ensures that all care and support staff receive pay, conditions, training and access to progression which reflects their high value and skills**

Why Independent from the NHS

- Many people needing social care /support are in good health and have little involvement with the NHS.
- They are disabled by the barriers they face in negotiating a social world which is not inclusive.
- Looking at disability through a medical lens rather than a social model shapes individual not social responses and encourages a view of people as bundles of largely physical needs e.g. 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, organisational integration would mean that social care and support is likely to be swallowed up by the NHS and Integrated Care Boards and its priorities shaped to meet the needs of our struggling, underfunded, health system.
- Being independent from the NHS in no way minimises the need for effective co-ordination and streamlining of support to individuals when appropriate.

Why publicly funded and free to all at the point of use

- The current system is deeply unfair, often opaque and creates huge anxiety. When we are ill we expect the NHS to give us the best care available. When you have impairments at whatever 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 are likely to be means tested. If you have assets more than worth more than £23,250 you will have to pay the full costs of any care and support provided. If you own your home, charges can be recouped long after your death.
- Currently social care services are covertly rationed to meet budget restraints by constantly raising the thresholds for support. Over half the requests for local government-funded social care in England in 2023/24 resulted in no support, or advice or signposting. (1)
- Assessments for support have become dreaded, stressful and degrading. All lip service to strengths or asset based approaches goes out of the window as people are forced to convince social workers as well as DWP officials what they can't do rather than take pride in what they are managing to do. The humiliation is often exacerbated by feeling disbelieved and/or realising that the apparent "expert" assessing you lacks the experience and knowledge needed for the role. Staff forced to carry out these assessments are also diminished and frustrated. They train and enter social work to make a difference and enable vulnerable people, not act as gatekeepers for their employers and the government. Thus the best social workers normally leave the profession long before they need to.
- Disabled and older people are coming to serious harm in the community
    - Missing or inadequate support for people in their own homes increases the risk of injury or acute illness requiring hospital admission or readmission. We note that a recent analysis by the National Centre for Social Care Research (2) concludes that roughly one in four people with social care needs were subject to emergency hospital admissions on account of potentially avoidable conditions. However in Hammersmith and Fulham, where the Local Authority have provided free home care for over a decade, not only has the number of people aged 65 and over in residential care in the borough fallen dramatically, from 828.3 per 100,000 in 2014-2015 to 219.5 per 100,000

in 2024-2025 but in 2023-2024, 95.7 per cent of people in the local authority area remained at home 91 days after discharge, placing the borough fifth in national ratings.(3)

- 13 million people per year have their discharge from hospital delayed, many on account of the lack of appropriate and timely social care support. The large majority are older people. Much is said about the estimated £2.7bn financial cost of this to the NHS and the shocking catalogue of unnecessary deaths in the resulting crammed Emergency Departments – estimated by the Royal College of Emergency Medicine to be 305 per week. (4) What is less frequently highlighted is the fact that the people who are stuck in hospital waiting for discharge on wards without any or significant rehabilitation facilities also suffer harm. They rapidly lose mobility, independence skills and confidence and are at increased risk of falls and picking up hospital acquired infections.

- There has been a notable rise in the stigma and abuse aimed at disabled people both to their face and on social media. Inadvertently or not, this is being stoked by politicians constantly and publicly valorising "working people" by which they mean people in paid work, coupled with repeat efforts to cut benefits. Together these manoeuvres help to carve a furrow between those who are seen as the 'deserving' and 'undeserving' disabled**.** The huge economic and human contribution of disabled and older people to society, many in paid work and /or providing the bedrock of volunteers in local communities, supporting older relatives and younger family members with childcare etc. and offering peer support is almost entirely unrecognised or discounted.
  See Evidence from Rachael Tomlinson, Advocate living with Multiple Sclerosis: Appendix A

- Poverty unfairly impacts disabled people and their families. The poverty rate among working-age disabled adults in the UK is 23%, compared to 17% for those without a disability (5); in 2024 The Rowntree Trust estimated that 3 in 10 of the 13m people living in poverty were disabled. (6) If you add in carers and other household members almost half of those living in poverty are affected by disability. The fact that in some areas charges for home care have risen by 50% results in more disabled people falling into care charge debt. Some have said they felt they had little choice but to live without support services, others live in fear of court action. (7) A recent investigation by the BBC notes that 60,000 people had accumulated care charge debts and Local Authorities took legal action against at least 2,000 in 2022. (8) Meanwhile care home fees now average nearly £1,400 a week, having risen by more than a quarter since 2021-22**.** (9)

- Funding 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
  - More disabled people and family carers will be enabled to do paid work
  - At least 1.6 million care and support workers paid decent wages will contribute more to the Economy through taxes and disposable income
  - Investment in community based solutions rather than high cost segregated institutions, which are rarely what people want and need, will provide savings in the long run
  - Ensuring excellent care and support in the community will save billions for the NHS in terms of reduced hospital admissions, re-admissions and fewer delayed discharges

- 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. About £40 billion a year would bring spending up to 2% of GDP. This may look substantial but in practice is highly affordable. It is also essential to refocusing away from making

profits for the few towards developing a wellbeing economy for everyone. Steps in the right direction might include:

- A sliding scale wealth tax, estimated to raise £10bn from 140,000 rich individuals in the UK
- Taxing capital gains at the same rates as earned income and charging national insurance on the same could provide £25bn a year extra
- Taxing dividends at the same rate as earned income which could raise another £8bn-£10bn per year
- Recouping some of the £450bn and £1,500bn of tax revenue which has been lost since 2010 due to tax avoidance, evasion and error

See ESCaD's paper on funding a National Care, Support and Independent Living Service from Brian Fisher: Appendix B (10) but note that the suggested £41bn needed is not just to deliver a bigger and better version of what we have already but for a radically re-imagined service co-designed with all parties to ensure that everyone has equal access to a fulfilling life.

Why publicly provided and accountable

- 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 18,000 private providers. (11) Of approximately 5,000 of those providing care homes the five largest private providers own about 20% of the total beds. The asset value of privately owned care homes alone amounts to £245billion. All these private firms have no accountability to local people and can hide behind 'commercial confidentiality'. If they cannot turn a profit they will just walk away, leaving residents stranded. Eight hundred care homes closed between 2011 and 2023; thousands of older people who might have expected to experience some stability through the last phase of their life had to be shipped out, losing those familiar links to place and persons which help to preserve mental health. (Alison Milne, Emerita professor at Kent University) in an address to an ESCaD Public meeting 28.6.26 and in a book to be published later this year.

- When Local Authorities commission private providers they are ensuring that a percentage of public money is siphoned into the pockets of 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. For the 13 largest for-profit providers (Non-Private Equity) the level of leakage is £19.49 out of every £100 received, and amounts to £401m a year. (12)

- 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 to increase profit margins.

- The drive for profit has also had a negative effect on shaping services as the need to maximise profit trumps the need to preserve people's humanity and individuality while the narrow spectacles of the CQC, further undermined by a ham fisted, if not disastrous re-organisation can be part of the problem not the solution. (13) For large private companies or chains, building at scale is cost effective and enables firms to shuffle staff from one unit to another, a practice which proved disastrous in the pandemic. Such large units require substantial plots of land which are more likely to be found at some distance from local communities. This makes visiting or trips out more difficult and discourages friends and neighbours from dropping in, rapidly creating large holes in what was the warp and weft of a resident's previous life.
  The evidence on involuntary closures of residential homes between 2011 and 2023 also suggests that overall the quality of care in "for profit" care homes is worse than in 'not for profit' homes, as 5·7%) of

18 051 for-profit homes were rated inadequate in their latest inspection compared with 1.0% of 628 public sector homes and (2·1%) of 2,805 third sector homes were rated inadequate. (14)

- Far too many older people are still parked in rows of easily washable chairs on easily washable floors surveyed by staff in a glass box. Having occasional 'sing alongs' and school visits in residential homes for older people is miles away from providing rich environments where, for example, people who have enjoyed cooking all their lives can help with shopping for food, access a kitchen, and engage in food preparation while others help to plant out raised beds, run a shop, play games, share skills, exercise etc. Vital day centre provision is often unavailable on public holidays, disrupting the routines that provide security and stability for those using the services and increasing the stress on family carers.

- Disabled people of working age often fare much worse in institutions. There continue to be shockingly routine rates of death and harm in residential care settings. The horrific abuses of disabled people are well documented and subject to repeat "never again" reports whose recommendations run into the sand, from Winterbourne 2011 to Whorlton Hall 2019. What slithers by unseen are the regular, individual deaths that don't catch the headlines. When the adult disabled son of one of our activists, Anna Rose. died a preventable death from choking due to lack of oversight and a slow, uncertain response from staff, she discovered from the organisation "Inquest "that they knew of 18 other cases of learning disabled people dying from the same cause in a care setting and many more from all causes.
  See Anna Rose's video evidence: Appendix C and a book by Professor Sarah Ryan, also a bereaved mother, exploring 'Erasure and Social Murder' (15)
  Professor Ryan was one of our speakers at a series of public meetings we have been holding on 'Hidden Voices' to shine a torch on those disabled people of all ages who have difficulty speaking up for themselves yet often suffer the most harm. We have also been working with Mencap on harms since they sponsored a powerful exhibition in March on "Homes Not Hospitals: The Fight for Freedom".

- Privatisation has also resulted in increasingly institutionalised, undignified and unreliable support in people's own homes. Disabled and older people are objectified into bundles of largely physical needs; fed, toiletted, medicated and put to bed in a manner and at hours not of their choosing, by successions of ever changing staff. They lose not just privacy and dignity but agency. What matters most to people i.e. relationships, kind words, their individual personalities, skills, interests and engagement with local communities is demoted, if not dismissed. People employing their own Personal Assistant can have more choice and control but this comes with responsibilities many people do not want to manage and they are struggling to find PAs to work at the dire rates the LA enables them to pay.

Why services need to be nationally mandated but locally provided and co-produced with service users, offering choice, control, dignity and independence

- A national framework of support is essential to ensure universal and fair access to support and avoid postcode lotteries. A task force on independent living comprising people from organisations of service users should guide development and ensure that the right to independent living as outlined in Article 19 of the UN Convention on the Rights of Persons with Disabilities is enshrined in law and becomes a reality.

- 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, micro - enterprises, peer support services and inclusive, cross age opportunities for shared activities in local communities. See examples of green shoots of change in local communities in our ESCaD Steering Group member, Anne Gray's latest book : "Radical Approaches to the Care Crisis; Solidarity, Community and a National Care Service" (16)

- Alongside flexible personalised support there needs to be a powerful focus on fostering caring communities with fully inclusive local community facilities – housing, workplaces, transport, libraries, leisure etc. i.e. all twelve pillars of independent living.(17)

- As a start Local Authorities need to take serious steps to open up decision making to citizen participation. Consultation, focus groups and advisory bodies are not enough. Disabled and older people, carers, sector workers and local communities need to have active involvement in decision making and scrutiny processes**.**

Why give recognition, rights, flexible support and fair funding to family carers

- Carers UK estimates that the total number of carers in the UK today is around 10.6 million, that is 1 in 5 adults in addition to 800,000 children and the proportion of people providing more than 50 hours of unpaid care a week has increased to 1.4 million. Nonetheless The Kings Fund point out that fewer carers received support in 2025 than in 2014/15. (18) As for child carers aged 5-17, a study by the Children's Society found that over a third were having mental health problems and 27% were missing or having problems at school. (19) Younger carers often have to give up jobs and careers because they have few rights at work.

- Carers of all ages experience poverty, loneliness, poor mental and physical health. Many feel gagged or caught in a bind, fearing that if they indicate they are getting to their wits' end, the Authorities will put pressure on to move their loved one into a residential establishment, possibly many miles from home. If they are driven to the point of contemplating suicide, they are also in an impossible bind as they feel unable to abandon their loved one so have to soldier on or contemplate the thinkable, taking the life of another as well as their own. Almost all parents of adult disabled 'children' fear for the future when they die or are no longer able to carry on caring. Meanwhile they juggle grieving the life they didn't have, the jobs and careers they gave up, all while trying to manage on less money while trying to navigate a cumbersome. often opaque system and seemingly arbitrary divisions between Local Authority and Continuing Health Care funding , in order to try to get the best for their loved ones.

- Many if not most carers feel their knowledge and experience is undervalued, their views ignored or discounted, sometimes at the expense of the health and wellbeing of those they care for and a worrying number feel harassed, even bullied. This has got to stop; carers must be respected and fully integrated in decision making processes.

- When support is provided in the home it is not only often unreliable but the carers find themselves having to offer guidance and support to staff who often have a frightening lack of knowledge and skills.

- It is estimated that family carers save the treasury £184bn in England and Wales. (20) Without this positive army of carers our fragile social care system would have collapsed years ago.
  However they are dependent on fighting for benefits and are blocked by unfair rules e.g. where two people, often parents supporting adult disabled 'children' with challenging behaviour, only one can claim carer's allowance. Many still fear they might be hauled through the courts for inadvertent overpayments owing to the ridiculous cliff edge nature of carers allowance payments and the failure to bring a rapid end and compensation for grave injustices in the workings of the DWP. We think it is high time to look seriously at providing fulltime carers with a guaranteed income or stipend, based at least on the minimum wage for 35 hours support.

See written evidence from

- **Jo Walton, long term carer for her daughter who became seriously disabled in her twenties : Appendix D**
- **Chris W, carer for his adult, disabled sister: Appendix E**

And a paper from Jo Walton on the Case for a carer's Income/ Stipend; Appendix F

Why enhance pay, conditions and status for care and support workers

- 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 or the preserve of black and minority ethnic workers. 83% of care and support workers are women, 21% nationally are from black and minority ethnic backgrounds but in London it is 67%. 18% of care workers are from overseas.

- We welcome the Employment Rights Act as a slow step in the right direction to raise wages and conditions for staff but consider more urgent and significant action is needed now, starting with a rise in the minimum hourly rate to £15 per hour and an expectation on all care providers to ensure that staff are paid for travel time, sleep ins etc. and provided with training for what is complex, skilled and often exhausting work.
  The treatment of overseas workers has been particularly disgraceful; first enticed here in significant numbers in 2020 – 2022 to keep our social care system afloat, bound to and sometimes gagged by specific employers, made false promises, extorted for money and sometimes packed into accommodation in situations akin to modern slavery. Subsequently they have been stopped from bringing their children to the UK, overseas recruitment has been frozen and those workers hoping to get permanent leave to remain after 5 years have been informed that it will take 10 if not 15 years. We have heard from colleagues in the Pan African Workers Association how the separation from family is heart-breaking, overseas staff are feeling unwelcome and are increasingly the butt of racist abuse.

- Care and Support Workers should be paid an absolute minimum of £15 per hour – including sleep-in shifts, travel time etc. The TUC estimates that raising pay for care workers to £15ph would cost £5.9bn but would boost England's economy by £7.7bn.(21) Care staff should be entitled to sick pay, paid holidays, trade union recognition and full bargaining rights, training and a career structure. The exploitation of workers from overseas must end. 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 and generate green jobs. (22)

1. https://www.kingsfund.org.uk/insight-and-analysis/data-and-charts/key-facts-figures-adult-social-care
2. https://natcen.ac.uk/news/social-care-needs-linked-higher-risk-avoidable-hospital-admissions-study-finds

3. https://www.newstatesman.com/sponsored/2026/07/free-home-care-towards-a-national-care-service
4. https://rcem.ac.uk/press-release/how-many-deaths-will-it-take-before-we-see-a-meaningful-plan-to-end-the-crisis-deaths-associated-with-long-ed-waits-surge-almost-t/
5. https://appgpovertyinequality.org.uk/wp-content/uploads/2025/06/DisabilityReport-one-page.pdf
6. https://www.jrf.org.uk/uk-poverty-2025-the-essential-guide-to-understanding-poverty-in-the-uk
7. https://www.bbc.co.uk/news/uk-64668729
8. https://www.bbc.co.uk/news/articles/c9qd3xje9vvo
9. https://www.which.co.uk/news/article/care-home-costs-rise-to-1400-a-week-avlc06q7c4mrv
10. https://endsocialcaredisgrace.org/wp-content/uploads/2023/10/Adult-Social-Care-and-its-funding-ESCaD-draft-for-comment.pdf
11. https://www.kingsfund.org.uk/insight-and-analysis/data-and-charts/key-facts-figures-adult-social-care
12. https://www.chpi.org.uk/blog/investors-are-making-a-fortune-from-uk-healthcare-why-is-nobody-holding-private-equity-to-account
13. https://www.cqc.org.uk/publications/review-cqcs-single-assessment-framework-and-its-implementation
14. https://www.thelancet.com/journals/lanhl/article/PIIS2666-7568(24)00008-4/fulltext
15. https://www.routledge.com/Critical-Health-and-Learning-Disabilities-An-Exploration-of-Erasure-and-Social-Murder/Ryan/p/book/9781032605005
16. https://policy.bristoluniversitypress.co.uk/radical-approaches-to-the-care-crisis
17. https://breakthrough-uk.co.uk/principles-of-independent-living/
18. https://www.kingsfund.org.uk/insight-and-analysis/long-reads/social-care-360-workforce-carers#9.-carers
19. https://www.childrenssociety.org.uk/what-we-do/our-work/supporting-young-carers/facts-about-young-carers
20. https://www.carersuk.org/reports/valuing-carers/
21. https://www.tuc.org.uk/news/ps15-minimum-wage-care-workers-would-boost-englands-economy-ps77-billion
22. https://wbg.org.uk/wp-content/uploads/2020/06/Care-led-recovery-final.pdf

What we are asking the Commission to do

A. Insist that the Government bite the bullet and take bold action now to start co-producing a 'not for profit', free at the point of use, fundamentally re-imagined National Care, Support and Independent Living Service along the lines set out above. Its bedrock will be what matters to people – relationships, independence, control, choice, dignity, being part of a caring community. This has implications not just for staff, who will need to prioritise the needs of people first but also for funding. While we welcome efforts to create a broad, cross party consensus, in the light of repeat past failures to reach this goal we feel strongly that the struggle for consensus must not sink the ship of radical change yet again and the money can and must be found. **See more from Brian Fisher in our finance paper: Appendix B**

B. Fund and oblige Local Authorities to

- **i. make domiciliary support free at the point of use, without delay as in Hammersmith and Fulham and Tower Hamlets**
- **ii. Drop the pursuit of existing care charge debts**
- **iii. Work with disabled and older people, carers, care workers and local communities to develop 'not for profit' provision not just by the Local Authority but by Cooperatives, micro enterprises, peer support projects etc.**
- **iv. Work with carers in their area on setting up a flexible menu of practical and personal support.**

C. Pursue an immediate rise in the pay of care and support workers to a minimum of £15 per hour, without waiting for the slow implementation of the Employment Rights Act.

D. **Ensure that all sponsorship of care workers from overseas is transferred from individual providers to Government stewardship and rescind extensions to the "leave to remain" qualification period.**

E. **Start looking seriously at providing a guaranteed income /stipend rather than 'benefits' for carers.** **See the paper from Jo Walton: Appendix F**

F. **Start now challenging narratives that diminish us all, exclude and divide us one from another and block a radical transformation of social care i.**e.

i) Reframe Social Care as a universal service that any one of us might need at any time - sometimes with no notice, making clear that it is in everyone's interest to pool risks
ii) Challenge the 'othering' of disabled and older people and the narratives that deepen rather than close the gaps between us.
iii) Call out the harmfulness of neoliberalism, which creates profit shaped societies increasingly drained of human interactions and make clear it is a political choice not received wisdom.

G. **Promote close working together between the NHS and Social Care at all levels** with both seen as separate but equal partners in enhancing the physical and mental health and wellbeing of the population. Immediately it is necessary to protect the representation of Local Authorities on Integrated Care Boards which is under threat in the Health Bill 26/27.

H. **Join up with other Departments** – housing, transport, employment, education, culture, planning at national and local levels to make the radical transformation of care and support everybody's business, not limited to creating a special Care and Support Service but building inclusive communities where there is opportunity for everyone both to contribute and benefit.

Appendices

A. **Written and video evidence from Rachael Tomlinson who lives with MS**
B. **Funding Transformation in Adult Social Care and support: paper from Brian Fisher for ESCaD**
C. **Video evidence from Anna Rose whose adult disabled son, Marcus died a "preventable death" in residential care:** https://endsocialcaredisgrace.org/videos/
D. **Written evidence from Jo Walton, long term carer for her daughter who became severely disabled very suddenly in her early 20s**
E. **Summary written evidence from Chris Wade, carer for his disabled sister**
F. **The case for a Carers Income/Stipend by Jo Walton**

Appendix A: Written and video evidence from Rachael Tomlinson who lives with MS

Over the past year I have seen a significant increase in hostility towards disabled people, both online and in everyday life.

As a disabled content creator and advocate, I receive comments every day accusing disabled people of being fraudsters, scroungers or unwilling to work.

Much of this appears to follow negative media coverage and political debate around disability benefits.

Alongside this, many disabled people continue to describe assessment processes as exhausting, stressful and often dehumanising.

They are repeatedly required to prove their disability, despite living with lifelong or progressive conditions.

The fear of reassessments and potential loss of essential financial support has had a profound impact on people's mental wellbeing.

The challenges extend far beyond assessments.

Disabled people face increasing financial pressures due to the extra costs of disability, difficulties accessing health and social care, barriers to employment, inaccessible transport, and growing levels of public misunderstanding.

Online abuse has also intensified, with disabled people increasingly targeted simply for speaking publicly about their experiences.

Through my advocacy work and social media platform, I have documented hundreds of examples of this changing public narrative. The evidence suggests that hostile rhetoric surrounding disability is contributing to increased abuse, stigma and discrimination, leaving many disabled people feeling less safe and less valued within society.

Links to some of my videos on Facebook:

Sharon Brennan on PIP and the myths around benefits

Statistics Regulator Debate should be based on evidence not slogans

Debate is welcome – Abuse is not

……..

Appendix B: Funding Transformation in Adult Social care and support: paper by Brian Fisher for ESCaD

End Social Care Disgrace www.endsocialcaredisgrace.org campaigns for a radically transformed social care system.

We want a National Care, Support and Independent Living Service (NaCSILS) which will be publicly funded, free at the point of use and publicly provided, and not for profit. It should be nationally mandated but designed and delivered locally, co-produced with service users and democratically accountable. It must be underpinned by staff whose pay and conditions reflect true value and skills. It also must meet the needs of informal carers. It should be informed by a task force on independent living led by user-controlled groups from diverse backgrounds.

We campaign for this model of social care and support for a range of reasons – social, ethical and human rights – but in this short paper we focus solely on *funding* questions. Any debate on the future funding of social care seems to emphasise the costs involved, not the possible gains, which leads to a sense of the 'unaffordability' of change.

This paper builds on work done by one of its members - Ealing Reclaim Social Care Action Group (ERSCAG; www.erscag.org.uk) which brought together expert thinking about funding social care reform (see bibliography at the end). We have used publicly available data to make estimates of costs and benefits. This document applies to Adult Social Care only.

EXECUTIVE SUMMARY

Transforming social care as advocated by the End Social Care Disgrace campaign will bring important economic benefits and make an important contribution to the country's productivity and prosperity. It would be the equivalent to the creation of the NHS – hugely popular, transformational to community, civic life, and the standing of the country internationally.

The economic costs of not offering social care reform:

- Reduction in the potential for economic activity for working age disabled people
- The costs of people giving up economic activity in order to care
- The inability to recruit and retain staff in adequate numbers
- The burden to NHS funding of unplanned admissions to hospital and delayed discharges
- Profits going to companies rather than public service
- The cost of complaints, appeals, legal risk of not upholding the legal requirements of the Care Act

These total at least £45 billion. Some costs have been difficult to quantify and warrant more detailed research.

The contribution of social care and support to the economy

'Skills for Care' estimates that the economic contribution of adult social care to England was £50.3bn annually, more than its current cost of provision. A transformed, fully functioning adult social care and support system would also reinvest profits from the private sector and reduce delayed NHS discharges. There would also be increased taxation from increased earnings. The total contribution is approximately £66.5 billion

The finances needed for social care transformation

We calculate that the extra cost would be £41.2 billion, as a result of the following changes: ending the dependence on private care; replacing the income from charging; returning funding to 2009 levels; 25% salary and wage increases; Free domiciliary personal care – support for daily living; free residential care; other services; Direct Payments.

1. THE COSTS OF NOT OFFERING SOCIAL CARE REFORM – AT LEAST £45 BILLION

Government should consider the risks to our individual and national prosperity and economic well-being of NOT offering serious social care reform and change. We provide some financial estimates for some of these issues.

Poor social care reduces the potential of economic activity for working age disabled people as a result of poorer health and less autonomy and independence**,** with reduced taxes to Treasury; increased reliance on more expensive institutionalised care; pauperisation of disabled and older people given inadequate sick pay levels and clawing back of benefits. Institute for Public Policy Research (IPPR) estimates the earnings loss

associated with the onset of long-term health conditions at £43 billion in 2021[1]. We have not found an estimate of the savings to be made specifically as a result of improved social care and support but policy makers would be well advised to commission research into this question given the potential savings. We have added less than half of this figure to the total of this section.

The costs of people giving up economic activity to care with resultant lower taxes being received; more people becoming reliant on benefits and some 16% of informal carers in debt[2]. There was an increase in unpaid carers of 3.7 million between 2011 and 2020 (Office of National Statistics). We know that the costs to the state of young carers being excluded from work were £1.048 billion each year[3]. We cannot find an estimate of the cost to the Treasury of adult carers leaving work, but a conservative estimate might be £5 billion.

The inability to recruit and retain staff in adequate numbers, increasing workforce vacancies leading to economic pressures on those needing care, families, and other workers. Over a quarter of the UK's residential care workers lived in, or were on the brink of, poverty in 2020[4]. This has a considerable cost to the Treasury, and on the country's wider productivity and prosperity. The Health Foundation has estimated that England needs 627,000 extra social care staff to meet demand by 2030[5]. That staffing gap will not be met even partly without significant increases in pay. 93.8 per cent of GMB's (nearly 2,000) care worker members responding to their Care Survey this year believed that low wages were putting people off working in care. The staff recruitment/retention crisis in adult social care means that there is no alternative but to reform social care in the way that this paper proposes.

The risk to NHS funding of unplanned admissions to hospital and delayed discharges. 30% of delayed discharges are the result of delays in social care. It was estimated that lack of social care provision led to 2.5 million lost bed days between June 2017 and December 2019, at a cost of £587m to the NHS[6]. IPPR estimates an economic benefit in reducing delayed discharge of around £80bn due to increased productivity and reduced consumption of medical care. A reasonable saving by boosting social care could therefore be £20 billion a year.[7] This is likely to be an under-estimate as it relates to pre-pandemic figures, and both bed blockages due to social care delays as well as the system cost of an inpatient bed day have probably lengthened due to increased system pressures.

Profits going to companies rather than public services. The current fragmentation and highly privatised nature of social care means that monies are currently wasted on poor-quality care home services and are leaking away from public use into large care-home profits[8]. The asset value of privately owned care homes amounts to £245 billion. The 784 small to medium sized care home providers have a leakage rate in profits disguised as rent payments and management fees of £7 out of every £100 of income, and £13 out of every £100 for the largest 26 providers, equating to £1.5 billion a year taken out of the care system.

All of these processes contribute to leaving Local Councils with continually increasing and wasteful administrative costs (in recruitment/setting up/monitoring care charging systems, chasing up debts etc.). Not only does this leave Councils rationing care to only those in the very greatest need of care and support but it also leaves them with inadequate funds to invest in modernisation/tech/care quality standards – pitting short term need versus long term investment in better, and better value-for-money services.

Disabled people are impoverished by social care debt. There are probably more than 100,000 disabled people in social care debt across England[9]. In 2018 over 166,000 people were in arrears on their social care payments, nearly half of whom had debt management procedures started against them for non-payment.

People die when social care needs are not met. Research published in 2021 found that for the five years from 2010, the loss of social care funding caused 23,662 additional deaths[10]. It is likely this trend continued after the years under study up until the pandemic as cuts only worsened over that period.

Levelling up will be impeded, as the economic contribution of the social care sector is notably higher in areas that need levelling up[11].

2. CONTRIBUTION OF SOCIAL CARE TO THE NATIONAL ECONOMY – AT LEAST £66.5 BILLION

Rather than merely considering the costs of not providing adequate social care, we should also recognise the important contribution social care makes already – and could make in future – to the national economy. 'Skills for Care' estimates that the economic contribution of social care is more than its cost. See the IPPR report[12] and the bibliography for fuller explorations of the contribution made by improvements to the nation's physical and mental health to society's prosperity and well-being.

Contribution of care workers to the economy

Skills for Care in 2018 calculated that[13]:

- Care-workers represent 6% of total employment and have average earnings of £17,300. The average full time equivalent worker generates £19,700 of value towards the economy.
- The indirect effect of the adult social care sector (resulting from the purchase of intermediate goods and services by the adult social care sector in delivering its services) was estimated to contribute a further 603,500 jobs (424,800 Full Time Equivalents) and £10.8 billion of Gross Value Added to the UK economy.
- The induced effect of the adult social care sector (resulting from purchases made by those directly and indirectly employed in the adult social care sector) was estimated to contribute a further 251,300 jobs (176,100 FTEs) and £11.1 billion of GVA to the UK economy.
- The total direct, indirect and induced value of the adult social care sector in the UK was estimated to be 2.6 million jobs (1.8 million FTEs) and £46.2 billion.

The economic contribution of adult social care to England was £50.3bn annually, or just over twice its cost of provision[14] [15]

Raising pay for care workers boosts the economy

While the upfront cost to the Treasury of raising pay for all care workers in England to £15ph would be £5.9 billion, doing so would boost England's economy by £7.7 billion and significantly reduce such costs through wider returns to the Treasury in taxation and consumer spending[16]. It is worth noting that the current industry-wide average hourly rate in local authority care is £15.13 an hour. Unions actually believe a minimum of £15/hr is appropriate. Higher pay would presumably result in even more returns.

Some disabled people will restart work

More comprehensive ASC and support will liberate some disabled people to work. The earnings loss was estimated at £43 billion. If 20% of disabled people were able to work, that would add at least £8.5 billion into the economy.

Better social care could enable disabled people to access more services

One example is accessing social prescribing which has been shown to reduce demand on general practice. This is based on lived experience reporting.

Unpaid carers contribute to the economy

A lot of care is provided by family and friends. Support for them could help many of them remain economically active, but even in the current situation, it has been estimated that unpaid carers save the Treasury £132bn a year.[17].

For every £1 invested in social care, £1.75 is generated in the wider economy[18].

3. THE FINANCES NEEDED FOR SOCIAL CARE TRANSFORMATION

Numerous studies have explored these questions in some depth (see bibliography attached in the Appendix) and we can harness them to obtain an estimate of the cost of providing a NaCSILS – that is, a service free at the point of use, publicly funded and with no private provision of services. The key finance issues to consider are:

- Ending the dependence on private care
- Replacing the income from charging
- Returning funding to 2009 levels
- 25% salary and wage increases
- Free domiciliary personal care – support for daily living
- Free residential care
- Other services
- Direct Payments

3.1 THE CURRENT COST OF SOCIAL CARE

The Skills for Care documentation [19] estimates the current cost of social care at just over £30billion:

Table 2.1 Total expenditure by type of provider, England

	Public (£'000)	Voluntary (£'000)	Private (£'000)	Total (£'000)
Residential care	971,010	1,692,411	7,112,360	9,775,781
Nursing care	304,890	556,765	5,148,220	6,009,875
Domiciliary care	273,999	1,416,413	3,814,156	5,504,568
Day care[1]	-	-	-	-
Other services	3,855,108	1,117,513	2,268,889	7,241,510
Direct payments	0	0	1,592,620	1,592,620
Total	**5,405,008**	**4,783,101**	**19,936,245**	**30,124,354**

All values rounded to the nearest £1,000. Totals may not equal the sum of services due to rounding.

In countries with more generous public long-term care systems (Denmark, Netherlands, Sweden, Norway), public expenditure is around 3-4% of GDP [20] [21], which is more than double the current share in the UK. That would equate to about £87 billion.

By 2038, the Dept. of Social Care estimates that costs are likely to rise to £58bn (double current costs), if the current pattern of care continues. This is based on an estimated 29% increase in adults aged 18-64 requiring care with a concomitant rise in costs of 90%. Also an estimated 57% rise in over 65s requiring care with a concomitant rise in costs of 106%.

3.2 THE COSTS OF TRANSFORMING SOCIAL CARE

Replace the income from charging	£1 Billion, based on the costs in the SfC table above
Replace funding to 2009/10 levels:	£8 Billion [22]
25% salary and wage increases in ASC:	£5.9 Billion [23]
Free personal domiciliary care	£5.2 Billion, based on the costs in the SfC table above
Free residential care	£9 Billion, based on the costs in the SfC table above,
Other services	£3.5 billion, based on the costs in the SfC table above
Restore social care to meet current needs	£7 billion [24]
Direct Payments	£1.6 billion, based on the costs in the SfC table above
TOTAL	**£41.2 BILLION**

This would be offset, as explained above, by:

Increased earning and taxation from increasing wages to £15/hr	£7.7 billion
The economic contribution of adult social care to England	£50.3bn p/year
Re-investing profits from the private sector	£1.5 billion
Reducing delayed NHS discharges	£20 billion

And other savings that are impossible to estimate and require further research

3.3 HOW TO FUND THE NECESSARY CHANGES

Firstly, some principles to be considered. The House of Lords Committee[25] argued that social care funding should not be reliant on locally raised revenue which has little connection to local demand for social care and has led to a detrimental 'postcode lottery' in terms of social care provision. Accordingly, they argued (Paras 157-160) that:

- The additional funding needed for adult social care should be provided as a government grant, distributed directly to local authorities according to an appropriate national funding formula which takes into account differences in demand for care and ability to raise funds from local taxation.
- We do not support the introduction of a hypothecated tax/mandatory social insurance system. While some argue that this could help the public trust that extra taxation will be spent on social care, hypothecation could leave the amount of funding more sensitive to the performance of the economy.
- Funding social care should be approached in the same way as any other funding pressure. We recommend that social care is funded largely from general taxation.

Various proposals including from The Pensioners Convention[26] and others, including a paper from the Future Social Care Coalition[27] have been proffered to cover social care costs:

- **Increase wealth taxes.** A comprehensive review of wealth taxation to include possible reforms to inheritance tax, a wealth transfer tax and changes to capital gains and property taxation. A 2% tax on assets above £10m held by all members of the Sunday Times rich list could raise as much as £22bn. Other estimates of proceeds from a wealth tax are £260 billion[28]. Britain's 50 richest families hold more wealth than the entire bottom 50% of the nation's population and must make additional contributions. A wealth tax of 1.7% on people with more than £3m in assets could yield £2.7bn. On assets above £5m the tax rate could rise to 2.1%, raising another £3.2bn. Above the £10m threshold the rate could rise to 3.5 % and raise £4.6bn. That is a total of over £10bn from 140,000 rich individuals[29].

- **An additional 1% on employees' national insurance contribution** for those aged over 40 (£2 billion).

- **Increasing income tax by 1%** which would raise £5.4 bn in 20/21 at the basic rate, and £1.7bn at the higher rate

- **An increase to 3% in the additional rate of national insurance** for those above the upper earnings limit, timed to match extensions of free social care (£800 million)

- **Taxing capital gains** at the same rates as earned income and charging national insurance on the same can provide £25bn a year extra.

- **By taxing dividends at the same rate as earned income** another £8bn-£10bn can be raised. Currently, earnings between £12,570 and £50,270 are subjected to a 12% national insurance charge. Incomes above that attract a charge of only 2%. By extending the 12% charge to all income, an additional £15bn a year can be raised[30].

- **The net cost of pension income tax and NICs relief** is estimated to be £48.2 billion in 2020 to 2021. About two-thirds of this goes to wealthy individuals paying income tax at the marginal rate of 40% (on income between £50,271 and £125,140) and 45% (on income over £125,140). People with annual incomes below £12,570 get no pension tax relief. By restricting tax relief/credit to everyone at the rate of 20%, the government can generate £14.5bn a year[31].

- **The purchaser of shares pays a tax or duty of 0.5% on the transaction.** This ought to be extended to all marketable securities, including derivatives. Even at very modest rates it could raise nearly £4.7bn a year.

- **A higher rate of VAT (30%) on luxury goods** could raise £1.6bn a year.

- **More than 93% of the UK estates have zero inheritance tax liability.** In 2022-23, 41,000 estates paid inheritance tax amounting to £7.1bn. Too many are able to avoid it by using trusts. A clampdown on that is long overdue.

- **HMRC has been starved of resources** and has been unable to chase the rich and big corporations. Since 2010, between £450bn and £1,500bn of tax revenue has been lost due to avoidance, evasion and error. For every £1 of investment into large business investigation HMRC has yielded £69 in extra tax revenue. So, greater investment in enforcement is needed.

4. CONCLUSIONS

Our analysis shows:

- The cost of doing nothing is £45 billion
- The cost of the recommended reforms is £41.2 billion
- The return on that investment is £66.5 billion
- There are many ways of raising extra funds to fund a transformation in social care.

If these analyses and proposals are collated, there is a strong argument that:

- The programme advocated by the ESCaD campaign has a manageable cost.
- The cost is offset to a very large extent by the increased contribution of extra economic activity and savings in other parts of the economy. If anything, Adult Social Care is a net contributor to the economy, not a drain on it.
- There are ways to cover this extra investment.
- We understand that extra funding for Adult Social Care has to find its place with other demands on the Treasury. However, transforming social care in the way we recommend would be the equivalent to the creation of the NHS – hugely popular, transformational to community, civic life and the standing of the country internationally. This paper also argues that it will bring important economic benefits and make an important contribution to the country's productivity and prosperity
- We recommend that this investment be made over one Parliament.

Bibliography

ADASS - Association of Directors of Adult Social Services – see **https://www.adass.org.uk/waiting-for-care-adass-report-may-2022**

Care England - https://www.careengland.org.uk/wp-content/uploads/2023/03/Hft-Sector-Pulse-Check-2022-Single-Pages-Digital.pdf

Carers UK, see their website inc. - https://www.carersuk.org/policy-and-research/our-areasof-policy-work/social-care/

Cavendish- "Social care: independent report by Baroness Cavendish – how can we lock in the lessons of the crisis to built a more robust, sustainable, joined-up system of health and social care?", February 2022 - see https://www.gov.uk/government/publications/social-carereform-an-independent-review-by-baroness-cavendish

Competition and Markets Authority, "Care Homes market study, final report", 30 November 2017, see - https://www.gov.uk/cma-cases/care-homes-market-study

End Social Care Disgrace – Briefing for the NacSILS Local Government Election Campaign, 2023, see - https://nacsils.co.uk/wp-content/uploads/2023/04/BRIEFING-FOR-THE-END-SOCIAL-CARE-DISGRACE-LOCAL-ELECTION-CAMPAIGN.pdf

House of Commons, "Social care: funding and workforce", report of the Health and Social Care Committee, 22 October 2020, see - https://committees.parliament.uk/publications/3120/documents/29193/default/

Independent Living Strategy Group - "Charging for Social Care, a tax on the need for support?", published by Disability Rights UK, see - https://in-control.org.uk/charging-socialcare-tax-need-support/

Institute for Public Policy Research, "Healthy People, Prosperous Lives' – the first Interim Report of the IPPR Commission on Health and Prosperity, April 2023, see - https://www.ippr.org/health-and-prosperity/publications/

Journal of Epidemiology & Community Health, Volume 71, Issue 8, "Return on investment of public health interventions: a systematic review".

National Pensioners Convention: "Goodbye Cinderella: a new settlement for care services, moving forward from the pandemic" (May 2020), see - https://www.npcuk.org/productpage/goodbye-cinderella-a-new-settlement-for-care-services

New Economics Foundation/Women's Budget Group: "Universal Quality Social Care – Transforming Adult Social Care in England" (January 2022), see - https://neweconomics.org/2022/02/universal-quality-social-care

Open Letter signed by TUC and union leaders to Helen Whately, Minister for Social Care, reported on 5 April 2023, see - https://labourlist.org/2023/04/union-leaders-call-for-talks-withminister-about-social-care-workforce-crisis/

Reclaim Social Care: "Fully Funded Social Care" by Simon Duffy and Gordon Peters, 2019, see - https://citizen-network.org/uploads/attachment/660/fully-funded-social-care.pdf

Skills for Care "The value of adult social care in England" (published October 2021), see - https://www.skillsforcare.org.uk/Adult-Social-Care-Workforce-Data/Workforceintelligence/publications/national-information/Economic-value-report.aspx

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Appendix C: Video evidence from Anna Rose whose adult disabled son, Marcus died a "preventable death" in residential care. https://endsocialcaredisgrace.org/videos/

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Appendix D: Written evidence from Jo Walton, long term carer for her daughter who became severely disabled very suddenly in her early 20s

I would hazard a guess that the vast majority of us want as little to do with the NHS as possible. Barring our entry, or our children's entry, into the world and our preventative checks and vaccinations, we would prefer not to darken their doors. Life, however, no matter how careful you are, how well you look after yourself and those you love and how risk averse, has an unpleasant habit of throwing curveballs. Whether it is you personally or someone you love, being thrown into a world of doctors, hospital appointments and treatments is like stepping into a maelstrom and at that point the very last thing anyone needs is to be worrying about what your insurance covers or which treatments are free and which cost money. We need to know that the strong, free (at the point of delivery) arms of the NHS are there to hold us up and help us through and provide access to the best possible treatments and care. In the words of Bevan at the creation

of the NHS, 'No society can legitimately call itself civilised if a sick person is denied medical aid because of lack of means'. Yet today our NHS is being dismantled and we must fight both to preserve the NHS as a public service publicly run by publicly employed staff but also for the creation of a National Care Service mirroring the NHS and providing high-quality care by highly trained, respected and paid staff to those who require it, in the way that those people want it to be delivered.

I speak from the perspective of an unpaid carer. I was a 24/7/365 unpaid family carer for my adult daughter. It is as well that we always enjoyed each other's company because for many years we have been constant companions. I didn't ask for or seek the role; it became my life at the age of 50 whilst I was enjoying a very satisfying career in youth justice. My husband's life also changed; although he remained in full-time employment, the rest of his week was taken up with supporting the 24/7 care. My daughter, the focus of that care, didn't expect my change of role either nor what hit her. She was a fit and healthy 25 year old, training in midwifery, after a degree in cell and molecular biology, and enjoying life in the Capital. Completely out of left field, a neurological ticking time bomb exploded and she was left, within a year, unable to move or speak.

We have had 20+ years of interaction with our CCG, through a number of acronyms, and just entering another one in the ICBs. Until the final few years under the ICB we have had positive interaction with those staff who have understood the care we have sought for Sarah to support us to maintain her at home, which is where she, and we, wanted her to be. For those 20+ years of intense involvement with the NHS, we have witnessed the slow degradation of services, the increasingly low morale of staff as they were hit with wave after wave of reorganisation, leaving so many skilled workers not really knowing what their jobs were anymore. We've also witnessed the fragmentation and the lack of accountability which privatisation causes. In those 20+ years we have never had a functioning care package despite the NHS funding being there for it. Too often we have seen brilliant carers move on because they want a job with proper salaries, terms and conditions and public respect We have had that care delivered over the years by four different companies and our experience has spanned national companies through middle sized specialist companies to small local companies and we come across similar issues with all of them. They are big on promising and small on delivering!

I am not seeking to suggest that our experience is unique; in fact, I am absolutely sure that it is not. In the midst of attempting to care for someone who is suddenly and devastatingly ill, coming to terms with lost futures for the person you love and for yourselves, the last thing that we need is to find ourselves fighting for adequate care. Surely it should be a well-oiled, practiced and flexible 'machine' that fits the needs of those requiring it in the way that those people wish it to be delivered. I have concluded that the only way this will happen is when the service ceases to be commissioned and is actually governed by a single National organisation employing, training, supervising and paying staff to deliver and organised locally to meet the needs of those requiring the service.

During the course of time I have 'fallen over' a number of issues and I will provide you with a sample of them here in an attempt to demonstrate the frustrations the current system (or lack of them) presents

1) **Lack of accountability.**
   Sarah needed 24 hour nursing care. She became ill in February 2004 and by the end of November 2004 she had lost all of her mobility, her ability to speak and was receiving all of her medication – a complex combination – and food through a NG tube.

a) Our first package of care was provided for her through the Care manager operating within the Hospital. It was delivered by a variety of carers from a national Care Agency and consisted of night sitters and domiciliary 15-30 minute visits during the day. There was a constant succession of staff, the visits were inconsistent in their times. By the end of the 2nd year we only retained the night sitters and began to put together, with the care manager, a day care package which would enable my return to work part-time. This operated for 4 years but was unreliable at best. When I had to start taking time off work because staff were not turning up and there was no cover I gave up and took early retirement. It was my intention to return to an administrative role where other staff and vulnerable families were not relying on me, as you will see the circumstances never allowed this to happen.

b) I then spent time producing a comprehensive document detailing the care package we needed and worked with our, then new, care manager to interview Care companies and identified one claiming to be able to deliver, this time a moderate sized specialist in neurological packages. I interviewed and trained new staff and, with one who transferred over, started the new package. From the beginning, they had problems delivering the nurse within the day care part of the package. (I loathe that term, shall we refer to it as a contract instead?) When there wasn't a nurse, I had to fill in. As time went on the night care was also unreliable; when there wasn't a care worker we had to fill in.

c) We tried splitting the package between 2 companies and this time went for a small local company who were adamant that they could deliver the contract. They could not deliver the nurse and after 12 months of prevarication with me working alongside a carer 3 days a week and doing it on my own the rest of the time, we complained. The Ombudsman told us the contract was with the CCG and NHS and therefore we would have to take it up with them, but they have no penalties they can use with companies that do not deliver and they had tried to commission a package that should have worked.

d) We decided to explore ways that we could be part of the contract on Sarah's behalf and developed an Individual Support Agreement along with the CCG and a National Company – part of a logistics company. This time the package only covered the nights in the first instance in order to build confidence before embarking on a day package again, although that extension of activity was clearly laid out and agreed in the ISA. They were not reliable from the start and when there was no care worker, we had to cover the nights as well as doing all the day care. They then let us down at the beginning of the March Lockdown in 2020 because they had no PPE for their staff and Sarah was ill, so they withdrew the staff. They subsequently took the NHS money for 9 months without providing any care then made the staff redundant whom I had brought in – one of whom had been with us since 2004 – and dropped the contract. Apparently the contract had no teeth and there was nothing either the CCG or ourselves could do. We have been delivering the care night and day from then until February 2025, with me sleeping next to Sarah on a fold-down bed. Sarah would awaken up to 5 times a night and by some quirk of maternal instinct I woke with her comforted her or dealt with any issue and went back to sleep. I did get to the stage where I could literally fall asleep standing up!

e) Where exactly is the accountability for the quality of service delivery when the companies are being commissioned – always their shortcomings fall back on the household. We cannot have true accountability until the service is brought back in-house!

2) **Fire evacuation:**

During a series of form-filling exercises whilst trying to set up Sarah's care contract in in 2011 we stumbled onto advice which was being given to the Paid Carers in respect of what to do in the case of a fire at the premises. They had been instructed that they should 'secure the room with Sarah inside of it, leave the building and phone for the fire brigade from outside. The MOS who came with us from the

first contract confirmed that this was their instructions with them as well. As you can imagine, the thought of Sarah, who is unable to move or talk, being left alone in a burning building is not one we could contemplate so began to undertake research as to why such an instruction would be delivered. It appears that there is a gap in the 'Regulatory Reform (Fire Safety) Order 2005 (RRO)' which whilst it covers the evacuation of public buildings it does not cover domestic premises. We had a number of conversations with the Fire Service who confirmed that they would like to see the gap addressed and with our MP Alec Shelbrooke. He raised the issue with the then Minister for Communities and Local Authorities Brandan Lewis who declined to take any action because he said that the Fire Service could ask companies to organise evacuation. Unfortunately without the inclusion in the regulations, those who employ care staff do not feel the need to either train employees in evacuation nor insure them for injury to themselves or those they are evacuating during any evacuation process. This exposes poorly paid staff to risk of injury or litigation if they go against their employer's advice and is downright unfair. It has also left us, Sarah's mum and dad, with the conclusion that one of us has to be here at all times so that Sarah will be evacuated if the worst comes to the worst. Interestingly – it did – in March 2014, we had a house fire which necessitated our evacuation of Sarah. She was removed from her room on her bed sheet. Subsequently we remodelled her room to enable her evacuation directly to the outside from it and fought for and secured a mattress for her profiling bed with evacuation handles on it.

3) **Statutory Breaks**:
Both Mark, my husband, and myself have been managers in our careers. We are aware of many of the regulations in relation to working time directives. In the early days of Sarah's night care contract, we were visited by the District Nurse's Roaming Night teams. This was to help change Sarah or to move her position. As time went on neither activity was necessary and in fact disrupted her sleep. There were also occasions when I had to come down to break up arguments about how the pad should be put on or what position she should be in. The process was distressing Sarah so we stopped the activity. We did however, fight for and succeed in keeping the service to take over from the night sitter in order to give them a 20 minute break. They work from 10:30 to 07:30, a nine hour, shift and the working time directive from the 1998 Health and Safety at Work Act states clearly that no-one should work more than 6 hours without a break – no exemptions. As Sarah's care contract has been put out to tender again in 2023, we were informed that the requirement for the 20 minute visit was being removed because the service no longer existed and the DN had no intention of starting it back up and offering this service again. When I pointed out that a 9 hour shift without a break would be illegal, I was told that the Care Companies 'got around' this regulation by using the extreme circumstances clause in the contracts – effectively meaning that a clause meant to be used in extremis when something – eg the weather – made the break impossible was basically being used for every single shift contractually. The rules are not there to be got around – there are many reasons why that break is important both for the care worker and for Sarah and I cannot, as a trade union member myself, have people in this house who are not being fairly treated in terms of their terms and conditions. It does appear though that the directive is being ignored by both Care Companies and by commissioners within Health and Social Care. I suspect that few of those on direct payments are aware of it either. These are some of the poorest paid workers and no-one, even those in public service, are protecting their rights. It surely cannot continue.

4) **As the process of retendering got underway firstly through the CHC and then through the ICB, suddenly the agreement for 24 hour nursing care, written into the ISA was no longer and option.**
Firstly we were told by some panel known as the 'Exceptionality Panel' that should anything happen to myself or my husband that Sarah would be taken into hospital to be cared for there because 24 hour nursing care at home is too expensive and there are no care or nursing homes which could cope with the complexity of her needs. Where are the needs and wants of the assessment here – hospital is the last place which could cope with Sarah's care – they are not geared up for the needs of those who are

disabled and without her voice through us I would fear for her future. Our neurology consultant and GP agreed and when challenged, accompanied by a specialist solicitor, the attitude changed. We could have some support, some nights, maybe, and some 15-minute visits through the day; we have already been here. If that was not sufficient, then Sarah would have to go into a nursing home appropriate for her care needs, which had suddenly materialised as if by magic. It took a further 6 months to extract the details of these establishments to enable us to assess their suitability ourselves. We had begun this process when on the 26th February 2025, Sarah grew her wings. Her passing broke our hearts and not a day goes by when we do not miss her physical presence. It is a great condemnation of the system that my next emotion after overwhelming grief was relief. Relief that we no longer had to worry about or fight for adequate care for her when we were no longer able to deliver it ourselves. I also resent the amount of time we spent fighting for fair care instead of focusing on the care we were giving her, no matter how we tried not to let the fight impact, inevitably it raised blood pressures and preoccupied minds. It is interesting to note that one of the first organisations that the GP informs of the passing of a patient is the ICB/CHC. The only person who contacted us several weeks later was the retired care manager, not any of the staff who were supposed to be involved with Sarah. We wonder whether fear of litigation had tied their tongues.

I am sure that there are other issues which have arisen over the years and there are more that will emerge but I leave these in your capable hands

Care services in this country are broken. They have been broken by the fragmentation brought about through privatisation and the raiding of the funds provided by those services to provide profits for shareholders rather than quality professional services for the users. There is no room for profit in care.

Those who need care have become commodities, put up for auction to the lowest bidder, their details laid bare. Family homes become workplaces and lose the essential element of sanctuary.

We cannot go on accepting that we cannot afford a National Care Service free at the point of delivery and run and delivered by highly trained, well paid professional staff. With a National Care Service everyone wins, the economy, local and national, the NHS, workers and most importantly and centrally the mental and physical well-being of those needing the care. We shouldn't settle for less otherwise we are leaving the issues for generations to come.

All parties needs to listen to those who are involved, those needing care, carers and care workers and finish the work which Bevan began. From my perspective, it was my lived nightmare that my daughter's need for my care would outlive my ability to deliver it. It should be no-one's nightmare because the care that should replace it should be every bit as good – in fact, quite probably, considerably better.

To paraphrase Bevan's NHS quote:

'The need for care is neither an indulgence for which people should pay nor and offence for which they should be punished but a misfortune, the cost of which should be shared by the whole community.'

……

Appendix E: Summary of written evidence from Chris Wade, carer for his disabled sister

This document presents a 45-year case study illustrating the lived experience of a family caring for a woman with a learning disability, epilepsy, Parkinsons, mobility difficulties, and significant communication needs. It

highlights the family's lifelong commitment, the emotional impact of bereavement, and the serious failures of Adult Social Care when the family sought minimal support following the sudden death of the mother. The case exposes critical weaknesses in assessment processes, communication, safeguarding practice, commissioned care quality, and accountability mechanisms within Adult Social Care.

Background

The service user was born in the early 1970s. Her parents rejected institutionalisation after being told their daughter was "Mentally Retarded... for life" and advised to place her in a "Special Hospital". Instead, they chose to raise her at home, providing unconditional care, advocating for her dignity, and enabling her to participate in community life.

For 45 years, the family provided full-time support without receiving any adult social care services. They adapted their home extensively to maintain her independence, including installing grab rails and engineering bespoke mobility supports. Her mother and father ensured she lived a life of safety, inclusion, and love.

In spring 2015, the mother died suddenly following catastrophic organ failure. Her death left the elderly father-himself in declining health-solely responsible for his daughter's complex needs. He requested a very small amount of support: one hour each morning to help with washing, dressing, and breakfast.

Failures in Access and Assessment

Excessive Delays and Lack of Responsiveness

Despite repeated calls, emails, and urgent context, the family waited weeks for any meaningful action. Staff repeatedly stated that the assigned social worker was "busy", "in meetings", or "on annual leave". The department prioritised administrative systems over human need, stating they "could not find her on the system".

Failure to Contact Medical Professionals

The family GP confirmed that Adult Social Care had made no contact whatsoever, despite the service user's complex medical profile. The GP expressed "professional anger" at the neglect and intervened directly.

Discriminatory and Inappropriate Behaviour

Staff asked irrelevant historic questions and made discriminatory assumptions based on regional accents. These interactions caused humiliation, distress, and loss of trust.

Failures in Commissioned Care Provision

Unsafe Personal Care

A carer's behaviour during showering caused the service user to become terrified, leading her to refuse showers entirely. As a result, she was subsequently "washed on the toilet"-a clear violation of dignity, safety, and basic human rights.

Physical Control and Intimidation

Staff used physical force, including placing a hand on her chest and pushing her back into a chair while instructing her to "wait". Staff pulled her from room to room rather than allowing her to use the grab rails installed for her safety.

Ignoring NHS Care Plans

Staff used a large, sharp-edged “farmhouse spoon” to feed her, despite an NHS Eating and Drinking Plan specifying safe utensils.

Breach of Privacy
Staff attempted to let themselves into the home using a key-safe code rather than ringing the doorbell, demonstrating disregard for privacy and safeguarding.

Failures in Safeguarding Practice

Safeguarding Used Against the Family
Despite clear evidence of unsafe care, safeguarding procedures were directed against the family. The brother was falsely accused of being “only interested in the bungalow”.

Failure to Safeguard the Service User
Reports of unsafe showering, physical intimidation, inappropriate feeding, breach of privacy, and emotional harm were not investigated.

Coercion and Intimidation
During a meeting attended unexpectedly by multiple care-company staff and a director, the family was told: “There are cheaper environments for your sister to go.”

Withdrawal of Care Without Notice
After the father’s death, the care provider-supported by the social worker-withdrew all care without notice because the brother moved into the home to protect his sister. This left a grieving, disabled adult with no support, in direct violation of statutory duties.

Impact on the Family
The failures caused trauma and fear for the service user, deterioration in health and confidence, emotional exhaustion for the father, grief compounded by bureaucratic neglect, intimidation and discrimination toward the brother, and complete loss of trust in Adult Social Care.

Key Lessons for National Reform

- Timeliness and responsiveness must be mandated and monitored.
- Safeguarding must protect service users, not be misused against families.
- Commissioned care quality requires stronger oversight and accountability.
- Trauma-informed practice must be standard, especially during bereavement.
- Family expertise must be respected as essential evidence.
- Privacy and dignity must be non-negotiable.
- Complaints and concerns must trigger immediate investigation.

Conclusion
This case demonstrates systemic failure across assessment, safeguarding, care provision, and accountability. It shows how vulnerable adults and their families can be harmed by the very systems designed to protect them. The family submits this evidence to support national reform and to ensure that future social care systems uphold dignity, safety, and humanity

Appendix F: The Case for a Carer's Income/Stipend by Jo Walton

Carers don't ask for the job. It comes to them, knocks on the door and says 'Let me in'. It can happen at any time in a person's life, statistics indicate that 4.3 million people every year become carers, while 4 million leave their caring role. At least 5.8 million people in the UK are Carers, this is likely to be an underestimate, with other estimates at 13% of the population having caring responsibilities, somewhere between one in eight and one in nine people in the UK. 1.7 million are providing 50 hours, or over, of care every week.

Many Carers, across the whole age range, take years to realise that is what they are.

For some Carers, the label arrives overnight, as a result of a catastrophic event. For some, it creeps up on them over years, and for some, they are born into it and grow up through it. Yes, there are child Carers, 800,000 of them, some as young as 5, 140k of them, 3000 between the ages of 5 and 9, do 50hours and more of caring per week; quite honestly, it is a National disgrace!.

What are my credentials to talk here on this subject? I became a carer along with my husband in 2004. Our bright, intelligent, hard-working daughter went from being a degree-qualified midwifery student, living a satisfying life in London, to someone who needed 24-hour nursing care, all in the space of 10 months, because of a devastating degenerative neurological illness caused by the measles virus. We spent from May 2004 to February 2025 caring for her 24/7 with minimal help, that in itself is another discussion, and then it came to an abrupt end, and that is another story. Let's focus for now on how Carers survive.

The impact of caring on Carers' lives is significant. There is no work-life balance in households where care is needed and given through love. There may be paid work, but research shows that 44% of carers had to reduce their hours at work because of caring responsibilities. 2.7 million carers are not in paid work and of those who do work 38% are working part time.

Benefits for carers are dire. A measly £86.45 per week,

- only if you care for 35 hours or more,
- only for one person in the household even where 2 are needed to do the task;
- And don't dare earn more than £204 per week, otherwise you will have to pay it all of that money back, not the bit that was overpaid, all of it.

Carers are more likely to be in low wage, zero hour contracts or part time roles, where losing track of your earnings is easy, especially when juggling all the other fights for care, support, health interventions, adaptations. Benefits, education, transport and battling lack of sleep and emotional and physical exhaustion. But even with access to the information they need to prevent overpayments in the current system, the DWP would rather penalise Carers, adding more stress to their daily lives, than to give them the support they deserve.

Carers save the Treasury £184 billion a year, whilst constantly losing in terms of their own income. Recent research suggests that the lost paid labour of unpaid Carers costs the UK a further £47.7biliion, 1.7% of GDP

Carers miss out on the reassurance that they can earn a decent salary to keep the roof over their head, food in their stomachs and enough to save for a rainy day. Their rainy day has already come; nothing to do with lack of planning or hard work, it was just random and devastating.

- They lose careers.
- Chances in education
- The ability to own their own home.

- They lack the security of long term rental, there are massive issues about private rentals and adapted accommodation
- They lose the opportunity to spend leisure time with friends and relatives.
- They miss family celebrations.
- They don't go on holidays.
- They lose their own identity.

But still, the government wants them to work harder and survive on less. Carers have had enough. It's not unreasonable to expect appropriate support whilst undertaking a task that the government would otherwise have to shoulder. They may not be in paid full time employment, but they work hard, long, unsociable hours and without the benefits of working time directives and health and safety legislation.

The household expenses of those many carers who live with those needing care are vastly greater than in normal households. Research indicates that disabled households need an additional £1010 a month to have a similar standard of living to non-disabled households. And this continues to rise as the cost of living rises, especially energy costs.

Caring is not employment, but it is work. Carers are contributing to the economy. We accept the government would find it difficult to give Carers a wage because of health and safety issues and working time directives. But in order to have a reasonable standard of living, Carers deserve an income to compensate for the caring duties they undertake, a stipend if you like, which addresses the disproportionate impact that care has on household expenses. Carers need access to

- National Insurance contributions for pensions, for sickness benefits for paid holidays,
- To a works pension accumulation to supplement meagre state pensions in old age.
- The ability to save to pay for normal household expenditures.
- The ability to take out and maintain mortgages so they have security within their own home, or security of tenure on rental accommodation, which needs to continue even after the worst happens.

It is unlikely that the government will accept that Carers need to be paid minimum wage for the hours they care, although this would have some fairness about it. Those who care 24/7 would be entitled to £111k a year and even if you took out the notional 7 hours for sleep, which many don't get, it would be almost £79K.

ESCaD's Carer's group has looked around, made comparisons to similar types of roles where there are no time limits or health and safety on the job. There seems to be many similarities with the roles of ministers of religion across all the faiths. Stipends, their renumeration, vary from £17k to, in some cases £52k, not taking into account the added factor of tied housing, which makes that renumeration much higher. According to data from Zoopla, the average homeowner in the UK faces annual mortgage repayments of **£11,400** in 2024. This is up 60% since 2021, when repayments averaged £7,000 per year. According to NimbleFins analysis of official data, the **average rental** cost in the **UK** is now £954 a month per household for private renters and £484 for social renters (that is, local authority and housing association accommodation).

We looked at the research undertaken by various groups into how much income a person or family needs to live reasonably comfortably and have added in the disability premium we spoke of earlier. We feel that an income of £35k a year is not unreasonable. This could, of course, be adjusted to account for the time spent caring and the area of the country and the number of people required to undertake the task. Some kind of action would also be needed for those under 16, who truly do a very loving job but whose adulthood continues to be adversely affected by their altruism. It is no wonder that the Government prefer a measly £81.90 a week.

There would be benefits to the economy, though. The money in Carers pockets would be spent in the local economy, which would ‘trickle down’ to the Treasury through VAT returns, income tax and National Insurance of the Carers themselves and those who are employed on the back of the increased economy. It would push up employment rates across all those areas which the Carers would be accessing. People would be happier and healthier and incur less costs to the NHS. It's common sense. We expect nothing less. Our message to the Government, especially now as we approach the Autumn budget, is ‘Don't blow it’ Make your consultations work for the people who need, not those who don't. In the parlance of my dear departed daughter. ‘Tell you what, Carers, right? We deserve better!’