



www.endsocialcaredisgrace.org

✉ endsocialcaredisgrace@gmail.com

x@EndSCDisgrace Tel. 07419295754

<https://www.facebook.com/EndSocialCareDisgrace>

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, local communities**
- 6. Offers choice, control, dignity and independence**
- 7. Provides a range of practical and financial support to carers and values their expertise**
- 8. Ensures that staff pay and conditions reflect 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

- 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 £23,500 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.
- Disabled people are significantly more likely to live in poverty than non-disabled people (27% compared with 21%). (1) Many struggle to pay rising care charges. A BBC investigation in August 2021 (2) found that in 83 Councils charges for support had risen from £369m in 2018-19 to £420m in 2020-21 and in 22

Councils charges for people with learning disabilities had risen by the equivalent of £500 per person supported during the same period. In 20/22 more than 60,000 adults with disabilities and long-term illnesses in England were chased for debts after failing to pay for their social care support at home and Councils took legal action against 330. Some disabled people said they felt they had little choice but to live without home care, others feared bailiffs being called in over unpaid debts. (3)

- 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, potentially saving as much or more than it will cost 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
 - 1.6 million care and support workers paid decent wages will also 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. (4) 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 the tax lost in Britain through non-payment, avoidance and fraud in one year would raise more than £35bn

For more detail on affordability see (5) : <https://endsocialcaredisgrace.org/wp-content/uploads/2023/10/Adult-Social-Care-and-its-funding-ESCaD-draft-for-comment.pdf> 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 about 5,000 separate providers of care homes but the five largest private providers own about 20% of the total beds. The asset value of privately owned care homes alone amounts to £245billion. 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 will just walk away, leaving people stranded.
- 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. It is estimated that they pocket £13 out of every £100 income with medium sized companies taking about half that. (6)

- 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. It also contributed to increasing risk during the pandemic.

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 and peer support services.
- Alongside flexible personalised support there needs to be a powerful focus on developing fully inclusive local community facilities – housing, workplaces, transport, libraries, leisure etc. i.e. all twelve pillars of independent living.(7)
- 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 provide proper recognition and flexible support to family carers

- Most informal carers want to look after someone they love but in doing so they should not have to damage their physical or mental health or live in poverty. Even before the pandemic, Carers UK (8) found that 2 in 5 carers were ‘struggling to make ends meet’ and a study by the Children’s Society found that of the 800,000 children between 5-17 acting as carers, over a third were having mental health problems and 27% were missing or having problems at school. (9) The latest(2021) survey from the Office for National Statistics suggests there had been a drop in the number of unpaid carers in England and wales to 5million but a significant rise in the number of carers providing 20 – 50 hours care a week. However many carers are not on official radar and others don’t identify themselves as carers until desperate for help. Carers UK estimates that the total number of carers in the UK today is around 10.6 million, which means that 1 in5 adults are providing care. (10)

- It is estimated that family carers save the treasury £162 billion in England and Wales. (11) Without this positive army of carers our fragile social care system would have collapsed years ago. Little financial, emotional, or other support, such as respite assistance is provided.
- 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.
- They also need adequate funding and reliable support for those they look after and a guaranteed income to enable them to carry on providing support without financial hardship.

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, many of whom are being exploited and constrained in circumstances close to modern slavery. These upside down values are at odds with the way most of us want to live as part of extended networks of family, friends, neighbours and colleagues working with, not against each other.
- Care and Support Workers should be paid an absolute minimum of £15 per hour – including sleep-in shifts, travel time etc. It is estimated that raising pay for care workers to £15ph would cost £5.9bn but would boost England's economy by £7.7bn. (12) They should have sick pay and holiday pay, 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. (13)

1. <https://www.health.org.uk/evidence-hub/money-and-resources/poverty/inequalities-in-who-is-in-poverty>
2. <https://www.bbc.co.uk/news/uk-58259678>
3. <https://www.bbc.co.uk/news/uk-64668729>
4. <https://www.oecd-ilibrary.org/sites/cb584fa2-en/index.html?itemId=/content/component/cb584fa2-en#:~:text=In%202019%2C%201.5%25%20of%20gross,%25>
5. <https://endsocialcaredisgrace.org/wp-content/uploads/2023/10/Adult-Social-Care-and-its-funding-ESCaD-draft-for-comment.pdf>
6. <https://chpi.org.uk/papers/reports/plugging-the-leaks-in-the-uk-care-home-industry/#:~:text=Some%20of%20the%20largest%2026,supplies%20from%20a%20related%20company>
7. <https://breakthrough-uk.co.uk/principles-of-independent-living/>
8. <https://www.carersuk.org/news-and-campaigns>
9. <https://www.childrensociety.org.uk/what-we-do/our-work/supporting-young-carers/facts-about-young-carers>
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11. <https://www.sheffield.ac.uk/news/cost-unpaid-care-england-and-wales-now-exceeds-nhs-budget>
12. <https://www.tuc.org.uk/news/ps15-minimum-wage-care-workers-would-boost-englands-economy-ps77-billion>
13. <https://wbg.org.uk/wp-content/uploads/2020/06/Care-led-recovery-final.pdf>