End Social Care Disgrace

Campaign for a National Care, Support and Independent Living Service

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# A response from the End Social Care Disgrace Campaign to Andy Burnham's latest announcements on Social Care

**Looking on the bright side it is encouraging to have a Prime Minister who wants to dig social care out of the mud in which it has been sinking for three decades, surrounded by the flotsam of twenty two, long lost reports and reviews.** On 29th July he promised to bring forward the date for the Casey Commission to set out proposals for a National Care Service from mid '28 to mid '27 and to look at how to go beyond the agreed Fair Pay Agreement to uplift the care workforce and integrate it more with the NHS workforce. He also made clear his intention to start cross party talks immediately to try to reach a consensus and stop political infighting blocking progress.

**It isn't yet clear whether he has the courage and headwind to row against the neoliberal tide and official fiscal orthodoxy which will be necessary to get the boat afloat and whether Labour is prepared to go it alone if cross party efforts threaten to scupper it**. He has talked about the need to improve the quality of care but hasn't given any clear indication that he is committed to genuinely radical change, co-produced with disabled and older people, carers, care workers and local communities to deliver the kind of life enhancing support people want and need. This needs to be far cry from the current, largely institutionalised care that robs people of agency, choice, control and dignity. He has indicated previously that he wants to see much fairer and wider access to support but not whether he will make support free at the point of use. He has talked about stopping profiteering but not about reversing the privatisation of social care and developing 'not for profit', publicly accountable provision.

**Meanwhile the current deeply unfair, largely means tested, heavily rationed social care provision continues to cause serious harm and avoidable deaths**

- Around one in four people with unmet social care needs were subject to emergency hospital admissions on account of potentially avoidable conditions. Yet in Hammersmith and Fulham, where the Local Authority have provided free home care for over a decade, not only has the number of older people 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 within the Borough remained at home 91 days after discharge, placing them fifth in national ratings.

- **Over 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. Not only does this result in logjams in NHS Accident and Emergency Departments, which The Royal College of Emergency Medicine estimates contributes to 305 unnecessary deaths per week, 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.

- **Disabled people and their families are more likely to live in poverty.** In 2024 The Rowntree Trust estimated that 3 in 10 of the 13 million people living in poverty were disabled. If you add in carers and

other household members, almost half of those living in poverty are affected by disability. Meanwhile people who have to pay for the full cost of residential care, i.e. anyone with over £23,250 in assets, is now paying an average of £1,400 a week, a rise of more than a quarter since 2021-22**.**

- **The quality of life of many disabled and older people in receipt of support at home is often abysmal as the drive for profit distorts their daily lives**. 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, often untrained 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.

- **Residential care is not just institutionalised, with too many older people still parked in rows of easily washable chairs on easily washable floors surveyed by staff in a glass box; it cannot offer stability and peace of mind**. Private providers can go bust or pull out at short notice; they also account for all but twelve of the 800 establishments closed down by the CQC between 2011 and 2023. Overall eight hundred care homes closed between 2011 and 2023. Residents who had to be shipped out lost the familiar links to place and persons which are so important in preserving mental health.

- **There continue to be shockingly routine rates of death and harm in residential care and hospital settings.** The horrific abuses of learning 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, preventable deaths through accidents, choking, drowning in a bath etc. because of lack of supervision and training.

- **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.

- **Of an estimated 10 million unpaid carers, including 800,000 children, fewer received support in 2025 than in 2014/15.** Many note that the struggle to get appropriate help from the Local Authority, NHS and the DWP is more stressful than their caring responsibilities. They find that their knowledge and experience is undervalued, their views ignored or discounted and worrying numbers feel disbelieved harassed, even bullied. Some 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 unthinkable, 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 at the same time as navigating a cumbersome, often opaque system and seemingly arbitrary divisions between Local Authority and Continuing Health

Care funding. Some still fear being hauled through the courts for inadvertent overpayments owing to the ridiculous cliff edge nature of carers allowance payments and failures in the DWP to fix the problems. Meanwhile it is estimated that family carers save the treasury £184bn in England and Wales. Without this positive army of carers our fragile social care system would have collapsed years ago

- **Care and support workers doing stressful, demanding skilled work are seriously undervalued, under paid and often receive little or no training.** The median hourly rate for care workers in March 2025 was £12.00 and one fifth are on zero hours contracts. It's not surprising that turnover rate is close to 30% on average but 43.5% for those with less than one year's experience.

- **Overseas workers are in a particularly distressing situation,** 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 and made to feel unwelcome; 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!

**What we need from Burnham and Baroness Casey's Commission is a serious, radical and rapid plan to work not just with politicians but more importantly with disabled and older people, carers and care and support workers to set up a ground breaking National Care and Support Service which is free at the point of use, "not for profit" nationally mandated but locally designed to deliver what people truly want and need, alongside a commitment to build inclusive communities.**

**However, people suffering harm can't wait for jam tomorrow, should tomorrow come! Burnham has an opportunity to make a difference now and at the same time start laying down some tracks for the way forward. He could and should**

**A. 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

**B. 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.**

**C. 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.**

**D. Look seriously with DWP colleagues at providing a guaranteed income /stipend rather than 'benefits' for carers.**

**E. 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

**F. 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.

**G. Insist that other Departments -** housing, transport, employment, education, culture, planning etc.at national and local levels are on board with building inclusive communities where there is opportunity for everyone both to contribute and benefit.