



Newsletter

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Better with Burnham- we hope!

The pundits say that Burnham defeated Reform and Restore Britain in Makerfield but the flipside of 'his' victory is that enough ordinary people in Makerfield refused to side with hate and division, put their faith in a fairer society and crossed fingers that Burnham might be bold enough to jump start it.

Erin Mansell in Open Democracy suggests that "If Andy Burnham is serious about addressing the inequalities he has identified, reforming social care and creating the conditions for 'good growth', he will have to grapple with a fiscal framework that systematically undervalues social infrastructure, and fails to see it as an investment that generates long-term economic returns. Research by the Women's Budget Group suggests investing in care would produce 2.7 times as many jobs as an equivalent investment in construction. She suggests the Government should create a new category of investment spending alongside current and capital spending, allowing borrowing for social infrastructure while those returns are realised. And these reforms should be accompanied by a fairer and more progressive tax system that expands fiscal space by taxing wealth more effectively and equalising capital gains tax"

<https://www.opendemocracy.net/andy-burnhams-promises-of-growth-rely-on-real-investment-in-social-care/?ref=weekly-newsletter>

Burnham has said "It is urgent, the need to fix social care, and I personally would look at all of the kind of implications of that in relation to inheritance tax and care charges and everything. I wouldn't flinch from it." He has also made clear that he



would like the Casey Review published by the end of 2026 and Stephen Kinnock, Minister for Social Care, appears to agree.

Burnham does come with a reputation for engaging with disabled people in Manchester so let's travel hopefully and keep up the pressure!

Thanks to Brian we have a piece on Compass's website : <https://www.compassonline.org.uk/how-to-reform-the-social-care-sector/>.

New NHS Bill: risk to Social Care

This Bill, which had its second reading on 1st June, abolishes NHS England and seeks to strengthen Integrated Care Boards as the primary, local strategic commissioners while cutting their capacity and making them directly accountable to the Dept. of Health. Also under the axe is Health Watch, which is at least a semi- independent voice for the public, as well as mandatory representation of Local Authorities on Integrated Care Boards. The Kings Fund among others notes that this seriously risks undermining partnership work between the NHS, social care and public health at a local level. The Health and Social Care Committee has submitted an amendment to the Bill to retain the statutory requirement to include LAs on ICBs. When Casey was quizzed by MPs live last week she stressed the importance of not letting Acute Trusts run the show and suggested Local Authorities need a much higher profile, noting that people see the LAs as theirs! She also noted that what has been missing from previous reviews and commissions is an essential conversation with the public about how social care works, what people want and are prepared to do themselves, which the Commission will launch in July. See:

<https://www.youtube.com/watch?v=8wZFuvD0hKQ>

Supreme Court removes deprivation of liberty protections!

A Supreme Court Ruling on 2nd June removes a landmark 2014 legal framework known as

‘Cheshire West’ which established that if someone lacks mental capacity to consent to their care and living arrangements, is under continuous supervision and control and not free to leave, they were legally ‘deprived of their liberty’. This triggered vital legal safeguards (DoLS), requiring an independent assessor to regularly inspect care homes, supported living arrangements and locked units to ensure the placement is safe, justified, and in the person’s best interests.

A joint statement from Mencap, MIND and the National Autistic Society notes that stripping away these safeguards makes it easier for abuse and neglect to go unnoticed behind closed doors. A litany of previous wrongdoings demonstrate how closed cultures, lack of independent oversight and restrictive care can lead to abuse scandals. The Court implies that individuals with profound cognitive disabilities cannot be "deprived" of liberty because their condition limits their ability to experience it- view that devalues their fundamental rights. If a person appears passive or does not actively protest their arrangements, the law may recognise this as "consent" - even if they are subjected to routine physical restraint or chemical sedation or have never known a life without a high level of restriction. They call on the UK Govt. to act urgently to issue interim guidance to Local Authorities and health and care providers to prevent them being plunged into chaos by this ruling and to bring in new laws and guidance that strengthen protections for some of the people who are most at risk.

<https://www.mind.org.uk/news-campaigns/news/the-biggest-rollback-of-disability-rights-in-a-generation-charities-respond-to-supreme-court-ruling/>

Report from Rachael Tomlinson on the Disability front line



June has been another incredibly busy month in disability policy, and it's clear that welfare reform continues to dominate the conversation.

We've seen on-going debate around Personal Independence Payment (PIP), Universal Credit and proposals that could fundamentally change how disabled people are assessed and supported. While some discussions have focused on helping more people into work, many disabled people remain deeply concerned that reforms risk reducing

support without addressing the real barriers we face every day.

The latest PIP statistics painted a mixed picture. The number of people receiving PIP has continued to rise, but so have waiting times, while fewer new claimants are receiving awards than a year ago. These figures remind us that demand for disability support isn't disappearing, nor are the challenges people face navigating the system.

Access to Work has also remained firmly in the spotlight, with MPs hearing evidence about long delays and administrative problems that are preventing disabled people from taking up or staying in employment. If we're serious about improving employment opportunities, the support systems have to work.

In Westminster there have been some encouraging conversations around the future of social care, independent living and making public services more accessible. These issues are closely connected. Disability policy isn't just about benefits – it's about housing, transport, employment, healthcare and ensuring disabled people can participate fully in society.

As always, thank you to everyone who has shared your experiences with me. Your stories shape the conversations we're having and remind decision-makers that behind every statistic is a real person.

Dementia Rebels Change the Tune

Anne Karpf in the Guardian highlights the fight by a number of dementia activists against damaging stereotypes, the notion that dementia is a slow and sad death and the lack of support.

They suggest that a hybrid of ageism and ableism combine to perpetuate fear and anxiety and avoid people being seen as whole persons. When diagnosed with dementia, people are advised to pursue what Kate Swaffer calls “prescribed disengagement”: avoid risks, rest and get your affairs in order in preparation for death. A number of dementia ‘experts by experience’ have set up new groups like the Young Dementia Network and joined the Dementia Alliance International and Dementia Engagement and Empowerment Project. They are involved in research projects like ‘Living Well with Dementia’. Julie Hayden said that “Alongside my dementia, I lead a fulfilling life and actively contribute to my community. I’m not alone in this; countless others diagnosed with dementia live meaningful and active lives. Some do that for many years after diagnosis. We may need help and support and we will need to adapt our lives. We

have a voice and we need that voice to be heard.” They are calling for therapeutic interventions such as cognitive rehabilitation, speech therapy, access to dementia nurses and more schemes where people living with dementia act as “peer tutors” to those who are newly diagnosed.

<https://www.theguardian.com/society/2026/jun/09/dementia-rebels-diagnosed-determined-change-peoples-minds>

HIDDEN VOICES 2: OLDER PEOPLE: 18.6

To view the recording see here:

<https://www.youtube.com/watch?v=svOdSUVotCM>

ESCaD’s latest Public meeting on 18th June focused on the hidden/discounted voices of older people, the need to challenge ageism, self-organise and push for a radically re-imagined National Care, Support and independent Living Service.

Neil Duncan-Jordan, Labour MP for Poole, suggested that we can take people with us in arguing for collective public provision of Social Care as they see the inequities of having to pay huge amounts for the care of someone with dementia but not with cancer etc. He suggested that the Casey Commission was a massive missed opportunity. As it isn’t due to report until 2028 the current Government will have no opportunity to implement its recommendations in this Parliament. We have to turn this round. Government needs to tackle privatisation, the low pay and status of care workers, unhook certificates of sponsorship for workers from overseas from specific employers and address the massive lack of support for unpaid carers. We should start by taking domiciliary contracts back in house when they come up for renewal. Longer term we need to look at how care homes can be brought back into public ownership.

Neil said that he will be pressing for a commitment to a publicly provided, national care service to be



in the Labour manifesto. In answer to a question from Rosie about what we can do, referencing John McDonnell’s suggestion that we need

to create a social movement, Neil suggested that getting people to write to their Constituency MPs, asking them to raise questions in Parliament, table amendments, attend meetings and debates, sign petitions etc. really does work. It may be traditional but stirs MPs to act, particularly when they get multiple similar requests. He agreed with McDonnell that it helps enormously to have a movement outside Parliament as well.

Alisoun Milne, Emerita Professor. Kent Uni.

presented research showing that the market model comes with inbuilt risk and causes preventable harm. When firms running ‘care’ homes collapse or pull out and their workforce is precarious, residents suffer



physical, emotional, autonomy and relational harms, including acute distress. Two key causes of ruptures in care are financial instability and worker precarity, both of which are particularly high in the private sector. 8,000 care homes closed from 2011 – 2023; 20,000 people had to be found alternative places.

Disruptions to care at home through having a succession of carers, carers turning up erratically and lacking time to build a relationship, also cause harm. These harms particularly damage people who e.g. have dementia and are least equipped to act as autonomous, independent individuals.

Alisoun argued that human rights protections for older people need to be embedded in policy making and planning of care services: noting that the construction of care as an economic commodity has corrupted any alignment with a rights-based agenda. There is also need for stronger regulations and for foregrounding what matters to older people through ruptures e.g. protecting relationships with other residents as a care home closes.

We need to invest in preventative work which isn’t profitable to private firms and develop Cooperatives and not for profit alternatives.

Gordon Peters, ex-Director of Social Care

talked about a grassroots initiative by a few older people in Haringey recently diagnosed with mild cognitive impairment. They have come together both to support each other and challenge the prevailing but erroneous notion that MCI is always a precursor to dementia and nothing can be done.

Gordon noted that only 50% of people with MCI go on to develop dementia; early intervention can prevent 40% of cases but is largely non-existent. This needs to change.

The Council and Joint Partnership Board have been supportive, weekly group sessions have been set up and interest is growing. Gordon suggested that this is a short story about getting a significant health and social need recognized, tackling stigma or fear which stops people getting support and prising out willing professionals/ experts to work as equals on a local solution.

Marianne Lynch, carer and advocate

described how a striking deterioration in her 87 year old father's health in hospital after a routine operation, fall and hospital acquired Covid infection, was wrongly characterised as an inevitable consequence of aging. His voice went unheard, his whole self unseen and his needs dismissed. This started a long slide to his voice being ignored and needs not met. It was aggravated by the greed of care companies who employed and exploited poorly paid workers on sponsorship visas and didn't give them any training. She has had a long struggle to get her father the support that would enhance his life rather than deprive him of choice and agency. As his advocate she too felt unheard by professionals, the Council and whoever she approached. She tried to get Continuing Health Care funding without success. She resisted the suggestion that her father needed to go into a care home where she was sure that he would be unsafe and deteriorate rapidly.

Marianne ended her contribution by talking movingly about what her father is really like as a person and asked that we make sure his and other voices of older people are heard.

Councillor David Jenkins, Chair of the Age Friendly Board in Leeds, outlined how older



people from a wide range of backgrounds are involved in shaping developments in local transport, health services etc.

Tony Watts 'Later Life Agenda', and the Centre for Aging Better are useful resources. A number of organisations are campaigning for an Older People's Commissioner.



Thanks to attendees for all their contributions.

Colin who is involved in an embryo Equal Care Coop in Ealing suggested we should all be pursuing free home care and JOIN UP! Ealing CLP has a motion to Labour Conference on social care, he is organising a stand and Dame Sally Powell is arranging a fringe meeting.

Anne noted Local Govt. finances are incredibly insecure; in Haringey a fight to retain and remodel a LA home failed because of the lack of cash.

Jo and others spoke about the need to hammer home the argument that spending on social care is an investment not a drain.

Larry said the Government needs to start by doubling the pay and numbers of care workers

John queried whether Alisoun thought the CQC does anything to improve the quality of care. She said that over the years the CQC has become less about the things that matter to older people, relationships, time spent with them, activities etc. and more about numbers of fire



extinguishers etc. In the chat **Penny and Jacquie** noted that the CQC was damaged and rendered less effective by re-organisation.

Chris said that providers, social workers etc. must listen when people raise concerns not bully them!

Mike asked why the Supreme Court reduced DOL safeguards. Alisoun said she doesn't know but some people have noted that it saves money.

Gay hopes the Green Party's new councillors will counteract the influence of Reform and use their power to challenge aspects of the current system.

Gilda referred to the briefing for Green Party and other councillors on the ESCaD website:

<https://endsocialcaredisgrace.org/letter-to-green-councillors/>

John noted that Reform in Lincolnshire is closing dementia support services.

Jacquie has asked Hannah Spencer, her Green MP to raise Parliamentary questions re carers.

Sylvia made a plea for mental health support.

Join the Fight

Get in touch at 07419 295754 or

endsocialcaredisgrace@gmail.com, request our free postcards, hop on to planning meetings etc.

Solidarity and best wishes

