

Draft piece for the NPC newsletter from GP 7.8.24
From Carers to a National Care and Support Service

At last the unsung, unheard and largely unsupported army of unpaid carers have been thrust centre stage. Sadly this wasn't to receive recognition for the fantastic work they do or the £162bn they are estimated to save Government every year (1) but because they were being persecuted by the courts for over-payments of benefits inadvertently accrued owing to the ludicrous cliff edge nature of carers benefit, punitive restrictions on earned income (£151 per week) and failures in the DWP!

Let's hope that with a push there may be some overdue tweaking of the benefits system. However that would only scratch the surface of issues for carers.

Dig just below that surface and it becomes clear that much of the stress, exhaustion, frustration, isolation and impoverishment experienced by many carers is not caused by caring for their loved ones but by having to battle every step of the way. Many toil through the labyrinth trying to establish what financial and practical support might be available to them and the person they are caring for. Then they have to jump through demeaning hoops of repeat and intrusive assessments, sometimes carried out by staff with very limited knowledge and skills. As support is generally resource led not needs led, despite what it says in the Care Act, carers and disabled people have to highlight what they can't do in order to get help, knocking the stuffing out of their self-respect and pride. Finally carers have a massive uphill struggle to find and retain providers who can provide safe, expert and reliable support.

Throughout all these battles the stress is magnified by carers finding that their knowledge and experience is not recognised and they don't have any seat at the table when key decisions are being made regarding the people they love and care for. Many carers are also desperately anxious about what will happen to their loved ones if they are sick or die. However, cash strapped Local Authorities winging their way on very short term financial allocations and almost totally dependent on outsourcing live for the moment and can't offer any answers. Increasingly carers are calling on legal advice and advocacy to challenge decisions, bringing a whole new raft of work and anxiety while only open to those with the means to pay.

It is clear that all actors in Social Care are woven together by many of the same strands: being undervalued, unheard, marginalised and often poor. Unpicking these strands and challenging the myths that sustain them is essential if we are to make serious progress towards setting up a National Care and Support Service that works for everyone. Piecemeal change will not suffice.

A powerful myth is that older people and disabled people are not as valuable as "workers" as they contribute less to the economy. This runs deep in a society where the neo-liberal doctrine that making profit for a small elite is the only hope of creating trickle down growth and wealth for the many is passed off as common sense, even though it patently doesn't work. Recent research by Oxfam (2) exposed the fact that the world's five richest men have more than doubled their fortunes to £681bn since 2020, while the world's poorest 60% – almost 5 billion people – have lost

money. In the UK, where 1% hold more wealth than 70% of Britons, the growing inequality gap provides fertile ground for frustration and resentment. This was shamefully and blatantly stoked by the last Government who consistently blamed migrants then turned their fire on disabled people and those with long term illness.

Unfortunately, in Labour's enthusiasm to maintain the status quo and sail with the wind pre-election, they focused repeatedly and uncritically on "working people". Whether inadvertently or not, this discounts the vast amount of "work" we all do every day supporting our children, grandchildren, partners, friends, relatives and neighbours and opens the gates to older people and disabled people being seen as a cost, even a burden. We are offered benefits not a guaranteed income, charity rather than rights.

We need to call out the way people and relationships have been commodified and stand up for a different way of living and relating to each other which recognises our shared humanity.

Another closely related myth is that social care is not a universal service like the NHS: it only affects a minority of people - them not us. The truth is that almost half of us will fall into the orbit of social care at some stage of our life, sometimes in several roles at the same time e.g. being disabled and a carer and sometimes shifting between roles throughout our life cycle.

The Department for Work and Pensions' Family Resources Survey (3) noted that 24% of the UK population, or 16 million people, had a disability in the 2021/22 financial year. Official estimates of the number of carers are over 5 million but Carers UK estimates that there are over 10 million (4). If you add in 1.6 million care workers, that is 28 million people – more than half the adult population – with family members, neighbours and friends also affected and numbers set to rise. Over 45% of adults over State Pension age and 58% of people over 80 reported having a disability.

Other countries have hooked onto the importance of recognising the universality of social care and its place alongside health as part of the bedrock of core services that underpin the health, wellbeing and security of the population. In a piece for the Nuffield Trust in February this year (5), Natasha Curry notes that Japan, Germany and France have been successful in building public support for taxes and levies by creating a positive story, framing social care as something worthy of investment, an essential part of national infrastructure. Germany created a narrative about solidarity and mutual support. France has recently established social care as the fifth pillar of the welfare state, bestowing on it a status and value equivalent to health and pensions.

The third key myth that needs dismantling is the age old "We can't afford a National Care and Support Service"

A change of Government brings new hope. Taxing wealth, dividends and capital gains alone could release £40bn. which would go a long way to building a free and fair National Care and Support Service that would generate income and boost the economy. However, such arguments will fall on deaf ears as long as Labour continue to trundle along the tramlines of fiscal prudence determined by a totally flawed, neo-liberal, household budget model of the national economy. You don't have to go the whole hog with modern monetary theory to appreciate what Keynes said in 1942:

“anything we can actually do, we can afford”. Just look at how the NHS, education and social security systems were set up after the Second World War, when public debt was at 270% of GDP, and how the Conservative Government magically located £137bn to bail out the banks in 2008. The money can be found. What is needed is the political will.

So where do we go from here?

Tackling these myths, pushing for bold vision, insisting that change is needed across all sectors in social care and will benefit everyone is essential if we are to radically transform the current largely institutionalised and privatised, means tested, top down patchwork of provision in social care to one that offers choice, control, a guaranteed income, rights not charity.

But there are demands on Government that can be made here and now to alleviate suffering and to start chipping away in the right direction.

Backing improvements in pay and conditions for care and support workers is uncontroversial. Immediately improving benefits for carers and stopping prosecutions for debts will help. Dropping charges for care and support already has precedents - in Hammersmith and Fulham as well as in Scotland. Broadening and localising contracts for in-home support to enable carers to do tasks like taking people out rather than just basic physical care is happening in Haringey, Leeds and elsewhere. Cutting out the misery of reassessing people who have long term conditions that won't improve will actually save money. Setting up structures for genuine co-production of design and provision with disabled people, carers, care workers and local communities need not be hugely costly but will start laying the bedrock for change, as will encouraging innovative, local provision from user groups and co-operatives.

However all this has to go hand in glove with challenging the myths that keep Social Care tied to Cinderella's hearth, mobilising the parliamentary forces of Lib Dems, Greens and Independents to help give Labour a massive shove and building a broad based grassroots campaign for radical change. See www.endsocialcaredisgrace.org.

References.

1. <https://centreforcure.ac.uk/updates/2023/05/valuing-carers/>
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3. <https://commonslibrary.parliament.uk/research-briefings/cbp-9602/>
4. <https://www.carersuk.org/reports/state-of-caring-2022-report/>
5. <https://www.nuffieldtrust.org.uk/news-item/shifting-the-narrative-building-public-support-for-social-care-reform>