# Tackling the issue of Social Care in England: A "Three Elephant" Problem

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Disclaimer: The views in this paper are personal views of the authors, and are not representative of any organisations to which they are affiliated.

## There was no "once and for all" government plan for social care

We were misled back in 2019. Johnson's "*clear plan we have prepared*" for social care to fix it *"once and for all"* did not exist[2]. It was just that same old Boris telling us something he wanted us to hear – a hollow claim by the person elected to the highest office in the land on something that touches almost everyone at some point in their lives. We have become so mired in a politics of passed off untruths that this ranks as unremarkable. The revelations by Dominic Cummings in the last week of May 2021 just served to confirm that this sort of approach was not a one-off but the standard approach.

A decade on from the 2011 Dilnot Report, its author has described the ongoing situation for social care in England as a *"stain on the nation".* A political culture over decades could not find the will to tackle it. Yet again, insiders are already saying that, while there will be a plan, sorting out the national finances will have to come first. The old, old story. A system seriously flawed and waiting for reform is still in place and capable of shortening the lives of large numbers of the old and the vulnerable as the pandemic rolls on.

We know more about how this played out over the first two waves of Covid-19 from Cummings. Private care homes did not have the power to protect themselves from untested discharges from hospital. Families at home with loved ones suffering from dementia were left to cope as best they could as domiciliary care struggled to find staff and PPE.

While this was happening, the life savings and homes of people continued to be captured through unregulated private residential fees (assets transferred at scale into the global financial marketplace). This is a system that could see a 96 year old lady evicted from a care home when she could no longer afford to pay the £60,000 a year fee.[3] A "stain on the nation" indeed - and every day of delay on reform has a high cost to all those involved.

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[2] "*July 2019 "And so I am announcing now – on the steps of Downing Street – that we will fix the crisis in social care once and for all with a clear plan we have prepared to give every older person the dignity and security they deserve."* https://www.homecareinsight.co.uk/pm-pledges-to-fix-social-crisis-once-and-for-all-matt-hancock-retains-post/

[3] https://www.lbc.co.uk/radio/presenters/nick-ferrari/pensioner-96-forced-out-of-care-home-social-care-costs/

## An underwhelming White Paper: A system fix to deal with integration

Of course, the government did move to do *something* about social care. A government White Paper appeared in February 2021[4]. Maybe this was the grand plan? If so, it was distinctly underwhelming. The proposal was to deploy an organisational fix to those parts of the system that had been working more by default than by design. An important issue for social care that everyone had pointed to was the need for *more effective integration* - functionally and organisationally. This was something only a system design that was happy to leave provision in the hands of market forces could have failed to see as a basic flaw from the outset.

Provision by means of a private marketplace of competing purchasers and suppliers operating locally was never going to work well for the delivery of a fully integrated care service to older and vulnerable people. On grounds of sheer common sense, a mixture of complex elements needs to be brought together. The market approach brings the expectation of a variety of care suppliers. From the perspective of integration, variety pre-supposes differentiation and a risk of *fragmentation*.

When the service arrives with the client, a variety of professionals, community services and paid and unpaid carers needs to act in concert. The 'queue of people at the door' is to be anticipated. That the doorstep arrivals often tend to be *operating independently of each other* is where the problem lies. It gets worse where most are operating under different funding regimes and organisational structures distributed across different geographical domains. Anyone having to confront it for the first time quickly discovers that the system is *opaque, and hard to navigate.*

There have been many attempts to address these integration and coordination issues over the decades and things have improved. But what this has inevitably done is to add a series of *one-off funds, fixes and workarounds* – usually with their own acronyms – cluttering still further the terrain of provision. That the system works at all is a tribute to the added time, commitment, and goodwill of those employed in it. The 2021 White Paper directly acknowledges this particular problem and offers a "system fix" in the form of *Integrated Care Systems*. Most find this welcome, albeit partial in relation to the scale of what needs fixing[5]

## Still dodging the issue of dementia

Delivering effective person-centred care for older people is bound to bump into that 73 year-old binary division that separates an NHS "primary health need" from a "social" need. There is no sign of a plan to tackle this. To repeat again what we said in our earlier paper[6], under the Care Acts a person's *health needs* – not their diagnosis - determines whether they are eligible for funding. Dementia is regarded as not representing a "primary health need" and a *diagnosis of dementia* does not bring an entitlement to free NHS care[7]. Dementia sufferers and those who care for them are routed for assistance into *adult social care* unless they have some other health-related co-morbidity, or a condition that can qualify them for NHS Continuing Health Care[8].

A paywall exists, therefore, to limit greater integration in the health and social care system for older people. It marks that closely guarded boundary between care 'free at the point of use' and market-

[4] https://www.gov.uk/government/publications/working-together-to-improve-health-and-social-care-for-all
[5] It also seeks to regularise accountability and the chain of command - placing a Minister in charge.
[6] https://www.peter-lloyd.co.uk/app/download/5812160473/Health+and+Social+Care+Paper+Master+45a+Final.pdf
[7] https://www.continuing-healthcare.co.uk/continuing-healthcare-guidance/chc-funding-for-dementia
[8] https://www.nhs.uk/conditions/social-care-and-support-guide/money-work-and-benefits/nhs-continuing-healthcare/

provided care that has to be paid for either by a parsimonious state or by the dementia sufferer and their family[9]. The White Paper had nothing to say on this (nor does it seem to arise in the guesses of insiders for what is in the pipeline). Holistic and person-centred care is fine, but surely not with a paywall involved for those in the dementia category.

It seems this is the nearest we have currently come to the Prime Minister's "once and for all" plan to address social care. Perhaps the obvious reaction is that while the suggested fix in the White Paper is one long needed, it is like that old joke about a person asking the way and being told "I wouldn't start from here if I were you". The White Paper and the recent Queen's Speech skirt around three monstrous elephants in the room – so big that everything else gets squeezed to the edges.

## The "elephants in the room"
## Who pays? What do we want? How do we deal with dementia?

The first and most obvious major question is what sort of money is needed and where is it to come from? Even 'back of the envelope' guesses at this have been enough to frighten generations of politicians into inaction. It is huge and bound to grow. The second question is strongly conditioned by the answer to the first. Are we sure the system we have in place for providing social care is the right one?" We have been trusting the marketplace to do this job since 1990. The third is, of course, the ongoing scandal with regard to dementia care with its scary cost implications. Fixing the problem of integration gets nowhere near the real issues.

As our earlier paper says, there is much more to fixing the system than money - but funding is where visualising the scope for change usually begins. In the English context: the debate usually starts with "what we can afford?" This tends to take precedence in public policy over questions about what we would like to have. As we will show in the next section, it is entirely possible to pose the question the other way round. Until the 'three elephants' problem is addressed properly, and until someone does what Dilnot was commissioned to do in 2011 and tries to tackle things head on, policymakers are just working round the edges.

## Learning from others

We are just one among many countries in the world facing the problem of an ageing population and an urgent need to find a sustainable solution, so there is learning to be had. Japan had to grapple with this issue earlier than most and has already made radical tax adjustments to cope. However, a very different culture colours any learning from that case.

Much closer to home, however, it seems the Scots are already on the move to address the problem. They have come up with a bold plan for social care by proposing the creation of a separate *National Care Service* with equal status to the NHS[10]. The focus is, however, dominantly on regulation for existing provider arrangements and on raising workforce pay and standards. Welcome though this is, it is still about re-adjusting the system in place and serves to reinforce the binary model. Unsurprisingly, it gets nowhere near dealing with the big questions of finance and of raising taxes to foot the bill.

[9] The humiliating form filling and interrogation required to secure this boundary in relation to Continuing NHS Care is all too familiar to those who have had to experience it.
[10] https://www.ft.com/content/7c1663f8-77bc-49c8-b273-05435ada53bb

Things are clearly on the move in the wider UK context under the banner of devolution. But, further afield, there is another source for new ideas. Australia has put a four year in-depth effort into looking at what it calls "aged care". The Australian Royal Commission into *Aged Care Quality and Safety: Care, Dignity and Respect*[11], reported on 1st March 2021. The debate there is yet to begin in earnest but what the Commission came up with is of clear interest as a pointer to what we need to think about here.

## Australia seeing the same problems and looking at a bold solution

For what they call "aged care", the Australian system is remarkably similar to that in England. The common aim is that people should be able to stay in their own homes for as long as possible and, when this is no longer feasible, they should have a choice of residential care providers and a realistic option to change them. As in this country, the central government is the main funder of "aged care" to the tune of $A21 billion. Those who can afford it are required to contribute to home care costs and, when needed, residential care. They have a means test and an intricate system for co-funding care. Shortages in provision result in queuing. Significantly, the Australians operate under a Westminster inspired system of government and accountability.

Another clear commonality is that, since 1997, the system deployed for aged care provision in Australia has been based on a *market solution.* The providers broadly come in two forms; not-for-profit organisations and private-for-profit companies - with a stronger emphasis on the first group. The Federal Government takes responsibility for shaping and managing the marketplace (A clear difference with the English system is that here this function is devolved across the 150 higher tier local authorities). The Royal Commission report notes, however, that despite the powers of regulation, "*the approach has generally been that the market will take care of itself".*

When it comes to funding for aged care, the problems encountered read once again like a facsimile of our own. It is described as *"insufficient and insecure"* and subject to the fiscal priorities of the government of the day. Hard times economically for the nation, are seen to have produced active moves to *"restrain the growth of age care expenditure".* Decisions are generally biased towards *"measures to limit expenditure".* Demographic change is not factored in to the financial or system planning process. The Report declares that it is *"not a sustainable system into the future".*

On workforce matters, Australia sees what we see. This very large group in the nation's employment is on low wages. The numbers of nursing-qualified staff have fallen away and lower skilled "personal care workers" have come to account for 70 percent of residential care staff. Low pay, low skill and low attachment is common to both systems.

In terms of *access, safety and quality* for the aged care system, the Royal Commission goes into very great detail about just how bad things have become. This is far too large a component of the report to review here, but a glance through the salient points reveals a pandora's box of flaws and failures that are all too familiar from the English case. Suffice it to say that what emerged in Australia was disturbing enough to have them understand that *something radical had to be done.*

## A rights-based approach

Ruling out limited fixes in the functioning of the existing system, the Australian Royal Commission goes straight to the heart of things. It set out a *rights-based* approach with a clear mandate *"to provide an entitlement to support and care*".. This follows the *International Covenant on Economic, Social and*

[11] https://agedcare.royalcommission.gov.au/publications/final-report

*Cultural Rights*[12]*.* From this, the rights of people to aged care are set out in detail at the individual level. This flows through to set the purpose and guiding principles of a completely new aged care system.

Under the proposed new Act, mandatory principles will underpin *"a universal right to high quality, safe and timely support and care"* giving people the right *"to exercise choice and control, to ensure equity of access and to provide a regular and independent review of the system".* A *fair and effective system of governance* would manage the process. The two reporting Commissioners had varied views on what this would look like[13] - though they were in agreement about the basic reform principles. The new approach is described by the Royal Commission as "*revolutionary*".

## The issue of funding

The real issue is, as always, about money, where it will come from and how sustainable funding is likely to be. The Report tackles this head on. The recommendation is that public funds should come from *personal income tax* under either a *hypothecated aged care levy* or a *non-hypothecated age care improvement levy* (the Commissioners again had different views). Both agree, however, that the means test should be phased out.

Funding for the care providers would be set by a unique *body independent both of the government and the aged care sector.* The recommendation is to set up an *"Independent Pricing Authority"* with a determinative pricing power. This would, of course, take the whole issue of aged care away from seeing what government could afford; adjusting the system to meet this; and then leaving market forces to deal with provision. This body would conduct a thorough review of the costs of meeting the entitlement to high quality and safe care and on this basis establish prices. This is presented as the basis for a sustainable system for aged care.

## Dealing with dementia

Without having to face the issue of the paywall between free NHS care and social care; the Australian system is unencumbered in dealing with dementia and can give it the attention it deserves. Much of what the Royal Commission suggests is about raising the profile of dementia care with a major section of the Report dedicated to it. Dementia is identified as one of four areas for *"immediate attention"* – declaring that the current provision is "abysmal".

The recommendations for dementia are comprehensive. All mainstream care services should have a capacity to deliver it "at quality" and it should be "core business". A *"comprehensive and accessible post-diagnosis support pathway"* is to be created. There is strong emphasis on skills and training across the board under a *Specialist Dementia Care Programme* (already in place). A national network of *Specialist Dementia Care Units* with at least one operating in each of the country's 31 Primary Care Networks is proposed.

This situation could hardly be more different from that in England where dementia struggles to get the recognition and profile it deserves across the entire health and social care system. This brief sketch cannot do the Royal Commission justice on the subject, but the full documentation is there for all to see.

[12] https://www.ohchr.org/en/professionalinterest/pages/cescr.aspx

[13] One pressed for a *new body* with greater independence from the Australian government, while the other was in favour of a reform programme for the *existing institutions.*

## Conclusions: Some ideas going forward

### Being bold and radical

Going back to the "three elephants" issue raised earlier, the Australian Royal Commission has some things to say about them that – without having to spend four years looking at the issue – we can learn. What is needed is not just another fix applied to the way things currently work. Root and branch reform is vital. The Australians have "bitten the bullet" on this and gone for an *entitlement-based system* that starts by answering a question we put in our earlier paper:

> "*What principles should we set as a nation for the minimum requirements of a morally just and fairly applied system for those needing assistance as problems arise in the process of ageing?"*

The Australian response is "*to protect the safety, health and wellbeing of older people and put their preferences first".* It is not just about what, as a state, they can afford or what politically they can get away with. They propose to establish a body *independent of government and the aged care sector* to be the responsible agency and a *levy on personal income tax* to supply the funds.

By contrast, so much of what we currently hear about plans for reform in England is tainted by the fear either that the Treasury will not tolerate it, or that one voter constituency or another will be put out by it. The echo of past headlines about a "dementia tax" still rings in the ears of the politicians.

The real problem to be confronted comes second. That is why we find ourselves where we are. Adult social care may be too important an issue for us just to leave it entirely to the politicians. It would be a bold move indeed for us to acknowledge this and deal with it.

### Establishing the real costs of care and raising sustainable public funds by tax levy

A *tax levy* has surely to be strongly considered. The question of *hypothecation* is always a difficult one for governments, but the time has come for it to be taken on if a sustainable system is the ambition[14]. Looking always through the lens of the funds available is just another argument about rationing. The means test is about both "what can we afford and who should get it?" This has been a powerful influence in getting us to where we are. An *entitlement and levy approach* would move this onto a different terrain.

Under a system where care provision is by private-for-profit and Voluntary and Community Sector (VCS) organisations, we need to make a real effort to establish the real *costs and prices for the practical delivery* of the care under alternative models. Leaving it to the market to decide has not worked.

Knowing both costs and prices and having better metrics for what care actually constitutes, we could be better at knowing how much tax would need to be raised and what the state should pay to meet a universal entitlement to care. Then we could see how much it might be reasonable for private payers to contribute if they choose to do so.

[14] The expectation that a significant segment of new cohorts in the older population can fund their care from releasing equity in their homes is, for example, highly contingent to circumstances and not a sustainable solution.

## Appropriate and effective regulation and a quality workforce

If we are to retain a marketplace for care, it needs *far better regulation* to get us away from such things as the growth of offshore funded mega groups, from poor provision and lack of quality among smaller providers from sudden closures and from the ramping up of prices for private care. Having a national organisation like the CQC may be necessary but it is not enough. The Competition and Markets Authority has not had the powers to do what is needed. We should look closely at an *Independent Pricing Authority* and not expect 150 local authorities to be in a position to discharge the role as "market makers".

A vital part of the focus on the quality and continuity of care should be about the way labour is recruited, trained, and rewarded. The conditions for labour should not just arise from the marginality of providers in an under-funded sector delivering a vital public service. There is no excuse for a wage system in social care that drives so many workers into conditions of precarity.

## Time, Consultation, and a Local Perspective

The clear lesson from the Australian experience is just how much time is needed to get from where we are to where we need to be. Of course, we need to get on with reform but there is a real danger that, government will respond to criticism by jumping into action with some "grand plan" before doing the necessary broad-based thinking and consultation.

Whatever we might want to happen in terms of entitlements, tax levies, new independent bodies and the like, we have to remember that *care is delivered on the ground and in the local context*. To its credit, the White Paper does take this clearly on board. The local is where the real knowledge lies about what works and what does not. Wide consultation at local level is a necessary condition not just for the detail but to capture creative thinking for a bold and radical overall reform plan for care.

It is here that the newly minted *Integrated Care Systems* would offer an opportunity not just for better practice but for discussion and debate. As we pointed out in our earlier paper, care needs, care costs and the way integrated care is managed and delivered will vary substantially from local place to local place. Building a radical new superstructure is not enough. *Geography matters* and creative thinking at the local level is a vital component of what is needed.

## A 1948 moment for tackling the dementia issue

For reforming the adult social care system in England, it will no longer be good enough to focus on the means test limit and the private payment cap under a Dilnot style proposition. We are faced with a crisis on an enormous scale. Large numbers of older people had their lives unnecessarily shortened in the pandemic under a system we knew to be flawed. We need a "1948 moment" with the boldness of vision needed to do something at a time of national crisis.

An increasingly large proportion of the old and the vulnerable are known to suffer from some form of cognitive impairment[15] - if not of diagnosed dementia. It is a national scandal that this issue has for so long been pushed to one side while informal carers and self-payers have been drawn in to fill the breach in the health and social care system.

[15] https://www.nhs.uk/conditions/dementia/about/

Like the Australians, we should face the problem head on, give it the profile it needs and set up organisations and training programmes to make it a *featured component* of primary care.

The system of provision in place remains under-funded, fragmented, fragile and able to pay workers only the lowest wages. Without having a Royal Commission to look too closely, it is not hard to envision just what access, quality and safety for social care might look like at this juncture. Factor in demographic ageing and the future expansion of the cohort of older and vulnerable people and the known health burden this will levy on the NHS; and the challenge is clear. For every government that kicks the can further down the road, these problems will become more acute and the cost of overcoming them will increase.

We have learned from the pandemic that government can make massive amounts of funding available to face a problem if it chooses to do so. It is political will and integrity that we seem to be short of.