

Memo to Fabian Society inquiry on social care

July 2022

Introduction

Ealing Reclaim Social Care Action Group (ERSCAG)¹ welcomes the new inquiry established by the Fabian Society to “develop a roadmap towards a national care service for England”.² We understand that this study will be submitted to the Labour Policy Review and the Shadow Cabinet. ERSCAG works with and across all political parties, and therefore believes that it is vital that the Labour Party develop a vision, and a work programme, with a view to developing a National Care Support and Independent Living Service as soon as it secures the necessary parliamentary majority.

We note a few ‘language’ or conceptual questions at the outset: for example, many of us will argue for the use of more positive and constructive language for the new public service, since we believe that the earlier Labour policy position on a “National Care Service” did not adequately convey what is needed. England needs a service complementary to the NHS, and one which promotes independent living and one co-produced with those in receipt of care. We understand the attraction of a ‘parallel’ language to the National Health Service but feel that the word “health” itself is a positive concept (we never would have called it the National Illness Service!), whereas the sole reference to “care” is seen by many using this service to be derogatory and demeaning. Therefore, throughout this submission, where appropriate, we will refer to the need for a National Care Support and Independent Living Service (NaCSILS), and we would direct your attention in particular to the campaign to this end (www.nacsils.co.uk)

Moreover, we will refer frequently to the importance of the concept of ‘independent living’. We are using this terminology in line with its general usage by disability rights activists, and Article 19 of the United Nations convention on the rights of disabled people (UNCRPD).³ We also note the importance of the concept of co-production for rights advocates and were disappointed to learn that interventions to make this Fabian Society study one developed in a co-productive way have been rejected (see <https://www.disabilitynewsservice.com/labour-refuses-to-make-co-production-pledge-for-new-social-care-inquiry/>). ERSCAG is not itself a disabled persons’ organisation, but we believe very strongly that the Fabian Society study itself should work closely with those most likely to be affected by its eventual proposals. Your process must reach out effectively to involve those who have lived experience of the care system and involve them at all stages of your research if it is to arrive at worthwhile and workable proposals. Anything less is likely to result in bad design outcomes. We are concerned that the efforts to start from this premise with a clear commitment to co-production have not been taken on board and may already have deterred collaboration with those you most need to engage with.

Proposals

Based on the press release about your study you set out the five key topics your report will cover:

¹ Ealing Reclaim Social Care Action Group (ERSCAG) is a voluntary group, based in the London Borough of Ealing, working for a “transformed social care system” at the local and national level (www.erscag.org.uk).

² ERSCAG’s work, this document, and (we presume?) the Fabian Society study will be focused on Adult Social Care (not the very different needs of care-services for children). We will also restrict our proposals to the situation in England, but it is worth noting that both the Scottish and Welsh governments are exploring the idea of a national care service, and they will have useful research to be shared/built upon.

³ Specifically, “the equal right of all persons with disabilities to live in the community, with choices equal to others, and (the State Party) shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community” – not, as sometimes mistakenly understood by the general public to be ‘doing everything for and by oneself’!

1. Context and Issues to Consider:

ERSCAG has developed an extensive list of national organisations working on social care, and a bibliography of some key texts, for our website (www.erscag.org.uk). We attach these resource lists for your convenience. ERSCAG believes that the following issues need to be considered:

- We believe that the concept of ‘social care’ is not widely understood by the general public (with the possible exception – heightened by the pandemic – of the situation of older people in care homes).⁴ Accordingly, it would be good for your report to delineate exactly why it had been intended to create a ‘National Health Service’ and a ‘National Care Service’ post World War Two. These were always seen as complementary – but distinct – public services. ERSCAG believes strongly that it is essential that there is close cooperation and close working relations between a National Care Support and Independent Living Service and the National Health Service, but we would oppose strongly any attempt to merge the two services.
- Under the rubric of ‘care’ we believe that you need to include **concepts of independent living, co-production, and living a fulfilled and fulfilling life**. ‘Care’ is not only about ‘preventing’ people going into hospital/residential care (though that is important) but, if properly managed, it is about complementing a life-saving body (the NHS) with a life-changing body (with a NaCSILS). Nearly one third of recipients of social care are working-age people with disabilities, with the rest over 65 – and they all need support in living and socialising, rather than an assumption that ‘warehousing’ care will suffice. Your study should probably provide useful statistics and some case-studies about the importance of GOOD care services.⁵
- The paper will need to consider many different issues –
 - What should be done **nationally and what should be done locally**? ERSCAG thinks it should be a genuine mix of both – with a national body setting standards, providing training, and representing the sector in national policy making. At the same time, needs vary extensively at local level (depending on demography, ethnicity, urban/rural etc.) and these should be catered to, without falling into the ‘postcode lottery’ problem.
 - The **role of privatisation** in current arrangements. It is unfortunate that the failure to create a ‘National Care Service’ alongside the NHS in 1948 has meant that, in the intervening 70+years, the market has become the main provider of this vital public service. Whilst we try to stem the further privatisation of the NHS, any reform of care has to tackle the reality that care is already almost entirely privatised. Will the Labour Party want a total revolution of present provision, or will it prefer to take only some aspects into public ownership? Your inquiry should explore a variety of options for them to choose between. At least, the study must examine some of the problems created by the marketisation of care – and propose mitigation measures.
 - How to put **the person at the centre of any future process**? The study will clearly have to focus on ‘big picture’ proposals, but there need to be principles built into

⁴ See ERSCAG submission to House of Lords’ Adult Social Care Committee’s current Inquiry into “Lifting the Veil: Removing the Invisibility of Adult Social Care”, May 2022 (www.erscag.org.uk).

⁵ See resource lists attached for national groups and studies of possible help in this regard.

any models proposed that allow for effective accountability, and ones in which the people in receipt of care and support are active agents in decisions affecting them.⁶

- **The models** will have to address residential, domiciliary, and day-care provision; the needs of working age disabled people; the needs of older people; the needs of people able to articulate their needs and those unable or incapable of doing so; the vital role played by family carers as well as the pay, working conditions, training and career progression of Personal Assistants and care-workers; and the funding required to provide an adequate service.⁷
- We also understand from the brief that the inquiry will address both short-term mitigating measures towards a National Care Support and Independent Living Service as well as the overall aspirations for a future service. At this point, we would emphasise that any (understandable) emphasis on the IDEAL FUTURE model should not fail to address **the immediate problems** created by current provision (see on).

2. Essential features of a National Care Support and Independent Living Service

As noted above, the name of the new arrangements matters. For other essential features:

- At the national level, principles of person-centred, independent living and co-production must be centre-stage and upheld with national standards. In the Fabian press release, some of these concepts are presumably included in the terminology of ‘individual preferences and needs’, but your study should set these principles out more fully and explain how they align with international standards.⁸ The establishment, promotion and monitoring of these standards would be essential even if one of the models you explore is a ‘very light touch’ national body.
- Similarly, even a ‘light touch’ national structure must set appropriate professional standards and terms and conditions for care-workers. It is clear that the staff need much greater support and help. Currently many care-workers still do not receive the Living Wage; often have ridiculously short periods allocated for visits; receive limited training; and are not paid for travel time between home visits. The role of paid carer is not awarded the status it deserves, and the workforce is subject to extensive turnover – efforts to recruit, retain, and develop the skills and expertise of the role are vital.
- A NaCSILS must also recognise and support the role of family/informal carers who are often key advocates on behalf of those in receipt of care. However good the professional mechanisms that are set up in future, the contribution of family and other informal carers will often remain vital to the well-being of the person concerned. These carers also need support if both they, and the person(s) worked with, are to flourish.
- What is less clear is how to ensure that this national body adapts to local needs and circumstances? Clearly a NaCSILS must work closely with the local organs of delivery – but should it do this via close ties into Local Authorities, or deal directly with the whole plethora of service providers (care homes, care agencies, charitable groups providing day-care and other such services)? ERSCAG, like many others, wants care to be publicly provided in a not-

⁶ In London, Hammersmith and Fulham Council have built in co-production as an organising principle for its social care efforts. Some co-operative models might provide some good practice examples – see, for example, North West Care Co-operative (NWCC) in Chester, the Equal Care Co-op in Calder Valley. The Welsh government has an interesting approach to social care value - https://socialcare.wales/cms_assets/hub-downloads/Co-operatives_delivering_social_care_and_support.pdf

⁷ See list of sources e.g. <https://www.centreforwelfarereform.org/.../fully-funded-social-care.pdf>; the [House of Lords Economic Affairs Committee: Social Care Funding – Time to end a national scandal \(June 2019\)](#), and excellent research regularly carried out by specialist think-tanks like the Kings Fund (www.kingsfund.org.uk) & the much-earlier Dilnot Review.

⁸ International standards such as the UN convention on disabled people (UNCRPD) www.un.org/disabilities/documents/convention/convoptprot-e.pdf & [United Nations Principles for Older Persons | OHCHR](#)

for-profit system - not least because the currently fragmented and privatised nature of the provision of care is broken. Can the Fabian Society suggest a series of organisational models (with the pros and cons) which run from a light-touch to heavy-touch NaCSILS in terms of its relationships with Local Authorities and individual care providers?

- A related factor to the relationship between NaCSILS and the highly privatised care market is that of accountability. As a local group based in Ealing, we appreciate the fact that we can lobby local Councillors and MPs, and attend Council meetings as members of the public, to alert elected officials to problems in the provision of social care locally.⁹ Local Authorities however have had their budgets squeezed greatly by central government; they do not always see the provision of good-quality care as a political imperative (given that it is often an 'invisible' service for many Council tax-payers and voters); and they are operating within a largely privatised market-place over which they have limited levers of control.
- The service must be publicly funded and various documents listed in the attached bibliography suggest different financing models.

3. Design options/alternative models

Our local group does not have much to offer to this element of your study (but again you may find some of the attached material of interest by way of background thinking).¹⁰

4. Costs and benefits

ERSCAG believes that the Fabian Society study should incorporate into the chapter on costs and benefits, some of the costs which arise as a result of the current "broken" social care system:

- Disabled people of working age unable to contribute to society on an equal footing with non-disabled people
- People who should be receiving social care fearsome of seeking help because of the financial problems this would create for them; and the fear that this instils.¹¹
- Family carers who have to withdraw from the workforce, in whole or in part, to compensate for otherwise poor provision for their loved ones.
- The administrative costs involved in administering a charging system, the write offs involved, and the extensive financial costs (and emotional turmoil) created by pursuing those clients who fall into debt.¹²
- The impact on the National Health Service of a poor social care system – leading to delayed hospital discharges and serious inefficiencies.¹³

On the benefits side, there are surely savings to be made (not least in the reduction of off-shore profits being made by companies investing in for-profit carehomes) and there are enormous benefits created for local economies in providing good quality social care and social care jobs.

⁹ At the same time, many disabled and older people have argued that Local Authorities have not proved an effective accountability mechanism for their concerns: their constituencies of action are relatively small in comparison to the overall number of rate-payers who may have quite different funding priorities.

¹⁰ There is no reference to the US 'Obamacare' option in the attached resource lists, but apparently this model requires that the public service option always be included as one of the options that someone can consider.

¹¹ See ERSCAG case-study paper giving specific lived examples of the fear and emotional upset caused by social care charging.

¹² The London Borough of Ealing recorded the following 'expenses' involved in securing income from social care clients – ie on administration and sums 'written off' - £687,675 (2018/2019); £1.04 m (2019-2020); and £1.13 m (2020-2021). In June 2022, 688 (residential) and 1470 (non residential) people are in arrears and are in receipt of 1st/2nd/3rd/final reminders or are the subject of manual debt recovery actions or legal referrals.

¹³ The incoming president of the Royal College of Emergency Medicine, Dr Adrian Boyle, said on a recent (July 2022) Radio 4 PM programme that the single most effective way of assisting him and his colleagues in the NHS do a better job would be "to fix the crisis in social care".

5. The roadmap to reform and the sequencing of measures

ERSCAG understands the enormity of the challenge facing any government intending to create from scratch a corollary to the National Health Service which will tackle the effective provision of care. We therefore accept that it may not be possible to develop any model that will work ‘overnight’ but, in the meantime, individuals are seriously suffering from the current arrangements.

Accordingly, we think that the inquiry might usefully consider the following:

- **How to create a political and public climate which would be amenable to the creation of a National Care Support and Independent Living Service?** Talk about seeking a party-political consensus in the past has constantly foundered when the latest election is announced and ‘care’ loses its invisibility and becomes a highly contested site. There is unlikely to be any single model which will secure support from all parties, but there may be more agreement than expected on the principles to be pursued. There is also likely to be extensive support for Labour government reform in this area from its non-Tory comrades (eg Green Party and Liberal Democrats), with MPs from devolved areas also likely to be supportive.¹⁴ But formal party-political structures are not the only way to reach out to secure public support – the trade union movement, the churches and other faith groups,¹⁵ policy think tanks, professional associations, and the media need to be convinced that the NHS needs a sister-organisation to cater more effectively for the needs of disabled and older people. Our aspiration should be to develop a National Care Support and Independent Living Service which will have the same level of public commitment and respect currently offered to our marvellous NHS.¹⁶

Very importantly, many people cannot await a 10-year plan. Disabled and older people are suffering now from the crisis in social care, and many may well not be here to benefit from the ‘ideal model’ evolved over several parliaments. **Urgent action must be taken now.** At the very least, the study should propose the following kinds of measures to go alongside debates about the future structure of the National Care Support and Independent Living Service:

- Scrap social care charging (some Councils have already made the political decision to do that) – why should Labour controlled Councils not commit to a cost-benefit analysis as soon as possible with a view to cutting care charging completely?
- A freeze on any rise in LA care charges in coming years;
- A serious uplift to all benefits (to be tagged to inflation rises) including both the statutory and discretionary elements of the Minimum Income Guarantee (MIG). The statutory element was frozen by government for seven years from 2014, and has not risen in line with inflation since then, as was promised. The discretionary element is determined by Local Authorities and the practice currently varies greatly from Council to Council and creates the postcode lottery the general public rightly dislike so much;
- Action to deal with the handling of arrears and debt recovery for the period that charging is maintained, and an assessment of how Councils are complying with the “wellbeing principle” laid out in the Care Act 2014 in any actions taken to pursue arrears.

¹⁴ Indeed, there is extensive agreement already across the political parties in Scotland (See, The Herald, 4 June 2022) for full page spread on party political consensus.

¹⁵ The Anglican church has established a commission to ‘reimagine’ social care; it is expected to report in September <https://www.churchofengland.org/about/archbishops-commissions/reimagining-care-commission>

¹⁶ See #socialcarefuture for further discussion

- Develop “an emergency plan” to address dramatic cost-of-living hikes that disproportionately affect those dependent on care (eg the cost of utility services essential, not optional, for charging electric wheelchairs, breathing equipment, hoists etc). The same emergency plan could cancel outstanding care charge debts or, at least, offer a moratorium and Councils would at times of such crisis, cease all debt recovery agency referrals and court actions taken against disabled service users unable to pay.
- Give specific proposals about how to better implement the system of discounted Disability Related Expenditures (DREs). Though the Care Act 2014 stipulates that a disabled person has legitimate DREs that should be offset by the Local Authority against their non-residential care charges, some Local Authorities do not make this information fully accessible or promote details widely enough, leaving the awareness of this cost-saving option little known to service users.
- Call for a radical overhaul of the system of assessments which currently is seen by users as an opportunity for Council cost-cutting, rather than a genuine assessment of needs. For example, many Councils insist on re-assessments of people with long term health conditions that cannot improve to see if they still qualify for benefits and their motives are distrusted. Such measures should be stopped.
- Local Authorities should ring-fence any more funds they receive for the Household Support Fund for disabled social care users who are in debt to the authority for social care charge arrears. Currently Household Support Fund is statutorily ring-fenced to support children and older people, but though it refers to ‘vulnerable’ residents, it does not explicitly refer to the needs of disabled people, many of whom are particularly disadvantaged by the hike in cost of living.

Conclusions

This submission is assuming that “everything is on the table” in this study. Re-reading the press release about the study, we note however that: *“The endpoint may be national standards and values rather than a single national organisation”*. It should be apparent from everything said above, that ERSCAG believes that we need to have BOTH a set of national standards and values AND a single national organisation to ensure that those standards and values are upheld.

The NHS is multi-layered, decentralised, and highly responsive to needs on the ground, but it was in part its ability to ‘speak with one voice’ that gave it such coherence and strength in response to the covid 19 outbreak. The care sector suffered greatly from having no such coherence and its very fragmentation meant that social care users suffered disproportionately. At least one of the lessons from covid (and there are many for future social care provision) must be that social care needs to be better coordinated and regulated in any future model. ERSCAG believes we in fact need a National Care Support and Independent Living Service, and we hope that the Fabian Society can put some shape and structure to this vision.

Submitted on behalf of Ealing Reclaim Social Care Action Group
 By Maggie Beirne (ERSCAG Secretary)
www.erscag.org.uk
maggiebeirne@googlemail.com; or erscaginfo@gmail.com
 20 July 2022