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Consultation response from Dr. Anne Gray

- **How much is inaction on adult social care reform costing the NHS and local authorities, and what impact does this have on patients and the public?**

Many sources have attested the difficulties caused to the NHS by 'bed blocking'.

Inaction causes greater load on informal carers, some of whom will therefore contribute less paid work to the economy and also be less able to care for relatives. It is important in this context that the bulk of informal care for older people now comes from their partners, so that the partners' state of health has a double impact on demand for formal care. As for unpaid carers of working age, some researchers have found evidence that caring for over 10 hours per week leads to a reduction in paid work; others have put the trigger level at 20 hours per week. According to the Family Resources Survey, almost half of all unpaid carers do 20 hours per week or more. Over one third of unpaid carers are people *of working age* doing more than 20 hours care; that means at least 1.7 million people.

Many people are excluded from adequate care by the current means test; they cannot afford to pay so they do not access the services they need. The capital threshold in the means test has remained unchanged in England since 2010/11. Over 60,000 people were pursued for care charge debts in 2020. Some don't apply for council care because of the likely co- payment. For example, I have met one mother who was faced with a charge of £90 per day for a day placement of her severely autistic teenage son. But others are not even offered the choice of accepting their care costs unless they arrange care privately for themselves, because councils lack capacity, with long waits even for assessment. According to the Health Survey of England, in 2011, 8.8% of seniors with some ADL or IADL difficulties had some free homecare paid for by their local council, but by 2018 only 3.1% did.

The application of clinical needs criteria seems to have been affected by the shortage of funds. Since 2014, councils are thought to have exercised 'subjective eligibility rationing' because of financial constraints (Samuel, 2023). This has also affected the size of homecare packages. By 2018/ 19, care packages for people over 65 averaged ten hours per week, compared to 12 hours in 2009/10 (Bedford and Button, 2022).

The quality of care is adversely affected by the low prices local authorities offer because of the scarcity of funding. This means that some patients miss out on chances of recovery or their condition gets worse. An example from someone I know well: a 59 year old woman, severely injured in a domestic fire, still faces paralysis in three of her four limbs five months after the injury and is thus bedridden. The paralysis is expected to be temporary but it is very unpredictable how long it will continue. She is also diabetic. Care workers do not have sufficient time to toilet her frequently, so she becomes dehydrated, for example waiting from 7pm at night till after 10am the next morning hardly daring to take a sip of water. They do not have time to prepare meals properly, nor are they adequately trained to do so, appearing to have very little knowledge of typical European foods - even in the case of one worker not understanding simple words like 'bread', 'toast', or 'apple'. This affects her nutrition, and their erratically timed visits often mean she goes without food too long. Care workers handle her badly and

impatiently, so now she suffers back pain and some spinal deterioration has been detected. They often do not have time to transfer her from bed to chair and back again, which worsens her pain and impedes her recovery. Her physiotherapist has told her that it is important to spend a daily period sitting in a chair, but for a week following the delivery of her first wheelchair she has not had a chance to sit it in because they refuse to help her do so. She is keen to get well and return to work, but such poor quality care reduces her chances of doing so and risks her descent into long-term dependency. The care workers travel very long distances to visit her, so they are very tired after commuting. This is a reflection of the poor wages the care industry can pay at current local authority billing rates, and of the consequent shortage of staff. There are currently over 130,000 vacancies for care workers nationally.

This is an example of how due to the lack of care reform, some care-needers of working age will suffer failure or delay of recovery from incapacity to work, thus contributing less paid work and remaining more dependent on state benefits. The person mentioned is also an example of how medical conditions (e.g. diabetes, spinal damage) can worsen with inadequate care, resulting in later costs to the NHS.

Some failed or delayed recoveries will impact provision of unpaid childcare to relatives, with adverse consequences for child development and increased excess demand for paid childcare places. It must be remembered in this context that about a quarter of the childcare needed whilst parents are at work is provided by grandparents.

- **What NHS and local authority service reforms are not happening as a result of adult social care pressures, and what benefits are patients and the public missing out on?**

  A shift towards early help and prevention requires investment in new capacity, which cannot be achieved if all the budget is taken up with addressing urgent current needs.

  Early help is important to maximise chances of rehabilitation and reduce long term dependency as well as deterioration of health conditions which lead to costs for the NHS. But early help cannot be provided when waiting times even for assessment are many months. Another friend of mine retired 2 or 3 years early to care for his wife with Parkinson's disease, which became increasingly difficult as her condition worsened to the point where she had to be lifted in and out of a bed or chair. He waited over 2 years for a carer's assessment and still had not received one by the time she passed away.

  Home adaptations such as walk-in showers, grab rails, entry ramps and stair lifts are a crucial element in 'early help'. Difficulty with washing (either because a person cannot manage stairs to the bathroom or because the bathroom is difficult for them to use) are the main ADL for which some form of assistance is needed, according to national surveys. But waiting times for home adaptations are often far too long because councils lack either assessment capacity or funding to carry out the works. For example, across four south London boroughs in April 2024, 2,000 people were on waiting lists for occupational therapy assessments or housing adaptations, of whom 146 had been waiting more than a year (Southwark News, 20.4.2024; https://southwarknews.co.uk/featured/revealed-the-shocking-waiting-times-disabled-people-face-for-home-adaptations-in-south-london/)

  Many people have other serious unmet needs while awaiting general care assessments; the queue has become much longer in recent years. Waiting lists had over 225,000 people

across England in March 2023, over a quarter of them having waited longer than six months (Institute for Government, 2023). A year later, 470,476 people were waiting for assessment, review or for care packages to *begin* (Public Accounts Committee, 2024). After assessment, over a quarter of those making requests receive no services. This may be because their needs can be met by referral to other services (for example a voluntary sector organisation or to cash benefits) but is often because their council is short of capacity, or they decline services on finding they need to pay (Nuffield Trust, 2023).

Across England, waiting times for residential placements have also risen by 40 per cent since 2010. There is poor provision of residential care in some areas, including Haringey where I live. Privately run homes are profit-driven and consequently 'cherry pick' the types of patient who need relatively less daily care. For example when searching for a residential place for the bedridden person mentioned in the last question, it came to light that many local homes cannot provide for as much as 30 hours attention per week for a bedridden person who needs hoisting to the bathroom; they appear to prefer dementia patients who have less intensive care needs. There is also a considerable shortage locally in this area of both residential and day care placements for younger people with complex needs and/or severe autism.

Nationally, public investment in new capacity for day services and residential services is impeded by the budgetary shortage. The private sector finds this type of investment yields a reasonable return, provided that the real estate involved is not heavily indebted to a separate company which is often the source of care home closure. So investment in residential care could be capable of covering costs and interest charges particularly if built on public land – it is a viable option for municipal enterprise. However, residential care is very expensive per patient per year and across Europe, there has been a recent tendency to try to replace it with homecare. Many people could be better served by well staffed extra-care housing rather than traditional residential care; not only is extra-care housing cheaper to run, but residents can benefit from living in a mixed-dependency community where capable neighbours provide company and often friendly help to the more dependent. But there is a shortage of public sector resources to expand extra-care provision. Whilst a shift away from residential care to homecare is also desirable, it is unlikely to happen without improvements both in the quality of homecare and a reform of the means test. Free personal care in Scotland (FPC) led to fall in use of residential care which is very expensive for local authorities to provide. This happened partly because relatives felt more able to cope when their loved one had a right to free personal care, partly because the FPC policy increased the cost differential between homecare and residential care (owing to the continued 'accommodation costs' that clients have to pay in residential care, contrasting with free care at home).

Further details and source references on this question and others here are provided in my forthcoming book, Radical Approaches to the Care Crisis; Solidarity, Community and a National Care Service, Bristol University Press, spring 2025.

- **What is the cost of inaction to individuals and how might people's lives change with action on adult social care reform?**

  Lack of care and debt for care charges has already been mentioned above. Care charges at current levels induce poverty, as does the inability of many unpaid carers to sustain employment full time or even at all. Better and more accessible care would lead to an

increased rate of recovery, where medical conditions are amenable to rehabilitation, and better ability to provide services to others, both paid work and unpaid services such as childcare and care of other disabled, or ageing and frail, family members.

- **Where in the system is the cost of inaction on adult social care reform being borne the most?**

  Intensive informal carers are often driven to reduce or even abandon paid work by obligations to family members which often involve such heavy commitments that they become stressed and even ill. Burn-out of family carers occurs due to lack of formal care and long waiting lists. Carer burnout has frequently led to a breakdown of informal care arrangements (Care Management Matters,2023).).

  Carer stress has been amply documented by several reports from the Carers'Trust. Lack of support for family carers threatens the sustainability of their contribution, which continues to provide several times the volume of paid-for care. Without this unpaid work, the system of care would collapse. According to the Health Survey of England, in 2017 no support was recorded for 56 per cent of carers. Less than one in ten had help from a formal care service. Only one in 20 had advice from their local authority, 3 per cent help or advice from a charity, and only one in 50 had access to respite care. Day care provision has declined substantially since 2015/ 16 due to budget cuts (Nuffield Trust, 2023).

  Another issue is the dependence of intensive family carers on Carer's Allowance, a badly designed benefit system which involves a poverty trap and has led thousands of people to incur prosecution for their failure to sign off the benefit if they earn even a few pence per week over the maximum earnings limit. Carer's Allowance should be re-designed as a payment for work, with far less restrictive earnings rules and without the 'cliff edge' created by the total withdrawal of benefit at the maximum income level. In so far as sustaining family care helps to avoid more expensive formal care, this would save the government money. Funding for Carer's Allowance reform could come from transforming Attendance Allowance, from allowing the personal budget for a personal assistant to be claimed by family members, and from greater taxes on wealth and higher incomes.

- **What contribution does adult social care make to the economy and HM Treasury and how might this change with action on reform?**

  The care sector involves at least 1.2 million jobs, including homecare, residential care and ancillary services
  (King's Fund, https://www.kingsfund.org.uk/insight-and-analysis/data-andcharts/key-facts-figures-adult-social-care). If all severe needs were met by formal services for those who wanted them (based on actual take-up rates by the Scottish population, and thus taking into account that many families would still prefer to rely on informal arrangements), the Women's Budget Group and the New Economics Foundation (Bedford and Button 2022) estimate that an extra half a million care workers would be needed. The effect of this on GDP depends on where they would be recruited from and at what wage rates. There would only be an addition to GDP if the new care workers were previously economically inactive, or had not worked in the UK previously, or were employed elsewhere in the UK but at lower weekly wages. Currently the care sector has huge recruitment difficulties; the low pay rates available with current budgets, and current restrictive rules on work visas for migrants are responsible for this. Better pay, making visas and new-migrant NHS charges cheaper, and

allowing dependents to accompany them to the UK, would all help to draw in more people from overseas to fill these vitally important jobs. The tax yield from creating jobs by increasing the number of care workers, or from paying them more per hour, obviously offsets the gross budgetary cost to some extent. The more care workers are paid the less they will need in Universal Credit too; the bill here must be high for such a low waged sector. It is worth pointing out that many care workers still do not effectively receive the national minimum wage since they are not always paid for travelling time. It is also worth noting that even their employers, through the UK Home Care Association, recommended that councils pay enough to finance a minimum wage rate of £15 per hour in 2024. Assuming that most care workers do claim Universal Credit, any pay rise would reduce the overall public cost of that at the rate of 55p per extra £1 they earn.

- **To what extent are the costs of inaction on adult social care reform considered by the Government when evaluating policies, including within the Budget and Spending Reviews? How should these costs be assessed and evaluated?**

  A narrow cost-benefit approach would be inappropriate for a reform which is so important for social well-being. The costs of inaction must be measured in misery as well as money and economic productivity. However there are vast costs to the NHS and to the economy….The unpaid economy of caring for children and for disabled or frail family members also suffers.

  The cost to the NHS of inaction has already been noted above; the lack of residential places or adequate hospital discharge arrangements leading to 'bed blocking' in hospitals; the worsening of existing medical conditions under inadequate care; the additional sickness burden suffered by unpaid family carers under extreme stress.

References

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December 2024