Health and Care Bill: Carers UK briefing for 2nd Reading in House of Lords – 7 December 2021

Summary and overview:

Carers UK welcomes the aims of the Health and Care Bill to facilitate collaboration within the NHS and with partners. Greater integration of health and care services is something that carers want to see more of; carers’ lives are often made much harder when services are not joined up and when data is not shared effectively and efficiently.

Carers play an essential role in supporting the NHS and social care systems. Without their support, our health and care systems would have not been able to cope with the increased demand they have seen during the pandemic.

Not only do carers need to be recognised for the important support they provide, but the aims for integration as outlined in the White Paper can only work if unpaid carers are visible, recognised, and counted as part of the NHS.

Carers UK is calling for the Bill to:

- Not undermine carers’ rights in relation to hospital discharge; we believe (Clause 80) is removing a key element of their rights.
- Place a duty on the NHS to have regard to carers and to promote their health and wellbeing.
- Ensure that the cap on care costs fairly protects the assets of those on moderate incomes (clause 140)
- Ensure the definition of carers in the bill includes young carers and parent carers.

Carers UK welcomes:

- The Duty on NHS England to consult carers (Clause 6)
- The Duty on Integrated Care Boards to consult carers around planning and commissioning and around services relating to the patient for prevention, treatment and diagnosis (Clause 20)
- The introduction of new powers for the Care Quality Commission to assess local authorities (Clause 137).

Key facts about unpaid carers:

- The support provided by people caring for a family member or friend who is older, disabled, or has a long term condition is vast – prior to the pandemic, estimated to be £132 billion per annum and during the pandemic in one year around £193 billion.¹
- We estimate at the height of the pandemic there were 13.6 million unpaid carers, with 4.5 million people taking on new caring responsibilities.² With an ageing population we are likely to continue to see a rise in the number of people providing care.
- Carers health is often impacted by caring, those that care for more than 50 hours a week than twice as likely to be in bad health than non-carers.³

³ Census 2011
Carers UK’s suggested amendments to the Bill:

A new Duty on the NHS to have regard to carers and promote their health and wellbeing

The NHS depends heavily on the role and input of people who care unpaid – usually family and friends, but also neighbours – in supporting people with long term conditions and disabilities in the community. 1.4 million people in the UK provide over 50 hours of unpaid care per week. Carers’ health is often impacted by their caring role and they are twice as likely to have ill health because of caring.4

While unpaid carers provide the bulk of care, and are often relied upon, they are not systematically identified, supported or included throughout the NHS. Good practice exists in certain areas, but this is neither systematic nor systemic throughout the NHS. This lack of recognition and support for carers hinders evaluation and measurements of effectiveness. Carer-experience surveys are highly valuable measures and demonstrate that carers’ experiences of accessing health and care services are either static or worsening.

Closer integration between health and social care means that while one system (social care) recognises carers legally as an equal part, the other (the NHS) does not. For effective integration across the system to be achieved, we believe that both the NHS and social care need to have a statutory duty to have regard to carers and to promote their wellbeing.

The lack of systematic identification and support for carers across the NHS has significant risks, including:

- Negative impact on carers’ mental and physical health
- Carers having to cope with more complex conditions at home/in the relative’s/friend’s home
- For certain carers, significant risks to their ability to juggle work and care
- Increased direct health costs in the longer term
- Increased health inequalities
- Increased disparity in the social determinants of ill-health

We believe the Bill should introduce a duty on the NHS to have regard to carers and to promote their health and wellbeing.

Removal of requirement to assess prior to hospital discharge (Clause 80)

Through Clause 80 in the Health and Care Bill, the Government is seeking to pass legislation which would enact the Discharge to Assess approach that has recently been deployed by NHS England, and repeal the Community Care (Delayed Discharges, etc.) Act 2003. The 2003 Act contains a very direct requirement of the NHS body to identify and consult and carer before a discharge notice is issued.

Hospital discharge can be one of the most difficult points in the care system for unpaid carers, who often take on caring responsibilities without the right support. Prior research shows that carers are often not consulted before discharge of the person they care for: 26% of carers were not consulted about discharge and a third (33%) were only consulted at the last minute.

4 Census 2011
The Discharge to Assess guidance was published twice (first in 2020, and again in 2021) without any reference to any of carers’ rights. This has now been addressed by the inclusion of two paragraphs referring to the Care Act 2014 Part 1 provisions. We do not believe this is sufficient to protect carers’ rights, which we want to be maintained and not reduced in the passing of this Bill.

The Government’s own impact assessment of the Bill highlights the impact that this legislation could have on unpaid carers’ ability to work, as well as their finances, recognising that it will lead to many carers having to take on even more care – it states: “There is an expectation that unpaid carers might need to allocate more time to care for patients who are discharged from hospital earlier. For some, this could require a reduction in workhours and associated financial costs.”

Carers UK will seek to retain carers’ rights that are being taken away by the Health and Care Bill, as it repeals the Community Care (Delayed Discharges, etc.) Act 2003. The 2003 Act contains a very direct requirement of the NHS body to identify and consult and carer before a discharge notice is issued.

We will look to amend the Bill to introduce a new requirement to ensure that the NHS considers the carer’s health and wellbeing. This is to ensure that local authorities are not the only statutory body with responsibilities towards carers but that the NHS plays its equal part.

We will also look to amend the Bill to ensure that the NHS considers any broader impact of their decisions to provide services. This is to ensure that the carer has services which protect their wellbeing and that assumptions are not being made that they will automatically provide care.

While the local authority has the statutory duty to ensure that carers are assessed, and to consider carer’s willingness and ability to care, too many decisions are made by the NHS without considering carers’ own needs. This affects how they will manage, how they will continue in paid employment or how young carers will care safely or promote their education.

**Cap on care costs for charging purposes (Clause 140)**

Clause 140 of the Bill amends the Care Act 2014 to change the cap-and-floor model of social care funding. The change means that any local authority contribution towards paying for a person’s care would no longer be counted towards the cap on their total costs. This significantly reduces protection against very high care costs for people with low to moderate assets, while those who are wealthier will be able to keep a higher proportion of their assets.

Research by Carers UK found that 63% of carers were contributing financially towards equipment and services for the person they care for. While for some this was relatively modest, for others this ran into hundreds or thousands of pounds per month. This change will leave many families worried about how they will be able the potential costs of care. We recognise that under the new proposals everyone will be better off than under the existing system, but the main beneficiaries are people with higher assets, while the benefits for people with low to moderate assets will be marginal.

**Clarification needed about young carers and parent carers**

The Health and Care Bill does not define “carers”. We are therefore assuming that, since the NHS is an all-age service, “carers” would include the same definition as the Care Act 2014, “parent carers” under the Children and Families Act 2014 and the Carers (Recognition and Services) Act 1995 and “young carers” under the same legislation. This needs to be clarified and clearly stated in statutory guidance, or on the face of the Bill.
In the Bill, Carers UK welcomes:

**Duties on NHS England to involve and consult carers (Clause 5)**
We are pleased to see that where the NHS must involve and consult patients, they must now also consult carers. Taking carers’ views on board also ensures that they will be included for commissioning highly specialised services and the other commissioning functions of NHS England. Carers UK hopes that this will prevent situations where NHS England has failed to include carers properly in consultations or guidance e.g., Discharge to Assess guidance, where carers were not included in two versions of published guidance.

**Duties on Integrated Care Boards (ICBs) to consult and involve carers (Clause 19)**
This includes two provisions to ensure that ICBs consult and involve carers in the planning of commissioning arrangements, and secondly, in relation to any services related to diagnosis, treatment, or prevention in terms of the patient. These are vital measures to ensure that carers’ views are taken on board, since they provide the bulk of care in the UK – equivalent to that of the NHS. This moves closer towards carers being considered equal partners in care – which is what carers want – alongside the NHS considering their own needs as a carer.

**Newly created duties for the Care Quality Commission (CQC) (Clause 121)**
This means the CQC will have a new duty to review the performance of English local authorities in their delivery of their adult social care functions, under Part 1 of the Care Act 2014. We hope that this will also include their duties to carers under Part 1 of the Care Act.

**Contact**

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