

# **Carers UK briefing: Health and Care Bill**

## **July 2021**

**Note: this briefing covers England only and will be updated as the Bill progresses**

### **Introduction:**

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The Government has introduced the Health and Care Bill. Government's view is that the new Bill aims to facilitate greater collaboration within the NHS (and between the NHS, local government, and other partners), to improve the health and wellbeing of local people and to support any recovery from the Covid-19 pandemic. The Bill makes a number of changes in terms of structures as well as other important areas which affect carers which we set out below.

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.

Unpaid carers were not initially included in the Government's Health and Care White Paper and we expressed our disappointment. Carers UK has been working with Government to redress this and we welcome the proposals that directly include carers in public consultations, decisions about prevention and treatment of illness and commissioning of health services. We have set out these provisions below.

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

The Bill represents an opportunity for the Government to formally recognise the vital role played by carers supporting their relatives' health, and ensure they aren't overlooked but are visible and valued. We believe they should introduce a new duty for the NHS to have regard to carers. Government must leave a positive legacy for carers following the pandemic that sees their role acknowledged throughout the system.

### **Carers UK's detailed views on the Bill:**

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We want to ensure that carers are a clear part of the reforms that are being proposed by Government and are explicitly referenced in future plans.

#### **We welcome:**

- Duty on NHS England to consult carers (Clause 5)
- 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 19)
- New powers for the Care Quality Commission to assess local authorities (Clause 121).

**Carers UK is concerned about:**

- The Bill undermines carers' rights in relation to hospital discharge (Clause 78) removing a key element of their rights.
- There are no requirements to have carers or carers' representatives on either the Integrated Care Board or the Integrated Care Partnership (Clause 13).

**Clarification is needed:**

- To ensure that the definition of carers includes young carers and parent carers.
- That the people that the Integrated Care Board (ICB) have responsibility for, also extend to carers.

**Areas that need strengthening in the Bill**

- To place a duty on the NHS to have regard to carers and to promote their health and wellbeing – this goes beyond a duty to consult and involve but makes carers' a specific group who must be considered in terms of their own needs.
- To strengthen the planning and delivery of carers' breaks and carers' rights to a break.
- Consistent references to carers e.g., in the promotion of the NHS Constitution.

**Areas of the Bill we welcome:**

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**Consultation duties to include an explicit reference to carers, Clause 5 Public involvement and Clause 19 General Duties for ICB's**

Carers and people who use care services bring particular experience and having a non-specific consultation duty misses out the very specific contribution and experience of carers to the NHS.

There is a new duty on NHS England to involve and consult carers as part of public involvement (Clause 5). This is long overdue and where NHS England must involve and consult patients, they must now also include carers where services are being or will be provided. 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.

There are new 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.

Given that carers are part of and often responsible for the care of millions of patients and people who use care services in England, these measures help ensure that the system pays the appropriate level of attention to carers and their experiences. The experience of carers and people who use care services are essential to good integrated services.

## **Areas of the Bill we are concerned about:**

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### **Hospital Discharge, Clause 78 Hospital patients with care and support needs: repeals**

The Bill proposes updating the approach to hospital discharge by changing the legislative framework to enable a 'discharge to assess' model. This model includes enabling Care Act assessments to take place after an individual has been discharged from acute care. It removes the need to assess a patient at the point of hospital discharge by repealing the Community Care (Delayed Discharges, etc.) Act 2003 and Section 74 and Schedule 3 of the Care Act 2014 which has the same provisions. This removes carers' fundamental right to have a carer's assessment which includes consideration that services are provided to make sure that the patient is safe to discharge into their care. This is different to the Care Act 2014 rights that carers have and is very explicit.

Discharge from hospital following treatment can be a critical time for families, with many people finding they become unpaid carers overnight when their loved one comes home from hospital (or other healthcare settings). 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.<sup>1</sup> Even those who have been caring for a long time can face new and difficult challenges looking after someone who is recovering from an operation, as their needs for support may increase. It is crucial that families are prepared for this and that the right support is in place to help them cope.

To enact this 'discharge to assess' model, the government plans to repeal existing requirements to assess for care needs prior to hospital discharge, and the accompanying process of assessment and discharge notices.

Carers UK previously raised the important issue that the guidance did not include carers' rights during the process, so we are pleased that the update guidance published on the 5 July. While the updated guidance has addressed carers by the inclusion of two paragraphs referring to the Care Act 2014 Part 1 provisions, it does not replace the fact that other important rights of carers are being removed. Carers UK wants to see carers' rights maintained and not reduced.

We believe to remove this provision to ensure safe discharge would undermine carers' rights at a time when social care is extremely stretched and underfunded. The rights also confer a level of responsibility on the NHS to ensure that the patient is safe to discharge.

### **Care Quality Commission, Clause 121 Regulation of adult social care**

The Bill introduces a new duty for the Care Quality Commission (CQC) to review and make an assessment of the performance of English local authorities in their delivery of their adult social care functions under Part 1 of the Care Act 2014. **Carers UK welcomes the newly proposed powers for the CQC.**

We believe that the founding regulations of CQC need to be amended to explicitly reference carers, to ensure they do not just refer to people to who use services. This especially important as Part 1 of the Care Act 2014 includes duties on local authorities to promote carers wellbeing, and to carry out an assessment of their needs.

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<sup>1</sup> Carers UK (2016) 'Pressure points: carers and the NHS'

It is vital in the review and assessment of the performance of local authorities' delivery of adult social care functions includes a review of the support provided to and the assessment of the needs of carers in a local area.

### **Membership and constitution of ICBs (Clause 13)**

The Bill stipulates that ICBs must have a Chair and at least 3 ordinary members; one jointly nominated by NHS Trusts and NHS Foundation Trusts, one jointly nominated by persons who provide primary medical services, and one jointly nominated by local authorities. We are disappointed that including the experience of the voluntary and community sector, patients, people who use social services and carers will not be required for all ICBs. In designing and delivering health services it is vital that the experiences of the people using the services, and their carers, are included. We believe it is fundamental to ensure that carers or carers representatives, alongside the voluntary and community sector are members of all ICB's.

## **Areas of the Bill that need to be clarified:**

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### **Definition of 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. We are asking for this to be clarified.

### **Clarification about people for whom the ICB is responsible:**

The Bill is unclear about whether the ICB would have specific responsibilities towards carers and several provisions are linked to this. Carers UK will be seeking to clarify this further. Our belief is that the Bill, regulations and guidance need to clarify this point.

## **Areas where the Bill could be strengthened:**

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### **Improving carers' health and wellbeing as well as outcomes for people who need health and care – introducing a duty to have regard to carers**

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.<sup>2</sup> During the pandemic, the number of carers rose dramatically at one point as many as 13.6 million carers across the UK or one in four of the population.<sup>3</sup>

Carers health is often impacted by their caring role and they are twice as likely to have ill-health because of caring.<sup>4</sup> Carers often play numerous roles simultaneously; administering

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<sup>2</sup> Census 2011, figures for UK, published in Facts About Carers. Increased figures from Understanding Society suggests that this has increased since 2011 in Carers, Social Market Foundation, 2018

<sup>3</sup> Carers Week (2020) Carers Week Research 2020

<sup>4</sup> Carers UK (2019) Facts about Carers 2019

medication, supporting daily activities of life such as eating, drinking, dressing, moving, supervision and cognitive support, through to more complex specialised nursing care.

Whilst 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.

NHS legislation currently does not have to have regard to carers own wellbeing explicitly, nor does it have to identify carers. This is not the case for social care, which treats carers equally in legislation alongside people who use services. Closer integration between health and social care means that one system recognises carers legally as an equal part, the other 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 are therefore recommending that the Bill includes a duty on the NHS to have regard to carers and to promote their health and wellbeing.**

### **Carers Breaks**

We are concerned that currently there is insufficient supply of services to provide breaks to carers, and that many carers are not able to access the breaks they need to look after their health and wellbeing. Even before the pandemic carers were struggling to access meaningful breaks, with 44% of carers saying they did not get the breaks they needed. This situation has worsened during the pandemic, during which 72% of carers have not had any breaks; of those carers who did get breaks two thirds (66%) said they had fewer breaks or insufficient breaks to look after their physical and mental health<sup>5</sup>. Carers reported that they had on average, 25 hours of support per month over the past 18 months<sup>6</sup>.

Carers are reporting high levels of fatigue and stress after caring during the pandemic, with almost three quarters (74%) reporting feeling exhausted and worn out as a result of caring during the COVID-19 pandemic. Nearly two thirds (63%) are worried about continuing to care without a break.

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<sup>5</sup> Carers Week, (2021) Breaks or Breakdown

<sup>6</sup> Carers Week, (2021) Breaks or Breakdown

Carers access to breaks are essential to manage their own health and wellbeing and prevent carer breakdown. We believe the bill should introduce a requirement on health and social care to ensure the sufficiency of supply of carers breaks, and to give every carer a right to a break.

## **What the Bill does overall explained and implications for carers and local services:**

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The Bill creates several different elements that will affect carers:

### **What is an Integrated Care Board?**

It creates an Integrated Care Board, essentially an NHS based organisation which will replace Clinical Commissioning Groups and most of their roles. The plan is to delegate more of NHS England's responsibilities to these ICBs over time, which is why the provisions to consult and involve carers are so important. This will mean that the consultation mechanisms carers are used to in local areas will change. The geography over which carers are consulted will also change. Government is planning to publish guidance on ICBs.

### **What is an Integrated Care Partnership?**

The Bill creates an Integrated Care Partnership which would include local authorities, the voluntary sector, and others, including the Integrated Care Boards. This is closer to the Integrated Care System as they are currently set up locally. This is where we would expect local carers' organisations and carers to be involved. There are currently no duties on the ICP to involve or consult carers. However, since the ICB and local authorities both have separate duties to consult carers, we would expect this to happen. Government is planning to publish guidance on ICPs. We would expect carers to be clearly included in this guidance and consultation clarified.

### **Duty on Integrated Care Boards to reduce inequalities**

This updates duties on CCGs to reduce inequalities in access to health services and outcomes from health services. Given the inequalities faced by carers, this could be used to work with ICBs to reduce these and improve carers' outcomes. Caring has also been declared a social determinant of health by Public Health England.

### **Duty on Integrated Care Boards to promote integration**

This provision looks at the ICB promoting integration with health services and social care services to improve quality and reduce inequalities as set out above. There is also a reference to housing.

### **Duty on the Integrated Care Board to publish a forward plan**

Each ICB has to publish a forward plan for the next 5 years at the start of each financial year. They must have regard to the local Health and Wellbeing Strategy and they must consult people for whom they have core responsibility and anyone else who may be prescribed. Carers UK is clarifying this point and how it fits with Clause 19. We would expect carers to be consulted on the Forward Plan.

### **New provisions around the NHS Mandate and how that affects carers**

Previously the Government had to make an annual Mandate to NHS England setting out what it wanted NHS England to achieve specifically in that year. In the past, the Mandate has set out an aspiration for CCGs to have systems in place for identifying carers but more recent mandates have been very COVID focussed, understandably. The Bill changes this annual

cycle to something that is longer term, but can be amended as and when needed. The requirement for an NHS Mandate still exists. This means that any provisions for or references to carers must be at the start of this process.

**New provisions around the Better Care Fund**

The Bill gives NHS England and Integrated Care Boards stand-alone powers to use the Better Care Fund for integration. This changes the current provision where Ministers stipulate the BCF in the Mandate and it is ring-fenced.

**New duty on NHS organisations and the ‘Triple Aim’**

This Bill would introduce a new duty on NHS organisations to consider the effects of their decisions on the better health and wellbeing of everyone, the quality of care for all patients, and the sustainable use of NHS resources - the policy referred to in the White Paper “Working together to improve health and social care for all” as the “Triple Aim”.

**Contact us:**

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