carersUK
making life better for carers

Policy Briefing
March 2021

Briefing on the NHS White Paper setting out legislative proposals for a Health and Care Bill

Introduction:

The Government published a White Paper on the legislative proposals for the Health and Care Bill. The new legislative framework seeks 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.

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.

We are **very** disappointed, however, there is currently no explicit mention of unpaid carers in the White Paper proposals for the Bill.

Carers play an essential role in supporting the NHS and social care systems. The pandemic has clearly underlined the essential role that unpaid carers play. 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 deserve 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.

This is an opportunity to acknowledge the role of carers in supporting our health and social care systems and provide support for them to look after themselves and the person they care for.

Summary of our views:

We are calling for carers to be a clear part of the reforms that are being proposed by Government. **Carers must be explicitly referenced in future plans.**

Our main calls for the forthcoming Bill include:

- A duty on the NHS to have regard to carers and to promote their health and wellbeing.
- Clear and explicit references to carers when there are duties for new bodies to consult.
- A carer representative on key decision-making bodies.
- Clear inclusion of carers in the Care Quality Commission's proposed new responsibilities around the Care Act 2014.

In addition:

- We do not want to see the duties around discharge to assess being removed -without some safeguards about carers' rights under the Care Act 2014.

We welcome:

- Measures to share data. These will be enhanced if carers are clearly flagged within data systems and their experience tracked across different parts of the health and care system.
- The objectives around integration.
- The proposal for the Care Quality Commission to review commissioning by local authorities under the Care Act 2014.

We want to see the NHS given new legal responsibilities to consider unpaid carers and promote their health and wellbeing and for these proposals to be included in any future Bill.

We are also concerned about the proposals which would allow for carers' statutory right to a Carer's Assessment to take place after the person they care for is discharged from hospital, which we believe erode carers rights as set out in the Care Act 2014. Therefore, we are concerned about the proposals relating to the removal of the requirement for assessment and discharge notices, without the right explicit safeguards in place for carers.

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.[1] 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.[2]

Carers health is often impacted by their caring role and they are twice as likely to have ill-health because of caring.[3] Carers often play numerous roles simultaneously; administering 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.

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[1] 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

[2] Carers Week (2020) Carers Week Research 2020

[3] Carers UK (2019) Facts about Carers 2019

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.

A requirement for consultation duties to include an explicit reference to carers:

We believe that this is essential and must also go alongside consultation duties that explicitly includes people who use care services with regards to any integrated service. This goes beyond "patients and citizens, or patients and their families". 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. Given that carers are part of and responsible for the care of millions of patients and people who use care services in England, this would ensure that the system paid 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.

A requirement for representation of a carer and a person who uses care services on any decision-making committee or body:

For similar reasons as set out above, we consider it necessary to include this.

Hospital Discharge:

The White Paper 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.

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). 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.

We are also deeply concerned that the Discharge to Assess guidance published by the NHS did not include any reference to carers' rights under the Care Act 2014. The only reference to carers in the main body of the guidance was to be contacted to collect the person they cared for from hospital. If this process were to be followed it would be unlawful. The Care Act 2014 requires an assessment of the carers' willingness and ability to care.

Carers should expect to be involved in decisions about care and to receive support that meets their own needs following discharge. They must also be informed of their rights.

We are concerned that the proposals erode carers rights and do not allow for effective decision making on whether the amount of care provided by individual carers or families is sustainable. A core element and intention of the Care Act 2014 is to determine if carers are able and willing to continue caring at the same or increased levels.

During the pandemic 78% of carers have reported an increase in the needs of the person they care for.[4] This will result in any documentation that the council holds in relation to the carers' needs, willingness, and ability to care will also be out of date since the majority of carers have increased care, decreased mental and physical wellbeing.

We are concerned about the removal of the requirement for assessment and discharge notices without explicit safeguards in place for carers. Any new primary legislation for discharge to assess must ensure that, before someone is discharged from hospital, their carer is willing and able to care for that person. Under the Care Act 2014, this is an important right along with unpaid carers' right to a Carer's Assessment and this needs to be reflected in any future legislation.

Care Quality Commission – additional duties:

In redrawing the **regulations regarding the Care Quality Commission** to encompass the Care Act 2014, this needs **to explicitly reference carers** to reflect the Act.

The White Paper proposals a new duty for the Care Quality Commission to assess local authorities' delivery of their adult social care duties. Why this is important, is because the founding regulations of the CQCs duties only refer to people to who use services and do not include carers.

Carers UK welcomes the newly proposed powers for the Care Quality Commission.

Integration and the establishment of Integrated Care Systems:

We welcome the steps towards integration and a legal footing for Integrated Care Systems alongside objectives to ensure that there is integration within and between different NHS organisations as well as social care. Carers often say that the lack of integration causes additional stress and difficulty.

Increased data sharing:

Carers UK welcomes the proposal that there is increased data sharing. Carers become very frustrated when they have to continually repeat information to different agencies. A key plea

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[4] Carers UK (2020) 'Caring Behind Closed Doors – Six Months On'

from carers is not to have to repeat information, but also be connected with support earlier in their caring journey. Data sharing has the power to improve carers' lives in this way if carried out appropriately. It would be vastly enhanced if carers were flagged on key records and their journey potentially tracked as well.

Contact

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