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making life better for carers

Policy Briefing
November 2020

Carers UK response:
Consultation on NICE Draft Quality Standard for Carers

Introduction and about the consultation

NICE (National Institute for Clinical Excellence) has been consulting on a Quality Standard for Carers, which spans health and social care. The quality standards were published for consultation on 12 October 2020 and the consultation closed at 5pm on Monday 9 November 2020. You can find more information about the consultation, here.

Responding to the consultation: We are concerned that responding to the consultation has not been straightforward, as local organisations are not able to register to comment on the draft guideline, and therefore can only submit comments as "individuals". We feel that this misses out a great deal of expertise from local organisations who implement these standards.

Due to time constraints because of lockdown we were not able to gather comments from local organisations, but in the future would see to do so.

Carers UK's overall response

We are concerned that some of the quality statements, as currently written, fall short of current laws on social care. Whilst we recognise that some of the standards might help to increase support across the NHS, the standards in their current form are not fully compatible in their breadth with good practice work such as the NHSE GP Quality Markers.

NICE standards and statements are developed for use by a whole range of different stakeholders. Given that we feel these statements fall short of carers' existing rights, we would suggest that this is providing inaccurate information to those stakeholders, due to the limited nature of the statements.

We would strongly suggest that the standards are rewritten to reflect social care law and the NHSE/I GP Quality Markers good practice work.

Broader issues needing to be tackled by Government

NHS legislation and carers: What this work highlights are the differences between the legislation across health and social care. Whereas in social care legislation, carers have parity of esteem, within health legislation they are legally less visible. We believe that the Government needs to level-up the legislation with social care and ensure that future NHS legislation recognises carers clearly.

Data collection and monitoring: A second issue highlighted by this work are the different ways in which data collection and monitoring are limited across social care, but almost non-existent particularly across health care. The most valuable data source in healthcare is the GP Patient Survey which we feel could be utilised better.

Carers UK's views on the individual Quality Statements

Our views on the individual Quality Statements are as follows:

- **Statement 1: Carers are identified by health and social care practitioners at appointments for people with long-term conditions.**

We consider this statement to be falling short of the law under the Care Act 2014. Local authorities have a duty under s.4 of the Care Act 2014 to identify carers. This is not limited to appointments for people with long term conditions, but a wide-ranging duty to identify carers broadly. We do not believe this is an appropriate statement of quality for social care. Given the practice of local authorities currently, which is broad and diverse, and the way that they commission local services, this statement falls short.

In terms of health, it falls short of the GP quality markers statements that are produced by NHSE, and which are in the NHS Long Term Plan as a target to fulfil. We do not feel it is useful to have a quality marker that differs from other quality-related work published by NHSE. We have endorsed NHSE's work and give it our full backing.

The definition also does not promote identification at key points of the system, e.g. hospital discharge. Some conditions may involve intense caring for many months but may not constitute a long-term condition, e.g. late diagnosis terminal cancer, recovery from a major operation, or a road traffic accident.

Furthermore, the legislation for adult social care sets out a requirement to identify any children within the household and this should be incorporated within the statement. Whilst there is a focus on adults, those implementing legislation from adult services must be implementing the Care Act 2014 legislation.

We have redrafted the quality statement to reflect the level of the law and practice along the lines of which we would consider to be acceptable – see below:

Carers, including young carers, are identified through a variety of measures by local authorities. GP practices regularly identify carers through the GP quality markers and carers are identified through community trusts and secondary care.

- **Statement 2: Carers are kept up to date and contribute to decision making and care planning for the person they care for, with the person's consent.**

This statement is close to practice. It should be pointed out in the background information that there are several different areas that need to be considered.

- **Statement 3: Carers having a carer's assessment are asked about what matters most to them, including consideration of their health, wellbeing and social care needs, and work, education, or training.**

Practice is tending towards a "what matters most to you" question, to focus on carers' needs, but it is essential to ensure that any carer's assessment appropriately explores the full range of areas that need to be considered under the Care Act 2014 provisions for carer's assessments.

This What Matters Most approach is already adopted in Wales and we have some concerns that this is starting to truncate the carer's assessment process in a way that then overlooks key areas that are important to carers and a core part of the Care Act 2014. We would urge you to look at the experience of Wales in Carers Wales Track the Act publication here: https://www.carersuk.org/wales/news-campaigns/track-the-act/track-the-act-survey-briefings

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- **Statement 4: Carers discuss, during their routine assessments and reviews, the value of having a break from caring and the options available to them.**

This statement may be appropriate in some instances for health services but would be considered necessary for any Care Act assessment or review. The background evidence does not really explore the definition of routine. Are routine assessments "routine" for the organisation, or for the individual? Carers do not have carer's assessments routinely. Many do not even receive an annual review. Other some of the routine health assessments would be highly appropriate to identify carers and discuss breaks. Health checks, for examples should collect identification of carers as a standard. Other routine assessments might need further discussion, e.g. medication reviews, which may take place with doctors or with pharmacists. The latter are very well placed to identify carers and signpost to support, but less well placed to discuss breaks and options open to carers. It should also be noted that in all carer's assessments, breaks should be a core part of the assessment, according to policy guidance and not an optional statement relating to quality.

- **Statement 5: Carers work in organisations that offer supportive working arrangements.**

This statement is acceptable as it incorporates the law and goes beyond that to broader measures to support carers.

Unfortunately, the data set would be limited, since it will only record those carers who are in touch with local authorities. It would not cover carers whose relatives are in residential care, self-funders, those in touch with voluntary organisations, those with CHC funding, those only who have contact with health bodies as they have a complex health condition, and those who manage without help.

It is also widely evidenced that, by the time a carer is known to a local authority and requests a carer's assessment, they are less likely to be in work. Whilst we recognise that data collection is limited, we would encourage broader sources of data collection to be added to this to provide a more rounded view.

Contact us

For further information about this policy briefing, please contact: John Perryman, Senior Policy and Public Affairs Officer **(john.perryman@carersuk.org / 07481038183)**

Carers UK
20 Great Dover Street
London
SE1 4LX
Telephone: 020 73784 4999
Email: info@carersuk.org
Web: www.carersuk.org
Twitter: @CarersUK

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