

Carers' assessments:
developments, digital,
diversity, co-production
and good practice



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Introduction



This briefing document has been created by the Carers Partnership (Carers UK and Carers Trust) as part of the Health and Wellbeing Alliance. It examines current good practice in providing and delivering carers' assessments – in particular amongst local authorities and local carer organisations, some of which provide delegated statutory assessments.

The purpose of this document is to support commissioners, service providers and policy makers in looking at how assessments in England are provided to unpaid carers, in order to improve carers' outcomes. As well as evidence from unpaid carers, we include a number of different areas of practice in England.

Despite the COVID-19 pandemic, Census 2021 revealed that there was a surprising drop in the overall number of unpaid carers – from 5.8 million in the 2011 Census to 5 million in the 2021 Census, across England and Wales. The ONS suggests a number of reasons for this, including changes in the nature of caring during the pandemic and the high levels of deaths during the pandemic. However, it also suggests that the change in question framing could have made a difference. Whilst the 2011 Census question mentioned providing unpaid care for family, friends or neighbours, the 2021 question referred to caring for anyone. This will have had an impact because people don't recognise themselves as unpaid carers. The Census 2021 data does, however, show increases in the proportion of people in England who provide between 20 and 49 hours of unpaid care a week (from 1.5% in 2011 to 1.8% in 2021). The proportion of people in England who provide 50 or more hours of unpaid care a week remained similar (2.7% in 2011 and 2.7% in 2021).

In this document, we explore “what good looks like”, as well as areas for improvement regarding carers’ assessments, with a particular focus on the experiences of carers from communities who face additional barriers and other health inequalities. We aim to stimulate conversation around the unique challenges faced by carers from underrepresented backgrounds and make recommendations on how best to support them – especially Black, Asian and minority ethnic carers and LGBTQ+ carers.

In this document, we have concentrated on assessments for adults caring for adults. We have not looked at transitions to adulthood for young people with disabilities, but there is information developed by **Contact A Family**. Equally, we do not look at transitions for young carers into adulthood as this also warrants special attention beyond this work’s scope.

Section 1: About carers' assessments



Background to carers' assessments – the overall aim and purpose

Carers' assessments have been in operation since 1995 and are a central part of the Care Act 2014, where local authorities have a duty to assess carers (unpaid carers) where there is an appearance of need in relation to someone who may need care and support. Carers do not need to already be providing care to have a right to an assessment, they might also be about to take on a caring responsibility.

Carers' assessments can provide a useful point to look at what help, if any, they might need. Assessments are an opportunity for carers to look at their own goals and outcomes in relation to their caring responsibilities, allowing them to think long term and not just in the present moment.

There is extensive policy and practice guidance on carers' assessments in the Care Act 2014, which can be found in the Care and support statutory guidance.

The purpose of carers' assessments is to:

- Give carers an opportunity to discuss the outcomes that matter to them, the support they need, and make sure that they are able to make choices about the unpaid care they provide. The purpose of this is to promote carers' health and wellbeing.
- Improve the health and wellbeing of carers, as well as the person they care for, by getting support right for both. An assessment should ensure that the caring role is sustainable in a way that works for the carer.
- Provide the local authority with a good picture of the unpaid care being provided, including any risks, and to ensure that care is sustainable and appropriate. There is an important test requiring the assessor to ensure that the carer is both "willing and able" to care, building in choice and checking that carers are able to continue to care, or not, as well as when further support is needed (either to the carer or to the person needing care).

Carers' assessments should be proportionate (eg, lighter touch) and can be delivered in a variety of methods, including online, telephone or face-to-face. This must be appropriate to the situation and to the person. There cannot be one approach adopted.

As well as a carer's assessment being a statutory duty, there is evidence that a good assessment is also a therapeutic intervention in itself for the carer when done well – providing psychosocial and emotional benefits.¹

"X was the first person who sat down with me and asked, 'how are you?' It's always been about my husband, and no-one ever asks about me, that made such a difference."

– Testimony from a carer, provided by n-compass

Although carers' needs can be assessed through joint assessments, they are also entitled to a separate assessment of their own needs. This document looks at this good practice in relation to these standalone assessments which can often be a valuable time to focus on the carer's needs directly.

Whilst local authorities retain the overall duty and responsibility towards carers, they can delegate part or all of the process of carers' assessments to another organisation, including a health body, if they wish to. The Care Act 2014 statutory guidance clearly states that in delegating any function it is essential that:

"the body carrying out the assessment complies with all the requirements and fulfils all relevant duties under the Act and regulations."

¹ National Institute for Clinical Excellence (Jan 2020), *Supporting Adult Carers (NG150)*
www.nice.org.uk/guidance/ng150/chapter/Recommendations

Importantly, the guidance states that:

*“anything done by the body carrying out an assessment is treated as if done by the local authority”.*²

In other words, the local authority must assure themselves of processes and outcomes.

The guidance to the Care Act 2014 sets out the principle of making sure that carers know what a carer’s assessment is,³ as well as a legislative base for sharing what the conclusions and outcomes are and what services might be delivered either to them or the person they care for.

Carers and financial assessments

Carers’ assessments should not be subject to any charging, and it is recommended that services to unpaid carers are then provided free of charge and not financially assessed for them. Although local authorities are able to charge (ie, they have the power to do so), it is not a requirement under the Care Act 2014 to do a financial assessment of the unpaid carer in relation to any potentially chargeable support that might be delivered to meet carers’ outcomes. Charging carers can also be a barrier to taking up support when the primary goal is to improve carers’ health, wellbeing and outcomes.

Carers, joint assessments and whole family approaches

It is important that carers’ needs are still considered properly within joint assessments with the person being cared for and their needs and outcomes recorded. A standalone carer’s assessment should also fit in with a whole family approach, with consideration given to all other family members, including children within the family. Adult social services have a duty to identify young carers and ensure that sufficient support is provided to any adults with disabilities or long-term conditions to ensure that the young carer does not provide inappropriate levels of support.

Carers have a right to an assessment and support equal to that of the person they are providing care and support to. Joint assessments must take this into consideration – ensuring that any joint assessment only takes place if the carer chooses it and that carers are given the option of having a separate conversation with the assessor.

² Care Act 2014, para 6.99

³ See para 6.35 of the Care Act 2014 guidance www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance#first-contact-and-identifying-needs

NICE guideline on unpaid carers – relationship to carers’ assessments

The National Institute for Health and Care Excellence (NICE) has developed a specific set of quality standards and guidelines, Supporting Adult Carers.⁴ This includes a standard on carers’ assessments (Quality Standard 3) which states:

“Carers having a carer’s assessment are given the opportunity to discuss what matters most to them, including their own health, wellbeing and social care needs, and work, education, or training.”

The NICE guidelines and standards state that service providers should ensure that processes are in place for carers’ assessments to focus on what matters most to the carer and what will help them so that they can be better supported in their caring role. NICE stresses that an effective assessment should be jointly produced with the carer.

NICE also makes specific reference to equality and diversity considerations:

“Service providers that carry out carers’ assessments should make reasonable adjustments to ensure that carers with additional needs, such as physical, sensory or learning disabilities, and people who do not speak or read English, or who have reduced communication skills, can have an assessment that is accessible and takes account of their needs. People should have access to an interpreter (including British Sign Language) or advocate if needed.”



⁴ National Institute for Clinical Excellence (March 2021) *Supporting adult carers (QS200)*
www.nice.org.uk/guidance/QS200

People at the Heart of Care – “I” statements

The Government published a white paper, *People at the Heart of Care* in December 2021. It includes “I” statements relating to unpaid carers which provide an important guide for what a carer’s assessment should achieve.⁵

These include having unpaid carers be able to say:

- I am supported to provide care as I wish and do so in a way that takes into account my own access to education, employment, health and wellbeing.
- I have a life outside of caring and I am able to remain connected to the people who matter to me.
- I know my needs are equally recognised and my goals and aspirations are respected and fulfilled.
- I have the right information and advice to be able to make informed decisions.
- I have access to appropriate support, that suits my needs including respite care and carers’ breaks.
- I am able to navigate the health and care system with ease.
- I understand the support that is available to me in my area to maintain my own health and wellbeing, and achieve the outcomes that matter to me.
- I am provided with the necessary information and advice to make informed decisions about the care I provide.
- I am provided with the tailored information and advice I need to support and meet the needs of the person I care for.



⁵ Department of Health and Social Care (December 2021) *People at the Heart of Care: adult social care reform*

www.gov.uk/government/publications/people-at-the-heart-of-care-adult-social-care-reform-white-paper/people-at-the-heart-of-care-adult-social-care-reform

Care Quality Commission – local authority assurance

The Health and Care Act 2022 includes new provisions for the Care Quality Commission (CQC) to assess the performance of local authorities' delivery of their adult social care duties, as set out under the Care Act 2014. The CQC has been working with local government, the care sector and people with care and support needs to develop a framework for these assessments including how to consider local authorities' responsibilities to carers.

The needs of unpaid carers are referenced throughout the assessment framework.

The content of the local authority assessment framework will help to build up a picture of how local authorities are performing their key Care Act duties, including those related to unpaid carers. Rather than focussing on the needs of unpaid carers as a specific, standalone issue, the CQC will assess and report on the wider range of activities and functions that support this.

The assessment framework will be underpinned by relevant, nationally recognised best practice. This will include guidance relating to unpaid carers.

The evidence provided for this document has been designed to help inform that process for the Care Quality Commission and for local authorities in terms of looking for good process, commissioning criteria, evidence of carer involvement and outcomes.



Challenges around carers' assessments

There are a number of challenges around the delivery of carers' assessments, including:

- Volume of carers' assessments where there are delays in the system.
- Getting the balance right between recording enough information for sharing, audit and compliance, and making the process seem overwhelming.
- Getting the right balance between online or telephone assessments.
- Measuring outcomes against individual carers' goals and more linked to real time data collection.
- Ensuring that diversity gaps are clearly identifiable.
- Developing online systems for carers' assessments that are user friendly but which also link to other areas of development (eg, summary care record and shared care record).
- Awareness of carers' assessments from people who are providing care.
- Better funded outcomes and support.
- Data collection which is reflective of the broad diversity of carers' assessments and support systems.
- Ensuring that the outcome of a carer's assessment informs the assessment of the person needing care (which is a Care Act 2014 requirement).

Section 2. Carers' assessments – data and diversity



Recent data on carers' assessments

The Short and Long Term (SALT) data suggests that there has been an overall decline in the number of carers that have been supported or assessed/reviewed. The total number of carers supported or assessed/reviewed in 2021/22 in England was 380,725 – a fall of 2.1% from the 388,730 supported or assessed/reviewed in 2020/2021.⁶ Even if we go back to 2015/16, the total number of carers assessed for support was 386,605.⁷ The latest figures are far less than what would be expected given the Census 2021 results showing a growth in the number of unpaid carers providing substantial care of 20-49 hours a week (260,000) and 50 hours a week (152,000) between 2011 and 2021 and a deepening of the amount of care provided over time.⁸

⁶ Note that this disparity may be due to increased demand during the first year of the COVID-19 pandemic, with the role of unpaid carers increasing due to lockdowns and shielding in 2020-21. For discussion, read here: digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-activity-and-finance-report/2021-22/carers

⁷ Dr Charlotte Paddison and Dr Nadia Crellin, Nuffield Trust (October 2022) *Falling short: how far have we come in improving support for unpaid carers in England?* www.nuffieldtrust.org.uk/research/falling-short-how-far-have-we-come-in-improving-support-for-unpaid-carers-in-england

⁸ Census 2021 *Unpaid care, England and Wales* www.ons.gov.uk/people-populationandcommunity/healthandsocialcare/healthandwellbeing/bulletins/unpaidcareenglandandwales/census2021

The Adult Social Care Activity and Finance Report, England, 2021/22 found that of the total 380,725 carers supported or assessed/reviewed in 2021/22, 82.4% (313,575) received direct support, which includes direct payments, part direct payments, local authority managed personal budgets, local authority commissioned support and the provision of information advice and other universal services or signposting. This is a decrease from the previous year where 87% of carers received direct support.⁹

The Association of Directors of Adult Social Services (ADASS) has also highlighted a backlog in social care assessments and that different areas are experiencing different levels of waiting for carers' assessments.¹⁰

Who is more and less likely to have a carer's assessments?

Whilst the SALT data does not provide any diversity information in terms of carers from Black, Asian or ethnic minority communities or other equalities data, there is specifically more detail on unpaid carers known to their local authority when analysing the NHS Digital Survey of Adult Carers in England – which captures information about ethnicity, sexual orientation, religion, gender and age.¹¹ Carers UK also has evidence from their *State of Caring 2022* survey that some carers are less likely to have assessments than others. Other work has found that carers providing more substantial care are more likely to have a carer's assessment.¹² In later sections of this work, we look at where organisations are trying to address this.

Carers UK's survey captures data on carers, the majority of whom are providing very substantial care and are more likely to have been caring for longer. Analysing the data for 2022 in England, Carers UK found that the older a carer is, the more likely they will have an assessment. Carers aged 65+ are more likely to have an assessment (28%) than carers aged 18-64 (23%). There was no difference between male and female carers in the rate of assessment take-up (25%).

The report also found that the number of hours of care someone was providing each week was related to whether they had received a carer's assessment, with 28% of people caring over 35 hours a week having an assessment, compared to 17% of people caring for fewer than 35 hours.

Carers UK's *State of Caring* survey also highlights some interesting differences amongst groups from earlier surveys. Carers providing palliative care were slightly more likely to have had an assessment in the last year (31%).¹³

⁹ NHS (October 2022) *Adult Social Care Activity and Finance Report, England, 2021-22*

digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-activity-and-finance-report/2021-22/carers

¹⁰ The Association of Directors of Social Services (May 2022) *Waiting for care*

www.adass.org.uk/waiting-for-care-adass-report-may-2022

¹¹ NHS (October 2022) *Personal Social Services Adult Social Care Survey, England, 2021-22*

digital.nhs.uk/data-and-information/publications/statistical/personal-social-services-adult-social-care-survey/england-2021-22

¹² Jose-Luis Fernandez et. al, (January 2021) *Supporting carers following the implementation of the Care Act 2014: eligibility, support and prevention*

www.lse.ac.uk/cpec/assets/documents/cascfi-nalreport.pdf

¹³ Carers UK (November 2019) *State of Caring 2019*
www.carersuk.org/reports/state-of-caring-2019

In *State of Caring 2021*, those caring for someone with a mental health condition (26%) were also marginally more likely to have had a carer's assessment compared to those caring for someone with a physical health condition (23%).

Carers UK also found that carers from a Black, Asian or minority ethnic background are less likely to have a carer's assessment (21%) compared to those from a white background (25%). Lesbian, gay and bisexual carers are less likely to have an assessment (19%) than heterosexual carers (25%). There was little difference between carers who identify as having a disability and carers that do not have a disability (25% vs 24%). Overall, nearly a fifth of carers (19%) in the State of Caring 2022 survey said that they had not requested a carer's assessment as they didn't think it would be beneficial to them.

Specific targeting is needed to better reach groups most likely to experience health inequalities, or who may be less likely to access assessments, to ensure that they are aware of their statutory right to an assessment. The evidence in particular suggests that there are health inequalities between ethnic minority and white groups.¹⁴ This may be due to language barriers, or a lack of understanding from services around cultural differences.¹⁵ Some research has found that Black, Asian and minority ethnic carers need support to combat stigma around mental health conditions.¹⁶ Targeting is also important as Black, Asian and minority ethnic carers may not identify themselves as carers, perhaps because of cultural expectations around care.¹⁷

Carers UK has produced examples of good practice in relation to carers from Black, Asian and minority ethnic communities¹⁸ and the LGBTQ+ community,¹⁹ which suggest important approaches to how to target assessments. This includes consulting with Black, Asian and minority ethnic carers and local organisations supporting ethnic minority people about which languages would be most helpful, whether translated materials would be valuable, who might benefit from them and how these translated materials could be shared with different communities, as well as forming LGBTQ+ and Black, Asian and minority ethnic support networks or befriending programmes for carers who may find peer support helpful.

¹⁴ Veena Raleigh and Jonathon Holmes (September 2021) *The health of people from ethnic minority groups in England*

www.kingsfund.org.uk/publications/health-people-ethnic-minority-groups-england

¹⁵ Oluwatosin Ajayi (March 2021) *A perspective on health inequalities in BAME communities and how to improve access to primary care*

www.rcpjournals.org/content/futurehosp/8/1/36

¹⁶ Anjum Memon et. al, (September 2016) *Perceived barriers to accessing mental health services among black and minority ethnic (BME) communities: a qualitative study in Southeast England*

bmjopen.bmj.com/content/6/11/e012337

¹⁷ Nilufar Ahmed and Ian Rees Jones (January 2008) *'Habitus and Bureaucratic Routines', Cultural and Structural Factors in the Experience of Informal Care: A Qualitative Study of Bangladeshi Women Living in London*

journals.sagepub.com/doi/10.1177/0011392107084379

¹⁸ Carers UK (January, 2023) *Supporting Black, Asian and minority ethnic carers: A good practice briefing*

<https://www.carersuk.org/media/3izluvum/cuk-black-asian-and-minority-ethnic-carers-good-practice-briefing.pdf>

¹⁹ Carers UK (January, 2023) *Supporting LGBTQ+ carers: A good practice briefing*

<https://www.carersuk.org/media/3tppsbyc/carers-uk-lgbtq-briefing-2023-web.pdf>

Section 3. Carers' perspectives on good assessments



What are carers' views on carers' assessments?

There is evidence from regular engagement with carers and from research, that carers' assessments have the following challenges.²⁰

Carers:

- Don't always identify as a "carer" or wish to do so.
- The word "carer" doesn't translate into other languages easily.
- Don't know about carers' assessments and that they are entitled to one.
- Don't always know that they've had one.
- Are put off by the name "assessment" as it sounds like a test.
- Don't like processes which don't feel person-centred.
- Are concerned about the process being a 'tick box' exercise.
- Are worried about it being extra work or more difficult.
- Are sceptical about outcomes in a system that has funding challenges.

²⁰ Carers UK (various)

State of Caring 2018
[www.carersuk.org/
reports/state-of-caring-
2018-report](http://www.carersuk.org/reports/state-of-caring-2018-report)

State of Caring 2019
[www.carersuk.org/
reports/state-of-car-
ing-2019](http://www.carersuk.org/reports/state-of-caring-2019)

State of Caring 2021
[www.carersuk.org/
reports/state-of-caring-
2021-report](http://www.carersuk.org/reports/state-of-caring-2021-report)

State of Caring 2022
[www.carersuk.org/
reports/state-of-caring-
2022-report](http://www.carersuk.org/reports/state-of-caring-2022-report)

What good looks like for carers

“The assessment was very considerate of my needs and the person carrying it out was fully considerate and took on board all my needs.”

– Carer, *State of Caring 2022*

The carer’s assessment should adopt the following approaches:

- Value carer- and person-centred approaches which can mean creative solutions to support needs and outcomes.
- Ensure carers are being heard and that assessments have a focus on their needs.
- Be focussed on what matters to the carer.
- Looks at risk-based issues sensitively.
- Helps to think through the kinds of help needed, including community-based support.
- Meaningful follow-up.
- Culturally appropriate.
- Clear processes and knowing about outcomes.
- Accessibility and timeliness of carers’ assessments.
- Proportionate processes (ie, lighter touch or more detailed depending on the situation).
- Reviews at the right time.

“The assessment improved my health and wellbeing. I feel better connected with my local community. I have learned new skills and made some new social contacts. I have been supported to access a break with the support of a carers’ budget. I am now more aware of the support my local authority can offer in helping me continue in my caring role.”

– Testimony from a carer, provided by a local carers’ organisation

“One carer had an assessment and as a result, they got a few hours out of the caring role every week while someone was with the person they cared for. The carer used this time to go to the local archery club and would hire a crossbow and arrows to get some “downtime” from the stresses of the caring role. However, sometimes there were no crossbows to hire so they would go home deflated. We used the carer’s assessment to apply for some funding to get their own crossbow/arrows which meant they knew they would get some respite and downtime every week without fail. This made a massive difference to the carer’s wellbeing.”

– Local carers’ organisation

“The carer was identified as struggling at the carer’s assessment, caring for a partner with advanced cancer and end-stage kidney failure. She had both left- and right-sided weakness due to epilepsy and a stroke. The assessment showed that the carer was showering and toileting their partner alone and that this was safeguarding risk, as there was a high risk of falling. The carer had not realised this themselves. An urgent referral was made by our organisation to the local authority for additional support. The cared-for person later went into respite care and the carer rang us to thank us for our involvement, because she had not realised prior to this how much she was struggling and thanked us for listening to her and identifying what she needed.”

– Local carers’ organisation

Section 4. Taking a prevention approach



Local authorities have a duty to prevent, delay or reduce needs for care and support, of either the carer or the person needing care, under Section 2 of the Care Act 2014. Although there are statutory entitlements to an assessment, a preventative approach seeks to tackle issues before they arise or earlier on in a care or caring journey.

Some authorities take a prevention approach and encourage lighter touch earlier interventions with carers, as well as more in depth, statutory assessment. This is usually commissioned and delivered through local carers' support.

For example, any organisation in Leeds can make a referral directly to Carers Leeds using an online professional referral, and GP practices can also use the Yellow Card Referral Scheme. Carers will then be contacted by Carers Leeds and offered the opportunity to discuss what matters most to the carer and what will help them so that they can be better supported in their caring role. Carers may be encouraged to access the wide range of carer support services provided by Carers Leeds and/or signposted to other support. Where there is a need for a further in-depth more complex assessment, then a referral is made to the Leeds Adult Social Care team.

Surrey County Council has a similar preventative approach where Action for Carers Surrey provides early interventions and refers people to the local authority for a statutory carer's assessment. Action for Carers Surrey can allocate a carer's personal budget without a statutory carer's assessment conducted by the authority but following a lighter touch guided discussion.

The Carer Passport encourages carers to come forward because it provides local discounts, as well as serving as unofficial identification. It provides a non-stigmatising community-based approach which has encouraged thousands more carers to sign up to Carers in Hertfordshire's services. At the point of signing up, carers are asked a few questions which serve as a triage point. Those questions help the carer identify their own needs, and triaging helps the charity to put resources where they are most needed. More intensive support includes a more in-depth conversation about the carers' needs and support that can be offered without a formal carer's assessment. Equally, conversations can explain about the local authority carers' assessment, and Carers in Hertfordshire refer the carer to the local authority where they and the carer feel this would help.²¹ For all carers who come into contact with Carers in Hertfordshire, demographic data is requested and outcomes of support tracked, which allows them to understand which services carers are using as well as the difference those services make. This allows Carers in Hertfordshire to consider issues and outcomes and develop plans to address inequalities.



²¹ Carers in Hertfordshire, as of January 2023 Factsheet G3 – Carers Assessment
www.carersinherts.org.uk/resources-and-events/factsheets

Integration with health

Integration between health and care is a key priority for the health and care system, from Government and NHS England, Integrated Care Systems, including down to local place level and even neighbourhood level. Carers' own experiences show a strong preference toward integrated services across health and social care. Their experiences also show that when services don't work together, this can cause additional pressure, stress and even put health and wellbeing at risk. Good integrated services contribute positively to prevention, positive health and wellbeing and the ability to juggle caring with other priorities in life. Carers are often at the heart of the care circle, having to knit up and integrate services.

Integrated health and care services also have a key role to play around supporting carers, not just in relation to the care provided to the person they care for, but in relation to the carer's own health and wellbeing.

The NHS has a duty under the Health and Care Act 2022 to promote wellbeing and reduce inequalities, which is a shared duty with local authorities, and NHS bodies have a duty to respond to request from the local authority in relation to the delivery of its functions (s. 6 and s. 7 of the Care Act 2014). With increased integration, there is an opportunity to support carers in different ways.

There are several key interactions of health bodies, personnel or NHS owned processes with carers' assessments which include:

- Health professionals, including Allied Health Professions, awareness of carers' assessments in order to signpost to them or signpost to the local carers' organisation and support offer.
- Health bodies or professionals that include a specific referral to a local organisation or local authority for carers' support or for a carer's assessment.²²
- Assessments being made at the point of hospital discharge or shortly following discharge.²³
- Assessments made as part of intermediate care provision (eg, avoidance of admission to hospital).
- Assessments as part of virtual wards.²⁴
- Assessments as part of a Continuing Healthcare package of support. Whilst the Integrated Care Board is responsible for any carers' breaks under this package, the local authority is responsible for carers' assessments.²⁵

²² Department of Health and Social Care (July 2022) *National framework for NHS continuing healthcare and NHS-funded nursing care*, para. 355

assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1087562/National-Framework-for-NHS-Continuing-Healthcare-and-NHS-funded-Nursing-Care-July-2022-revised.pdf

National Institute for Clinical Excellence (March 2021) *Supporting Adult Carers* (QS200)

www.nice.org.uk/guidance/QS200

Department of Health and Social Care (July 2022) *Hospital discharge and community support guidance*

www.gov.uk/government/publications/hospital-discharge-and-community-support-guidance/hospital-discharge-and-community-support-guidance

²³ Department of Health and Social Care (July 2022) *Hospital discharge and community support guidance*

www.gov.uk/government/publications/hospital-discharge-and-community-support-guidance/hospital-discharge-and-community-support-guidance

Department of Health and Social Care (January 2023) *Care Act statutory guidance*

www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance

²⁴ NHS England (April 2022) *Enablers for success: virtual wards including hospital at home*

www.england.nhs.uk/publication/enablers-for-success-virtual-wards/

²⁵ Department of Health and Social Care (July 2022) *National framework for NHS continuing healthcare and NHS-funded nursing care*, paras. 353 and 356

assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1087562/National-Framework-for-NHS-Continuing-Healthcare-and-NHS-funded-Nursing-Care-July-2022-revised.pdf

Many GP practices are expected to signpost carers to carers' assessments if they are entitled to one. The NICE Quality Standard 1 refers to good practice guidance from NHS England in relation to identifying unpaid carers and is relevant to Quality Standard 3 on assessments.²⁶

In Barnet, local GPs and other professionals working in the NHS can refer carers to Barnet Carers for a carer's assessment. Surrey Heartlands also has a system of referrals as part of their GP carers' prescription which offers a range of support including preventative carers' support from Action for Carers Surrey and/or a carer's assessment through the local authority.

Devon Carers and Carers Support West Sussex are two areas that have in-reach services within their local NHS Trusts to support carers at the point of hospital discharge. These services involve carrying out assessments of the carer, which have the added benefit, according to these organisations, of ensuring that there are sufficient support services in the short and longer term. Devon Carers includes follow-up calls with carers a few weeks after assessment to check on the caring situation and can adjust support accordingly. Carers Support West Sussex has seen a benefit for carers through directly providing an in-reach hospital service, as well as undertaking carers assessments on behalf of the local authority. Carers are often too overwhelmed and uncertain at the point of admission to, or discharge from, hospital to be able to make future plans and discuss their carer needs in a comprehensive way during a statutory carer's assessment. The hospital team undertake a light touch assessment using the 'Carers Star', providing a quick, proportionate and practical service which feels more helpful for the carer. Once the future prognosis is clearer and the carer understands the impact their caring role will have, they are offered and can request a carer's assessment. This enables a smoother transition to the carer's assessment team and feels more joined up for the carer.

NHS Continuing Healthcare (CHC) guidance states that the assessment process should ensure that the carer is considered and included in discussions about what support to provide, regardless of whether a Care Act 2014 assessment has been made.²⁷ In essence, this performs many aspects of an assessment where the NHS has a duty to ensure that sufficient services are provided to give carers a break, including if that means additional care home placements. A comprehensive CHC assessment, that supports the provision of personal health budgets through a person-centred approach, also delivers positive outcomes for carers; allowing them time off, giving them breaks and checking in on their wellbeing.

²⁶ National Institute for Clinical Excellence (March 2021) *Supporting Adult Carers (QS200)*
www.nice.org.uk/guidance/QS200

²⁷ Department of Health and Social Care (July 2022) *National framework for NHS continuing healthcare and NHS-funded nursing care*
assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1087562/National-Framework-for-NHS-Continuing-Healthcare-and-NHS-funded-Nursing-Care-July-2022-revised.pdf

Practice points

- Health professionals have carer-awareness training and understand carers' needs.
- Health professionals understand carers' rights and communicate them to carers.
- Health professionals are aware of carers' support systems locally.
- Health professionals understand their responsibilities under the Care Act and other health duties.
- Systems and processes within the NHS either signpost or refer carers for support, potentially including an assessment.

We asked organisations whether health professionals undertook any carers' assessments, and, with the exception of Mental Health Trusts, no health personnel did this. With a multi-disciplinary blended team, this might be an option in the future for lighter touch approaches or first contact.

Involvement of the voluntary sector and sharing data systems

There are many different models of carers' assessments. This includes assessments being:

- Provided solely by the local authority.
- Delegated to local carers' organisations who carry out all standalone carers' assessments.
- Delegated to the carers' organisation, but the local authority carries out complex assessments.
- Pre-screened by the carers' organisation, but the main statutory assessments are carried out by the local authority.
- Carried out by multi-disciplinary team members (eg, occupational therapist, physiotherapist or nurse).
- A combination, including complex assessments carried out by the local authority.

Carers First, for instance, currently deliver carers' assessments in Lincolnshire. In the other areas they operate (ie, Essex, Hackney, Haringey, Lincolnshire, Medway, Newham, Southend-on-Sea and Waltham Forest), the relevant local authorities deliver carers' assessments.

One local carers' organisation also told us that their local authority commissions a joint service between the local voluntary organisation and local Mind. Mind supports the local carers' voluntary organisation in undertaking assessments

for people with mental health problems or autism or who are caring for someone with those conditions.

Local voluntary organisations which undertake delegated statutory assessments are often trained in and have access to local authority systems, uploading the carer's assessment when completed. The benefit of this is there is more connected and aligned client data capture and potential reconciliation with any assessment of the person needing care. The challenges with this can be older digital systems within local authorities which are less user friendly can be more time consuming and less attuned to a lighter touch approach.



From 2021-2022, n-compass (who operate in Lancashire, Rochdale, Bury, Carlisle, Staffordshire and Warrington) completed 5,341 new statutory carers' assessments and 12,812 statutory carers' assessment reviews. n-compass has a robust approach to monitoring outcomes of carers' assessments and utilise several tools for carers, one of these being "I" statements and recording whether they have been met:

- I have been treated with dignity and respect.
- I feel that the support has helped me to cope with my caring role.
- I have had my individual circumstances and interests taken into consideration.
- I have been offered the opportunity to take part in activities or encouraged to develop an interest outside of my caring role.
- I feel respected as an expert care partner.
- I have been supported to improve my health and wellbeing.

Other tools used by n-compass include 'getting the most out of life' (GTMOOL) ratings to see how the carer feels about different areas of their life and the 'Short Warwick-Edinburgh Mental Wellbeing Scales' (SWEMWBS), in which carers score from a scale of 1-5 ('1' being 'none of the time' and '5' being 'all of the time') on the statements about their thoughts and feelings over the past two weeks as of the time of completing the survey.

Below are some statements about feelings and thoughts.
Please circle the number that best describes you experience for each statement over the past two weeks (SWEMWEBS)

Statement	None of the time	Rarely	Some of the time	Often	All of the time
I've been feeling optimistic about the future	1	2	3	4	5
I've been feeling useful	1	2	3	4	5
I've been feeling relaxed	1	2	3	4	5
I've been dealing with problems well	1	2	3	4	5
I've been thinking clearly	1	2	3	4	5
I've been close to other people	1	2	3	4	5
I've been able to make my own mind up about things	1	2	3	4	5

On the back of the 'I' statements outcome tool, 99% of carers said that their needs had been met, and 99% of carers also stated the support that they had received had helped them to cope with their caring role.

The GTMOOL outcome tool saw 98% of carers reporting increased control and independence and 93% of carers reporting improved access to advice and support. The SWEMWBS outcome tool, meanwhile, saw 92% of carers reporting that n-compass' support had helped them cope in their caring role.

“Talking to you was a real tonic for me, as you facilitated my exploration of needs in a person-centred way – it was great, I felt heard and that you were really interested in me personally; the whole interview did not just feel like a professional doing an assessment. The unconditional positive regard made all the difference.”

Testimony from a carer, provided by n-compass

“Thank you for coming to complete the assessments with me, it wasn’t until we went through the questions that I realised how much I have taken on recently and how much caring for my Dad has taken the life out of me, I am waiting to hear back from Social Services about additional support but just wanted to say thanks for instigating the process and accommodating the appointment outside of your normal working hours.”

Testimony from a carer, provided by n-compass

Digital opportunities for carers’ assessments

Since the COVID-19 pandemic, nearly all organisations we spoke to included more telephone assessments and reviews in relation to carers. This practice increased during the pandemic because of the challenges around face-to-face contact. This has remained and in some areas is seen to help manage demand as well as keep in touch with carers.

There are a number of digital opportunities in relation to carers’ assessments, which include:

- Including infrastructure and support for processes.
- Digital carers’ assessments.
- Supporting the delivery of outcomes from assessments.

Around 40% of the local areas we contacted had introduced an online option or element to carers’ assessments. Many used blended approaches according to carers’ needs.

“We offer a mixture of telephone, Zoom/online and face to face. If funding is involved for the carer, then it’s face to face.”

– Local carers’ organisation

“We are trialling simple online reviews for less complex caring situations. This is to help carers quickly access their carer’s budget and to streamline due to the volume of assessments.”

– Local carers’ organisation

Some local organisations had reviewed carers’ wishes for online or telephone assessments, as well as face-to-face assessments.

Some carers who had less complex or continuing situations were very happy with a light touch approach and organisations gained good feedback. Other organisations had feedback that face-to-face carers' assessments were preferred over digital platforms or telephone reviews.

In terms of digital infrastructure, some local voluntary organisations who carry out carers' assessments have access to local authority carers' assessments platforms to directly upload information. Where they also have access to summary care records, this could provide useful support for local carers' organisations who have ongoing and continuing support for and with carers.

There are also robust referral processes across different sectors. In Surrey Heartlands, the carers' prescription is a partnership between the local Integrated Care Board, local GP practices, the local voluntary sector and the local authority. This involves trusted relationships as well as a referral system that provides feedback to the original GP practice that the support identified has been actioned.

Carers' assessments must be proportionate and carrying them out solely digitally would not be legally or practically appropriate. However, the development of digital carers' assessment platforms can mean that processes are more accessible, can improve diversity and quality of experience and can engage other community-based organisations in carers' assessments.

Self-accessed digital assessments can also be used quickly to triage a situation and, according to the organisations who use these, allow the assessing organisation to deploy resources more efficiently. However, it is important that there is not an over-reliance on digital assessments as this can miss important detail and is less accessible for people who are less able to express themselves in English or in written form. Telephone assessments and face-to-face assessments are often better for more complex situations or for carers with particular barriers.

An online assessment can allow an articulate carer to complete an assessment in their own time in their own way. Digital can be some people's preferred method of communication. It can also be used as a tool for supported self-assessment, whether by the local carers' organisation, local health assessor or any other community organisation who is supporting carers (see below). Used in the right way, this can be an effective tool in delivering positive diversity practice.

Examples of supported self-assessment

The Social Care Institute for Excellence (SCIE) gives the following definition for supported self-assessments:

*“A local authority should offer an individual the opportunity to undertake a supported self-assessment which places the individual fully in control of the assessment, to a point where they themselves complete their assessment. If an individual wants to do a self-assessment, the local authority has to provide the necessary information, advice and support. The supported self-assessment should use the same assessment materials as used in other assessments of needs and the local authority must assure itself that it is an accurate reflection of the individual’s needs.”*²⁸

For example, Stockton-on-Tees successfully obtained Mind the Gap funding to work with refugee, asylum seeker and migrant communities,²⁹ to consider how best to engage with and support carers from these groups. The role of voluntary and community groups who work with people from the refugee, asylum seeker and migrant communities is recognised, and their expertise has been used to review existing literature on carers services to ensure it is appropriate and accessible, rather than just being a direct translation (as the word ‘carer’ is often not a recognised concept in many under-represented communities).

Within these voluntary and community groups, Carers Champions are being established to disseminate information within the communities and to support self-assessments through the local authority system. In terms of carers not connected to the internet, Stockton-on-Tees does a lot of work to communicate relevant information by identifying carers through GPs, community centres and hospital discharge teams.



²⁸ The Social Care Institute for Excellence, as of January 2023 *Assessment of needs under the Care Act 2014*

www.scie.org.uk/care-act-2014/assessment-and-eligibility/assessment-needs

²⁹ Short term NHS funding to support carers from minority ethnic groups www.catalyststockton.org/mind-the-gap/

Important features on online assessments

- Clear explanations of what assessments are (if the term 'assessment' is used).
- Simple and clear wording that translates well for any app or machine language translations.
- Explains the word “carer” very clearly – a concept which is not translatable for many communities.
- The ability to save and return to the assessment.
- Provides the carer with a copy of what they have submitted.
- Can be easily linked to the assessment of the person being cared for.
- Clear explanation of what happens following the assessment.
- The option of an email exchange, phone call, or face-to-face appointment if necessary.
- Further information collection (eg, understanding whether the carer needs help with finances – which is a key prevention tool).
- Can be used to support identification in the NHS – either signposts the carer to registering with their GP or getting permission to email the GP practice.
- Clear user testing and experience, with co-production at their heart.
- Striking a balance between overwhelming and long online forms and gathering sufficient information to take meaningful next steps.



Collecting and measuring outcomes from assessments

Collecting and measuring outcomes from assessments are important to know whether carers' identified outcomes are met, whether processes and support offers are working, whether any equalities issues need particular consideration and whether legal duties (eg the [Care Act 2014](#) and the [Equality Act 2010](#)) are being fulfilled.

In Carers UK's [State of Caring 2022](#) report, we asked carers who had undergone a carer's assessment whether they felt the assessment process had considered key areas. A third of carers who responded (33%) felt that the need to take regular breaks from caring was not properly considered in their assessment or the support they receive. Just under a third (32%) said that their ability to maintain relationships with friends and family was not properly considered in their assessment or the support they receive. Just under a third (31%) said their ability to have time to themselves was not considered, and the same percentage said there had been no consideration of what needs to be put in place in case of an emergency.

Collecting outcomes can help improve processes based on carers' experience, encompass diversity and identify patterns or changes in need. Collecting real-time information after statutory assessments are carried out or preventative support approaches can provide an excellent basis for this, as seen by [n-compass](#) above. [Carers in Hertfordshire](#) also analyses demographic and outcome data, using a mix of recognised outcome tools such as SWEMWB and external evaluation, in order to better understand support needs and target help through the use of, for instance, a worker who works specifically with ethnic minority carers to overcome barriers they face accessing breaks.

[Devon Carers](#), along with Devon County Council and Devon Integrated Care Board, also measure outcomes from carers' assessments. This resulted in better outcomes for the carer and the patient, and also provided proof of concept of the investment in improving hospital discharge outcomes and experiences.



33%

of carers surveyed felt the need to take regular breaks from caring was not properly considered in their assessment



31%

of carers surveyed said their ability to have time to themselves was not considered

Carers' assessments and diversity – LGBTQ+ carers

According to a survey conducted by [Gaddum](#) and [LGBT Foundation](#), of those LGBT carers who had accessed carers support services:

- 55% said that work commitments were a barrier to accessing services.
- 41% said that their mental wellbeing was a barrier.
- 38% said that awareness of support services available was a barrier.
- 34% said that their caring responsibilities were a barrier.
- 21% said that thinking that the service would not meet their needs as an LGBT person was a barrier.³⁰

Those who had accessed carers support services were also asked what would help them overcome barriers to accessing services – with the most agreed upon answer being ‘awareness of the support services available’ (53%). Indeed, Gaddum found that there was a fairly high demand for support among all respondents:

- 58% would like to access mental health support such as counselling.
- 45% would like to access an LGBT peer support group.
- 42% would like to access a peer support group for LGBT carers.
- 37% would like support and advice online.
- 33% would like to get some advice on what support they are eligible to access and how they can access this.
- 27% would like to access a carers advocacy service.³¹

More specifically, lesbian, gay and bisexual carers are less likely to have an assessment (19%) than heterosexual carers (25%), according to Carers UK's [State of Caring 2022](#) report.

More in-depth data was provided in the [2021 edition of the report](#), which found:

- Bisexual carers were less likely to have had an assessment (15%) compared with gay and lesbian carers (24%) and heterosexual carers (24%).
- Of those who hadn't received an assessment, gay and lesbian carers were most likely to say they didn't know what an assessment is (54%) compared with heterosexual carers (36%) and bisexual carers (28%).



55%

of LGBT carers surveyed said that work commitments were a barrier to accessing support services

³⁰ LGBT Foundation and Gaddum (2021) *Can you see us? Experiences of LGBT carers in England* lgbt.foundation/can-youseeus

³¹ Ibid

- Bisexual carers were most likely to say they didn't think an assessment would be beneficial (30%) compared to gay and lesbian carers (21%) and heterosexual carers (19%).

LGBTQ+ people are also consistently shown to have poorer mental health than their heterosexual counterparts. Stonewall's research in 2018 found that over half (52%) of LGBT people had experienced depression in the past year and 13% had attempted to take their own life.³² As carers also tend to have worse mental health than those who aren't caring,³³ LGBT carers are therefore likely to be at greater risk. Data from Carers UK's analysis of the GP patient survey in 2021 demonstrates this – with over a third (36%) of LGBQ carers having a long-term mental health condition compared to just 13% of heterosexual carers, making them almost three times as likely to be experiencing a long-term mental health condition.³⁴

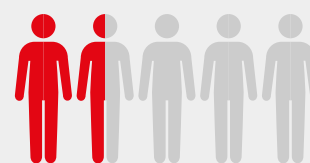
Considering how information can be communicated to carers who may not be in contact with services is key. This might include using the expertise of local LGBTQ+ community and voluntary groups to share information with people or attending local Pride events to raise awareness of support services. Identifying local groups which offer targeted support to LGBTQ+ people is necessary in order to build these links.³⁵

Carers Support West Sussex became the first carer organisation in the UK to earn the Pride in Care (PiC) quality standard in recognition of its commitment to continuously improve the quality of its care and support for LGBTQ+ people over 50 years old. Allsorts Youth have also delivered four LGBTQ Awareness Training sessions to Carers Support West Sussex staff, including wellbeing support workers, managers and trustees.

“Staff training forms part of our commitment to understand issues and discrimination faced by lesbian, gay, bisexual, transgender and queer/questioning people helping us to assess how inclusive and accessible our services are to LGBTQ Carers.”

– Carers Support West Sussex

With funding from Carers Trust to raise awareness amongst the LGBTQ+ community, organisations like Local Solutions in Liverpool have been working with local LGBTQ+ organisations to encourage LGBTQ+ carers to seek support – whether that be through support groups or mental health support. The online and the digital option here for a carer's assessment allows a supported self-assessment to be carried out via other organisations with trusted relationships. As a result, in Liverpool, they have seen a small but notable increase in the number of LGBTQ+ carers accessing carers' assessments.



30%

of Bisexual carers didn't think an assessment would be beneficial – compared to 21% of gay and lesbian carers and 19% of heterosexual carers

³² Stonewall (November 2018) *LGBT in Britain – Health*
www.stonewall.org.uk/system/files/lgbt_in_britain_health.pdf

³³ Public Health England, (March 2021) *Caring as a social determinant of health*
www.gov.uk/government/publications/caring-as-a-social-determinant-of-health-review-of-evidence

Nicola Brimblecombe and Javiera Cartagena Farias, (November 2022) *Inequalities in unpaid carer's health, employment status and social isolation*
onlinelibrary.wiley.com/doi/10.1111/hsc.14104

³⁴ Carers UK (2021) *Carers' health and experiences of primary care: Data from the 2021 GP Patient Survey*
www.carersuk.org/media/shbb4c0s/carers-uk-gp-patient-survey-report-2021-web.pdf

³⁵ Carers UK (September 2022) *The experiences of lesbian, gay and bisexual carers during and beyond the COVID-19 pandemic*
www.carersuk.org/reports/the-experiences-of-lesbian-gay-and-bisexual-carers-during-and-beyond-the-covid-19-pandemic/

Carers' assessments and diversity – Black, Asian and minority ethnic carers

Evidence shows that fewer people from Black, Asian and minority ethnic backgrounds access carers' assessments,³⁶ with Carers UK's latest *State of Caring* report finding that carers from a Black, Asian or minority ethnic background are less likely to have a carer's assessment (21%) compared to those from a white background (25%).

Carers UK's *State of Caring 2021* report went into further detail and asked carers who had not received a carer's assessment in the last twelve months to say what had stopped or prevented them. The most common response for carers from almost all ethnic groups was that they didn't know what a carer's assessment was: 40% of Asian carers, 37% of white British carers, 34% of carers from a mixed or multiple ethnic background and 30% of carers from any other white background selected this option. Black carers, however, were just as likely to say that they didn't think an assessment would be beneficial to them. 25% of black carers cited this as the reason for not having a carer's assessment, while 25% stated that they did not know what a carer's assessment was.

For all carers, there needs to be awareness raising around the carer's assessment to ensure that carers are aware of their statutory right to an assessment. For black carers, however, this may need to go further and ensure that the assessments they are accessing are beneficial for them and lead to real and sustained support.³⁷

In Tower Hamlets, one of the most diverse boroughs in London, the majority of assessments are done face-to-face in the Carers Centre. One of the biggest challenges Tower Hamlets has faced however is communicating what an assessment is to a multitude of diverse communities and letting these carers know how they are eligible for this support.

The number of assessments undertaken since the Centre was commissioned to carry out assessments in 2019 has nevertheless gone up – thanks to, in large part, the promotion of assessments in the community with a dedicated team of advocates who have steadily built-up relationships with key figures in Bengali, Somali and Urdu communities over the years. Such figures, who carry a lot of influence in their communities, effectively 'spread the word' as a result of this outreach and in turn encourage more carers to come forward.

With roughly 65% of the carers engaging with the Centre being Black, Asian or minority ethnic, and 20% requiring language support, one of the ways in which Tower Hamlets has been



Only

21%

of Black, Asian or minority ethnic background carers have had a carers' assessment – compared to 25% of those from a white background

³⁶ digital.nhs.uk/data-and-information/publications/statistical/personal-social-services-adult-social-care-survey/england-2021-22

³⁷ Carers UK (August 2021) *The experiences of Black, Asian and minority ethnic carers during and beyond the COVID-19 pandemic* www.carersuk.org/reports/the-experiences-of-black-asian-and-minority-ethnic-carers-during-and-beyond-the-covid-19-pandemic/



successful in communicating assessments to such hard-to-reach groups is through the English for Speakers of Other Languages (ESOL) Programme – which “seeks to improve the social, educational and employment outcomes for adults who speak English as a secondary language and are disadvantaged by systemic language barriers”.

With research suggesting that people from minority ethnic backgrounds may be less likely to recognise themselves as a ‘carer’ (as the word carer does not translate in certain languages) and that caring may not be regarded as distinct from other familial relationships, such programmes are key gateways for many carers that would otherwise not have considered undertaking an assessment.

Gypsies, Roma and Travellers are the largest ethnic minority group in West Sussex, and carers from the community have told Carers Support West Sussex that the most important things to them are:

- Having someone to talk to.
- Help accessing other services.
- Getting their voice heard.

After consultation with local Gypsies and Travellers experiencing difficulties accessing GP surgeries, one initiative that has been realised is a health help card for Gypsies and Travellers – which can be downloaded and used to explain to others what help, if any, may be needed to either book and/or attend appointments in an NHS setting.

Carers' assessments and disability

In Carers UK's *State of Caring 2022* report, many carers reported having disabilities, health issues or mobility issues which made their caring role more difficult (27% of respondents considered themselves to have a disability), while some felt that the demands of their caring role meant they were unable to look after their own health.

"I am severely overweight, borderline diabetic, cognitive problems, very unfit – keep thinking I need to look after my wife, so my health problems have to be ignored."

– Carer, *State of Caring 2022*

Some carers in *State of Caring 2022* reported that they would prefer face-to-face appointments rather than telephone appointments – particularly those who were deaf or hard of hearing or who had learning disabilities, but that these were not always available.

There is also a need to appropriately tailor assessment processes to make them accessible. As highlighted by Autism Bedfordshire, the autistic needs of carers are often forgotten and reasonable adjustment aren't made, leaving a carer isolated and alone trying to navigate a system that has been set up to exclude them and their needs.³⁸ Autism Bedfordshire have in the past run webinars for health and social care professionals that help them to better support autistic carers – such as a session on how to communicate and prepare for a carers' assessment.

Autism Bedfordshire also offer a monthly online carers support group in the evening which provides peer support and talks from professionals to reduce stress and equip carers to understand both their rights and those of the person they care for. After each session, easy read resources are made available.³⁹

Topics include:

- Emergency planning.
- Carers' assessments.
- Carers' benefits.
- Carers' passports.
- Talking to your GP.

Supporting and working closely with various advocacy organisations and charities that support carers with learning disabilities – like Barnet Carers, who work closely with Barnet Mencap – can be key to developing/designing an assessment process that is inclusive of everyone's needs.

³⁸ Autism Bedfordshire, as of (January 2023) *Autistic Carers Support*

www.autismbedfordshire.net/support-for-adults-in-milton-keynes/autistic-carers-support/

³⁹ Ibid

Co-production and accessibility of carers' assessments: other factors to consider

Co-production and developing carer friendly processes

As digital solutions have improved, several formal carers' assessments were developed and been offered by different companies. Whilst Care Act 2014 compliant, they don't always use an approach which is favoured by carers. Co-production with carers can offer a new route to develop different approaches to make the process more carer friendly and accessible.

Using accessible language in relation to carers' assessments

Feedback and research with carers shows that the word "assessment" is very formal and can put off carers who can also think that it is a test of their ability to care. This could, for example, be particularly stigmatising for carers from different cultural backgrounds, such as LGBTQ+ carers or disabled carers.

Local Solutions in Liverpool does not call carers' assessments as such, but Carer Conversations. Another organisation calls a review a "check-in". These organisations' advice to others is to start conversations about assessments with carers by using easily accessible language, but to then explain later that it is actually a carers' assessment or review, so that they are clear about their rights.

Co-production of carers' assessments processes

Some areas have consulted carers and paid staff about their views on carers' assessments. The following are two examples of where co-production with carers and staff have resulted in processes that are valued by both.

Portsmouth City Council took a year to properly review and implement changes to its assessments processes. They redesigned their carer's assessment based on conversations with carers to see what really mattered to them and mapped it against their duties under the Care Act 2014.

Kirklees Council took an innovative approach with carers that looked at key words used to describe how they felt both during and after the carer's assessment. The 'care navigators' (who carry out the assessments) get a good sense of what the direction of travel is for the carer.

4

How do you feel?

Please tick any / all words which describe how you feel. Tick as few or as many as you want to. If you want to add your own words please do in the space at the bottom.

For help, please see *Guidance notes for the Carer Assessment*.

- | | | |
|-------------------------------------|---|---|
| Depressed ☐ | Unwell/ill ☐ | Needed ☐ |
| Angry ☐ | Knowledgeable ☐ | |
| Time poor ☐ | Pressured ☐ | |
| Restless ☐ | Lonely/Alone ☐ | Skilled ☐ |
| Empowered ☐ | Confused ☐ | Rested ☐ |
| Guilty ☐ | Sleep deprived ☐ | |
| Coping ☐ | Stressed ☐ | Supported ☐ |
| Helped ☐ | Stimulated ☐ | Trapped ☐ |
| In control ☐ | Exhausted ☐ | Financial strain ☐ |
| Desperate ☐ | Inadequate ☐ | Sad ☐ |
| Valued ☐ | Tired ☐ | Frustrated ☐ |
| Not coping ☐ | Resentment ☐ | |
| Frightened ☐ | Overwhelmed ☐ | Healthy ☐ |
| Resilient ☐ | | |
| Anxious ☐ | Stigmatised ☐ | |
| Bored ☐ | Resourceful ☐ | Ignored ☐ |
| Isolated ☐ | Appreciated ☐ | Positive ☐ |
| Happy ☐ | | |

Section 5: future direction of travel in terms of carers' assessments



Where local areas would like carers' assessments to be further developed

We asked local authorities and carers' organisations in a questionnaire where they would like policy or practice to be further developed. Their responses included:

- Integration across health and social care and engagement of health more broadly.
- Greater training and awareness of carers' assessments and support across the wider health, social care and community sectors for local authorities, the NHS, voluntary organisations, etc.
- Better and clearer data on outcomes.

- Comparisons of post-assessment support and effectiveness.
- Methods and ways of dealing with volumes of assessments.
- Understanding boundaries between local carers' organisations assessments or pre-assessments support and local authority assessments.
- Supporting carers from diverse backgrounds, particularly LGBTQ+ carers and carers from ethnic minority backgrounds, and understanding how assessments can be made more accessible.
- Clearer carer pathways and more examples of carer pathways both positive and negative to learn from.
- Clearer assurance mechanisms so that carers or advocates can follow up.
- Better sharing of information post-assessment and outcomes between local authorities and carers organisations (with necessary permissions).
- Online assessments, how they are used, who uses them, efficacy versus telephone or online, accessibility, use in relation to volume, etc.

This last point in our questionnaire on examples of good online assessment models and the experience of setting-up, whilst prompted in the question, was the most frequent. One local NHS provider in particular wanted evidence regarding the efficacy of online versus telephone versus face-to-face assessments. As already discussed, online carers' assessments cannot be the only route for assessment as this would not be either Care Act 2014 or Equality Act 2010 compliant. There is some concern about moving to online – “online carers assessments are key, but there needs to be an alternative way to submit for older carers with limited IT skills”, although there are opportunities of mixed models of support.

Any online assessment model must be user-friendly and easy to find. Digital exclusion must also be considered, as some carers just can't afford to get online or may not wish to. Newcastle's Carers Wellbeing Fund, managed by Newcastle Carers, is a good example of getting people online in the most cost-effective way possible. The fund can pay for mobile phones/tablets for carers who are facing cost as a barrier, but is also flexible in being used for anything that supports a carer in their caring role (eg, education, training and health and wellbeing).

Connecting with LGBTQ+ carers and understanding their needs

As highlighted in Carer's UK's *The experiences of lesbian, gay and bisexual carers during and beyond the COVID-19 pandemic* report, in order to have a more comprehensive understanding of the experiences of LGBTQ+ carers, more research is required. This research should especially focus on the experiences of trans carers and LGBTQ+ carers from ethnic minorities as their experiences are likely to be different from white British LGBTQ+ carers. By improving the data we have on LGBTQ+ carers, interventions and support can be designed to be more effective. Providing bespoke services for these carers will have positive consequences for health, wellbeing and support.

Furthermore, professionals working with carers should be understanding of the different needs and experiences of LGBTQ+ carers and feel empowered to meet these needs. Again, as recommended by Carer's UK's experiences of lesbian, gay and bisexual carers report, this may include professionals having training to be aware of different communities, relationship structures and gender identities.

As mentioned previously, the *Can You See Us?* report by Gaddum and LGBT Foundation identified mental wellbeing as the top priority for LGBT carers, followed by being financially stable, having good physical health, having someone trusted to talk to, and being in contact with others in LGBT communities. Ensuring that these carers are included as part of any health improvement and disparities work is therefore crucial to help decrease health inequalities.



Translations and connections with carers from ethnic minorities

Culturally tailored support services, using the expertise of voluntary and community groups, should be provided. Information, advice and guidance needs to be available in a range of community languages and proactively targeted at carers from Black, Asian and minority ethnic groups.

The role of voluntary and community sector organisations led from within minority ethnic communities should be fully appreciated. As recommended in Carer's UK's *The experiences of Black, Asian and minority ethnic carers during and beyond the COVID-19 pandemic report*, these organisations should be adequately resourced to ensure they can reach carers who are not in touch with mainstream services.

Furthermore, there should be a concerted effort to identify the specific needs of different communities and to hear from carers in communities that are less likely to engage with services or respond to consultations – such as the Gypsy and Traveller community and the refugee and asylum seeker community.



Greater outreach work with local faith organisations

Communities play a positive role in supporting people, as highlighted by the *Care and Support Reimagined* report released by the Archbishops' Commission on Reimagining Care. This includes the voluntary sector and charities, informal support networks as well as churches, gurdwaras, mosques, and temples, in addition to chaplains and other faith leaders.

Membership of a faith community offers support and comfort to many carers, as well as access to services that meet the cultural needs of the person being cared for. Research has found that a higher proportion of many ethnic minority groups identify themselves as being a member of a religion, and it has more importance to them as a part of their identity.⁴⁰

Local authorities, the Archbishops' Commission writes, should therefore redouble their efforts to work in partnership with voluntary and community organisations, including faith organisations, to coordinate and collaborate in providing a network of community-based support for everyone, including disabled people and older people.



⁴⁰ Alita Nandi and Lucinda Platt (January 2014) *A note on ethnicity and identity among the UK born population in Understanding Society*
www.iser.essex.ac.uk/research/publications/working-papers/iser/2014-04

Conclusion and future developments



Carers' assessments have evolved from the first practice developments in the late 1980s and the first major legislation in 1995.⁴¹ Even since the Care Act 2014 was implemented in 2015, there have been continued developments in practice, with increased objectives around integration, digital opportunities, better understanding of diversity and data capture.

Identifying carers consistently through data records (including shared care and summary care records), the collection of data and measuring carer outcomes are fundamental building blocks for any system to be able to understand how and which carers are being supported.

Systems and practice which assess, review and build future processes which are co-produced are another key objective of any system. A carer's assessment is a key process as part of a set of tools towards better prevention and support.

With Integrated Care Boards, Partnerships and Systems developing further, it is essential that carers' assessments are an integrated part of delivery supporting carers – ensuring that a key opportunity to engage more of the system in a better integrated way for carers is realised. The Care Quality Commission's new assurance programme will, in particular, help build a picture of how local authorities are delivering their duties under the Care Act 2014, including the role of carers' assessments.

⁴¹ Carers (Recognition and Services) Act 1995
www.legislation.gov.uk/ukpga/1995/12/contents

Helpful resources

Autism Bedfordshire resources for autistic carers:
www.autismbedfordshire.net/support-for-adults-in-milton-keynes/autistic-carers-support/

Care Act 2014
www.legislation.gov.uk/ukpga/2014/23/contents/enacted

Care Act 2014 statutory guidance
www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance

Health and Care Act 2022
www.legislation.gov.uk/ukpga/2022/31/contents/enacted

Hospital Discharge and Community Support guidance
www.gov.uk/government/publications/hospital-discharge-and-community-support-guidance/hospital-discharge-and-community-support-guidance

Incorporating the NHS Continuing Healthcare practice guidance
www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care

National Institute for Clinical Excellence (NICE) quality standards
www.nice.org.uk/guidance/QS200

Social Care Institute for Excellence (SCIE) resources on carers' assessments
www.scie.org.uk/care-act-2014/assessment-and-eligibility

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