Quality of care and carers

How quality affects families, employers and the economy
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Introduction

As the number of people in need of care and support increases rapidly over the coming years, the pressure on families to provide care will also continue to grow. In fact, estimates suggest that the number of older people needing support will outstrip the number of working age family members able to provide it as early as 2017.¹

If families are to be able to take on these caring responsibilities – and juggle them alongside work and family life – then sufficient, affordable and good quality care services will be the lynchpin that helps them hold it all together. Without the right support in place for disabled and older family members, more carers will reach breaking point – with serious consequences for individuals, families, employers and the economy.

The quality of services is at the heart of this support. Carers need to know that their parent, child or partner is in good hands when they are at work, providing childcare or taking time for themselves. If services are unreliable or poor quality then arrangements break down – leaving carers to pick up the pieces, often at the expense of their careers, their relationships and their own wellbeing. Further, there is a clear impact on productivity within the workforce as families deal with the consequences when services and service quality falls short, which in turn has a knock-on effect on the UK economy.

What do good care services look like?
The Care Quality Commission (CQC) is the organisation responsible for regulating and inspecting adult social care and health services in England. Their essential standards of care (see page 4) set out what people should be able to expect from the services that they or their loved ones use.² Care services like home care, respite care and residential care, and health services like hospitals and GP surgeries, should provide safe, effective, compassionate and high-quality care and support that people can rely on.

Whilst there are examples of excellent care, the experiences of carers and their families show that this is not always the reality. Many carers do say that their lives have been made easier by good care and skilled professionals who understand the challenges that they face. However many others experience uncoordinated, unreliable or poor quality care which has a hugely stressful and disruptive impact on their lives.

Without the right support in place for disabled and older family members

**more carers will reach breaking point**

with serious consequences for individuals, families and the economy.


² Care Quality Commission (2010) Guidance about compliance: Summary of regulations, outcomes and judgement framework
The CQC has set out the essential outcomes that health providers, care homes and home care services must be able to demonstrate. The 28 outcomes (of which 16 are core quality and safety standards) are grouped into six key areas:

1. **Involvement and information**
   People who use services should expect to be respected, involved in their care and support, and told what’s happening at every stage.
   Carers acting on their behalf should also understand the choices available and be involved appropriately in making decisions about care, treatment and support.

2. **Personalised care, treatment and support**
   People who use services should receive effective, safe and appropriate care that meets their needs and protects their rights. They should be supported to have adequate nutrition and hydration.
   If someone has more than one care provider, or if they are moved between services, they should get coordinated care.

3. **Safeguarding and safety**
   People who use services should be protected from abuse and their human rights should be respected and upheld.
   Services should provide a clean, accessible and safe environment. People should get the medicines they need when they need them, and in a safe way. They should benefit from equipment that is comfortable and meets their needs and should not be harmed by unsafe or unsuitable equipment.

4. **Suitability of staffing**
   People who use services should have their needs met by sufficient numbers of fit, appropriately qualified, able and competent staff.

5. **Quality and management**
   Providers should monitor the quality of their services.
   Providers should listen to, and act on, comments and complaints made by the people using their services and carers acting on their behalf. People should know that they or the person they care for will not be discriminated against for making a complaint.
   Personal records should be accurate and kept safe and confidential.

6. **Suitability of management**
   People should have their needs met by the service because it is provided by an appropriate person and it is properly managed.
Carers’ experiences of services

Social care services
Over half (52%) of the 2,178 carers in England who responded to Carers UK’s survey had used care services such as home care or respite care.³

The highest proportion reported mixed experiences, with 1 in 5 (19%) saying they had experienced some good and some bad care, 15% reporting positive experiences (12% good and 4% excellent), 13% reporting negative experiences (7% bad and 5% terrible) and 5% describing their experiences as fair.⁴

Different groups of carers have had very different experiences of social care. Parent carers of children under 18 were more likely than other carers to report positive experiences and less likely to have had negative experiences of care.⁵ Carers looking after an older person aged 75 or over were also more likely than other carers to have had positive experiences of care services.⁶

Conversely, carers from BAME backgrounds were more likely than other carers to have had negative experiences of social care services and less likely to have had positive experiences.⁷ They were also twice as likely to have had ‘terrible’ experiences of social care (10% said this, compared to 5% of all carers).

"The quality of [respite] care [my grandfather received] was excellent, and made such a huge difference to myself and my grandmother in giving me some time to look after her, take her away for a few days and just get out of the dark place that day-to-day caring with no break can take you to."

"The worst one was where he was not given any drinks because he had wet the bed so it didn’t happen again. My son ended up in hospital severely dehydrated because of this and that was the last time, eight years ago, that we accessed residential respite care."

Over half of carers
52%

had used social care services such as home care or respite care.

¹ Unless otherwise specified, all figures in this report are from Carers UK’s State of Caring Survey 2013. Statistics are for respondents in England only due to the different quality standards, rules and bodies in each of the four nations and the focus here upon the Care Quality Commission’s standards of care.
² 8% reported negative experiences and 19% reported positive experiences.
³ 18% reported positive experiences.
⁴ 15% of BAME carers reported negative experiences and 11% reported positive experiences.
Health services

Only 1% of carers we surveyed had no experience of NHS services. Over a third of carers (34%) reported positive experiences of services like hospitals and GP surgeries (23% good and 11% excellent), while 16% said they had negative experiences (10% bad and 6% terrible). Half said that their experiences have been mixed (42%) or fair (8%).

Unlike with social care services, when it comes to NHS services parent carers were slightly more likely to have negative experiences and less likely to have positive experiences – this was the case for both those caring for a child under 18 and parent carers of adult children.

Distance carers and those looking after someone in a care home or hospice report the worst experiences of NHS services. Only 19% and 20% respectively say that they have had good or excellent experiences of health services, and a quarter (25%) of all of these carers say that their experiences have been bad or terrible.

Interestingly, there is also a big difference between the experiences of men and women. While 45% of male carers describe positive experiences of NHS services, only 31% of female carers do. Men are also slightly less likely to have negative experiences. This may be partly explained by the fact that men are more likely to be caring for a spouse or partner (while women are more likely to be caring for a child or parent). Carers who look after a spouse or partner also report better than average experiences of health services, and a quarter (25%) of all of these carers say that their experiences have been bad or terrible.

Over a third of carers 34% reported positive experiences of services like hospitals and GP surgeries.

I have an excellent relationship with all the professionals involved in my husband’s care, and the specialist nurse in particular has empowered me to learn about and manage his condition myself, so I rarely resort (touch wood) to any emergency services.

Poor care from health services can have a profound effect on the person being looked after. For example, 27% of carers of people with nutrition and hydration problems said that these problems occurred in hospital. Compassionate care from hospital staff can also be just as important as from social care staff. Being in hospital can be an extremely difficult, stressful and worrying time for both the person receiving treatment and their carer, and the quality of care provided by health professionals can make a huge difference to their overall experience.

8 Health services statistics are from Carers UK’s State of Caring Survey 2014. Figures are for respondents in England only.
9 19% reported negative experiences and 30% reported positive experiences
10 17% reported negative experiences and 29% reported positive experiences
11 13% of people caring for a spouse or partner reported negative experiences and 38% reported positive experiences
12 However, it is not clear whether carers of a spouse or partner have better experiences because of their relationship to the person they care for or because they are more likely than other groups of carers to be male.
13 11% of male carers report negative experiences of care services compared with 13% of female carers, and 18% of male carers report positive experiences of care services compared with 15% of female carers.
14 Carers UK (2013) Nutrition and Caring
Comparison: carers’ experiences of health and care services

The graph below shows that carers tend to report slightly more positive and less negative experiences of NHS services compared to social care services.

Carers’ experiences of social care services such as home care or respite care.

Compared to only 16% reporting negative experiences of NHS services like hospitals and GP surgeries.

A quarter of carers reported negative experiences of social care services such as home care or respite care.

Comparison: carers’ experiences of health and care services

- **Excellent**: 11% for NHS, 8% for social care
- **Good**: 23% for NHS, 22% for social care
- **Fair**: 8% for NHS, 9% for social care
- **Mixed**: 42% for NHS, 37% for social care
- **Some bad**: 10% for NHS, 14% for social care
- **Terrible**: 6% for NHS, 10% for social care
Care coordination

People who use more than one service are entitled to expect that these services are joined-up and coordinated. However this is often not the reality and disjointed, fragmented services are a big source of stress and frustration for many carers. Some of the most significant problems faced by families stem from a lack of coordination between health and social care as well as between services within these two systems. This is an issue which also extends into other areas such as housing, work, benefits and other related entitlements.

Carers, who are often already trying to juggle caring with other responsibilities such as work and young children, or who may be trying to care from the end of a motorway, find that they also have to take on the role of manager and coordinator, organising a disparate range of services for the person they look after. This can be a very difficult process – carers often use language like ‘fight’ and ‘battle’ to describe their experience of public services.

Of carers who have experience of both NHS services and social care services, half (50%) have experienced difficulties in the way that these services work together.\(^\text{15}\)

Distance carers are particularly likely to have experienced these difficulties, with 64% reporting problems, perhaps because it is especially hard to coordinate services when you cannot always be there in person. This has a critical bearing on families and the operation of services since the vast majority of people caring for others are caring at a distance. This group of people is also likely to grow in the future and they are more likely to be in employment.

BAME carers are also much more likely than other carers to experience problems, with 59% reporting difficulties in the way that NHS and social care services work together. This may be because some BAME carers are first generation immigrants, so do not have English as a first language or as much experience of how these services work – making it even harder to navigate a complicated and disjointed system.

Uncoordinated, fragmented services can have a huge impact on carers’ lives – when asked several years ago what causes carers to reach breaking point, the highest percentage (41%) put frustration with bureaucracy as the main reason.\(^\text{16}\)

Conversely, joined-up services can make a real difference, with over one third (37%) of carers who gave up work to care saying that help managing or coordinating care is among the top three things that would have made the biggest difference to keeping them in work.

\(^{15}\) State of Caring Survey 2014 (England only)

\(^{16}\) Figure from a Carers Week (2009) survey of over 1,900 carers
Recognising carers’ roles

Carers are experts in the care needs and preferences of the person that they look after and they should be treated as expert partners in care by health and social care professionals. Involving, informing and consulting carers about decisions affecting their loved ones benefits everyone – the professional benefits from the carer’s valuable knowledge and experience, the older or disabled person has their needs met more fully and safely, and the carer’s life is made much easier when they know what is going on.

However, many families say that professionals focus involvement and consultation on patients alone and fail to recognise the importance of involving them as carers. Carers also report that concerns about confidentiality result in professionals providing no information or support at all, even general advice not related to the specific condition or circumstances of the person they care for, and sometimes professionals just do not remember to make sure that carers are kept informed.

When we asked carers about their experiences of going to hospital with the person they care for only 1 in 5 carers (21%) told us that their role and expertise as a carer was recognised and valued by hospital staff. A further 1 in 5 (20%) felt that their caring role was ignored. Just under half (46%) reported mixed experiences, saying that sometimes their role as a carer is recognised and valued and other times not.

Parent carers of children under 18 were slightly more likely than other carers to feel valued (26%), and less likely to feel ignored (18%), suggesting that hospital staff often do recognise the important role that parents of disabled children play in their treatment, care and support. On the other hand, distance carers were least likely to feel that their role as carer is valued and recognised by hospital staff, most likely to feel ignored, and were also less likely to be given the information and support they need. This suggests that healthcare professionals need to do more to make sure that all carers are treated as expert partners in care, whether they live close by the person they look after or not.

Only 1 in 5 carers

19%

told us that their role and expertise as a carer was recognised and valued by hospital staff.

I was not recognised as a carer because he has mental health problems, rather than physical difficulties. Some staff did not appreciate that he needed a carer because of this.

I appreciate that confidentiality is in place to protect the rights of individuals but find that when this impacts on any support I need to give my mother, my needs and requirements are ignored. Usually the consequence of this is me getting very assertive!

There was far too much communication with the patient (who didn’t understand or remember it) and none with me.

6% of distance carers were given the information and support they need when they visited hospital with their loved one and 22% were not. 14% felt recognised and valued while 18% said their role as a carer is ignored and not recognised.

We are pleased to say that we have a good relationship with most of the more qualified professionals with whom we have to work. Many consultants realise that we know [our daughter] and her condition better than they ever could and use the information we give them in order to treat her more effectively.
Staff
The skills, suitability and reliability of staff are at the core of good quality care. Carers describe good care in terms of staff who are skilled, empathetic, kind and respectful. Bad care is seen in terms of staff being rude, disrespectful and inexperienced.

We asked carers to give us examples of good care and poor care – these included:

“Excellent care in [one] nursing home – helpful, cheerful, low-turnover staff with a genuine interest in the resident...”

“Incompetent workers who don’t know how to do things properly and talk to each other and ignore my husband. They treat my husband like a two-year-old.”

“Good care is friendly, considerate, motivated people. Bad care is failure to use equipment properly, cutting short visits, failure to do basic tasks.”

“Some care workers are better than others. The better ones provide much more than the basic services, e.g. emotional, empathic and companionship care. The excellent ones are a rarity.”

“Care workers cancel at the last minute or don’t turn up. The poor standard of care means I’m not happy to leave the home. Care workers often aren’t interested in their work and are sometimes on their phones.”

However, many carers were also keen to point out that it is not just the competence and attitude of the care workers that is important, but the way that they are managed and supported and the amount of time they are given to carry out tasks:

“By poor care I do not so much mean bad care itself, but I do mean the good care I receive is so stretched that a two person job only has one person assigned to it, and that one person, while doing his or her best, cannot cope and looks to me to step in to take over.”

“The private care agency gives care assistants 30 minutes to care for the person, then gives the assistant work 15 minutes away at the same time.”

As noted by the Cavendish Review, staff turnover is extremely high in social care. This is a particular worry for carers of people with, for example, dementia, autism, or mental health issues, who can become distressed by change or being looked after by people they don’t know. It also takes time for families to build trust with someone new. When it comes to home care services, it can be taxing and very time consuming for families who have to explain the care needs and preferences of their loved one to each new staff member.
Reporting concerns

Carers often tell us that they worry about complaining about inadequate or even dangerous care, in case they put their loved one at risk of retaliation, with nearly 1 in 5 (19%) carers saying that despite feeling concerned they did not raise the issue with their social care provider. However, nearly half (48%) of the carers who had used social care services have raised concerns about the care provided and a quarter (26%) have made a formal complaint. Nearly 3 in 10 (29%) have ended a service because of concerns about quality.

It is absolutely essential that families’ concerns are listened to and acted on if we are to safeguard against failures of care, for example those experienced by the NHS at Mid Staffordshire Foundation Trust - where, as described in the Francis report, there were inadequate processes for dealing with complaints and serious incidents, likely because the views and experiences of patients and staff were not thought to be important.\textsuperscript{19} No effective action was taken as a result, which meant that important warning signs were overlooked. Families have vital information about the quality of care being provided to their loved one, and services and regulators must place proper value on this.

Distance carers, despite being much more likely than other carers to have experience of social care services and just as likely to have had negative experiences of these services, are 15% less likely than other carers to have ended a service and 6% less likely to have made a formal complaint about the quality of services being provided to their loved one. They are more likely than other carers to have raised concerns informally, but also more likely to have felt concerned but not raised the issue with the provider (24% of distance carers said this, compared to 19% of other carers).

This may be because they feel their loved one could be particularly vulnerable if matters get worse following a complaint, as they are not close by and might not be able to check on the person they care for as often as they would like. They could also be especially reliant upon social care services and worry about rocking the boat – only 7% of distance carers have refused care due to concerns over quality (compared with 19% of all carers), despite being less likely than other carers to say that they have no experience of poor care. This suggests that they don’t feel that they have the option of turning services down.

Distance carers were also 9% more likely than other carers to have formally thanked a service provider, showing how valuable it can be to them when the person they support receives quality services that they can rely on.

Of carers who have experience of social care services over a fifth (21%) had formally thanked a provider who provided quality care, 36% had given positive comments and 15% had recommended a service to somebody else.


\textsuperscript{19} Francis, Robert (2013) Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry: Executive summary, p.44

“22 different care workers in 12 months. All have to be trained by us to care for our daughter – this takes hours.”

“Previously, when I complained about the alteration of times without consultation, I was told I would be reported to social services if I did not do what they wanted. I reported the care workers and social services said they could not do anything as it was my word against theirs.”

“Complaints are hard to put forward and fall on deaf ears. No-one ever asks how we are getting on or if there are any problems.”

“My husband was left in a shop while the care worker went to buy a car. He was distressed and fearful and in a terrible state. The complaint was ignored. An indoor help centre was worse – he was abused so much he pretended to go in when dropped off and then sat in the cold on a park bench for the whole three hours.”
Why quality matters

Good quality, reliable and accessible care services can make a huge difference to the lives of the people who use them and their families.

The value of good care

Good care, that meets the needs of their loved one, can improve carers’ ability to work, spend time with other family members, look after their own health and have a life of their own outside of their caring role.

Carers have told us that good care is important to them because:

- It means dignity, respect and a better life for the person they care for (83%)
- It gives them peace of mind knowing the person they care for is supported well (82%)
- They can take time off in the knowledge that their loved one is well looked after (67%)
- They don’t worry about the person they care for when they are not there in the knowledge they are well looked after (60%)
- It makes it easier to work (33% of all carers and 36% of working-age carers surveyed said this, rising to 72% for carers in full-time employment).

The majority of carers (83%) told us that good care means dignity, respect and a better life for the person they care for.

The care home where my father is currently a resident, which I use for respite, is excellent. It provides for all my father’s personal needs and more. They are inclusive of all family members and provide a multicultural environment which is useful for my father as he is Italian.

It gives me peace of mind that [my partner] is okay and I can relax and enjoy my break.

Good care workers can make my husband smile and allow him to feel safe and still in control.
Over half of carers 53% say that poor care services affect the amount of care they have to provide themselves.

A fifth of carers 19% have refused care altogether because they are too worried about quality.

The impact of poor care

Conversely, poor care can have a huge and damaging effect on the lives of ill, disabled or older people and their families. Two thirds (67%) of carers with experience of social care services told us that poor care has a negative impact on the health or independence of their loved one. A fifth (19%) have refused care altogether while a further 19% won’t buy or accept care because they are too worried about quality. Over half (53%) say that poor care services affect the amount of care they have to provide themselves, while 58% say that poor care is stressful, and means they worry all the time.

This is unsurprising given the many different areas of carers’ lives that poor care affects. Carers responding to our survey who have experience of social care services told us that it has a negative impact on:

- Their finances (for example because they have to reduce working hours, or pay more for additional or more expensive care services) 34%
- Their health and wellbeing 71%
- Their levels of stress 81%
- Their relationships with family and friends 48%
- Their ability to cope 65%
- Their ability to work (42% of all carers and 47% of working-age carers surveyed said this, rising to 70% for carers in full-time employment) 22%

Over a quarter (24%) said that one of the reasons was that services were not flexible enough, while 28% said there were no suitable replacement services available and 27% said services were too expensive. 1 in 5 (20%) said that services were not reliable enough. Respondents were able to choose multiple options.

Additionally, a further 29% said they gave up work or reduced working hours because the person they care for doesn’t want to use services.

Of carers who have given up work or reduced their working hours to care, 46% said that one of the reasons was a problem with care services.

Some groups of carers were particularly likely to experience these negative effects. BAME carers, for example, were more likely than other carers to see a negative impact on all of the areas listed above. Carers in full-time employment were also more likely to report a negative impact – not only on their ability to work, but on the other areas listed above as well, particularly their relationships with family and friends (62% chose this option, compared with 48% of all carers). There are several possible reasons for this. It could be that juggling work and the extra care needed following a breakdown of services leaves them with no time to spend with other family members or friends. It may also be that they are sometimes unable to step in to provide more care themselves without giving up their job or reducing their working hours – something which many carers do end up having to do so the extra responsibilities fall to other members of the family.

Poor care also has a particularly big impact on ‘sandwich carers’ – especially their finances (44%), relationships with family and friends (61%) and their ability to work (61%). Sandwich carers are already trying to manage caring with looking after children and are often working as well, so when care breaks down this can have a big effect on their ability to juggle all of these responsibilities.

20 Over a quarter (24%) said that one of the reasons were that services were not flexible enough, while 28% said there were no suitable replacement services available and 27% said services were too expensive. 1 in 5 (20%) said that services were not reliable enough. Respondents were able to choose multiple options.

21 Additionally, a further 29% said they gave up work or reduced working hours because the person they care for doesn’t want to use services.

22 2.3 million UK adults have given up work to care at some point in their lives and almost 3 million have reduced working hours (Carers UK/YouGov, 2013).

23 People who care for a disabled, older or seriously ill adult alongside looking after non-disabled children.

How quality affects families, employers and the economy
Carers’ priorities for improving care

When asked what recommendations they would make to improve care, carers told us that it is important to:

- Keep consistent staff so that carers know them (85%)
- Provide better training (79%)
- Give staff more time to carry out tasks (58%)
- Pay staff better (69%)
- Have better quality regulation (58%)
- If carers have worries these MUST be acted on (59%)

Often, carers say that the most important factors for improving the quality of care centre around staff – good care is impossible without well-trained, motivated, reliable health and care professionals who have the time to provide proper support. This is also an essential part of services meeting the CQC’s quality standards for care.

Another key recommendation, made by 6 in 10 carers with experience of social care services, is that if they have worries it is extremely important that these are acted on. If they do not believe that their concerns will be listened to, families can have no confidence in the service that is being provided.

Good care and the economy

Over the years, the mounting body of research from carers and employers has demonstrated a growing realisation that the quality of care and efficiently run services directly impact on carers’ ability to work, with 46% of carers who have left work to care citing problems with care services as a contributing factor.

2.3 million UK adults have given up work to care at some point in their lives and almost 3 million have reduced working hours, causing employers to lose skilled staff, often at the peak of their careers. Even when carers are able to work, the stress, illness and disruption brought on by not having the right support in place means that a significant number of days are lost every year. In fact, estimates suggest that work interruptions relating to eldercare could be costing UK businesses as much as £3.5 billion a year. This research shows, for the first time, a direct relationship between the quality of care and the impact on carers’ ability to work, which has profound implications for employment policy, employers who want to support carers and, ultimately, the economy.

Whilst employers are becoming increasingly flexible in supporting their staff who juggle caring responsibilities with work, there will be a limit to what extent this flexibility can, or indeed should, compensate for poor quality and badly coordinated services.

"Employ people you’d want to look after your family and pay them for the important job it is."

"Stop zero-hours contracts and pay for travel time. These both impact negatively on quality of care."

"Must be the right AMOUNT of care offered. Respite is being limited and refused to many."

"Better training and more respect for care staff – better pay and a career structure with rewards for success."

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24 Carers UK/YouGov (2013)

25 Carers UK (2014) Care leave: impact on business
Conclusion

When care is unsafe, unreliable or unsuitable, this has a knock-on effect on every area of carers’ lives. Poor quality care means disruptions to work which can lead to leaving employment altogether, a negative impact on carers’ own health and wellbeing, damage to relationships with family, friends and colleagues, financial losses, and constant worry – because you can’t trust that the person you love is in good hands and being treated well.

But good care can also have a huge impact on carers’ lives – helping them to keep working, maintain relationships, have lives of their own outside caring, and give them peace of mind that their loved one is safe and well looked after.

And it is not only carers who would benefit from improvements in care quality. With demographic change and public sector budgets under pressure, the health and social care systems will be increasingly unable to manage unless there is better partnership and support for families who provide care.

Our evidence shows that improvements in the quality of care would:

- Increase everyone’s health and wellbeing – the carer and the person needing care.
- Keep people who care for family members and friends in employment for longer, impacting positively on short-term income and longer-term pensions and savings.
- Raise business productivity and reduce ill-health and stress at work.
- Ensure the UK remains competitive on a global stage in terms of supporting its workforce.
- Provide better and more rewarding jobs for the future in the care sector – so that it offers a career of choice.
- Improve the efficiency and effectiveness of health and care services.
- Deliver a sector that the public is keen to invest in.
- Better demonstrate society’s values by supporting disabled and older people who need care.
Recommendations

With a shortfall of care, and pressure on budgets across health and social care, every pound counts. This report demonstrates the need for a whole-systems approach to the area of care quality – from staff training and pay and conditions to recognition of carers in care quality regulation.

As well as looking at carers’ own recommendations for change, there are some systemic recommendations that need to be fulfilled:

1. Regulation. In its inspections, rating and thematic work the Care Quality Commission must have a greater emphasis on what quality represents for the family and friends of those receiving care services. This should be built into quality measurement systems.

Informing, respecting and consulting carers is a key element of providing good care, with benefits for patients, professionals, providers and carers. Incorporating this into its work, and encouraging feedback from families and friends, will provide a rich source of information for the CQC and improve its decision making about when, where and what to inspect.

2. The NHS, in particular, needs to be better at identifying carers and supporting them with training and assistance with caring for their loved one – with interventions to help carers look after themselves and by directing carers to information and advice about financial and practical support. This could be facilitated by a duty on NHS bodies to identify and support carers – something that Carers UK has called for. A carer-friendly approach to the NHS should be developed and carers should be included as one of the CQC’s key patient groups.

A carer-friendly approach to the NHS with earlier identification and support for carers will help to prevent financial hardship, poor health and carer breakdown, thereby reducing costly unnecessary hospital admissions for the carer and the person they look after.

3. Information and advice delivered through local authorities and through the Care Act 2014 is critical in ensuring that carers and their families are empowered to raise concerns through social care providers, commissioners and health care organisations and to feed in comments, where necessary, to the CQC to aid regulation.

Empowering carers to feed in their comments and concerns will allow regulators and providers to benefit from carers’ knowledge and act on this early to improve services and prevent poor practice.

4. Commissioners of health and care services must understand what quality means for families. They should take into account the implications of this report and the key factors that contribute to quality of care for carers as well as people using services. They should look at effective ways of engaging carers and encouraging feedback from them and use this information to commission appropriately. Evidence suggests that formal complaints processes are not sufficient for information gathering as many carers who have valuable information do not want to make complaints in this way.

Taking into account carers’ concerns and experiences will allow commissioners to make more fully informed decisions when commissioning services and better meet the health and care needs of patients and carers.
5.
A workforce development strategy that looks to improve pay and conditions and provide adequate training for people working in the health and care sector is essential, as these are key drivers of quality. The health and social care workforce should be trained to be more carer aware – able to identify support that carers need as well as to recognise the importance of partnership between professionals and carers.

Improving conditions of work for health and care professionals will help to make care a career of choice, while more carer-focused training will allow providers and professionals to benefit from carers’ valuable knowledge and improve the experiences of families and carers, who will be better informed and supported.

6.
Sustainable funding of health and social care services. Pressure on local authority social care spending has led to a downward pressure on care services. This is resulting in depressed wages, high staff turnover, short home care visits and understaffing in residential settings.

If an effective workforce strategy is to work in practice then it must be properly funded in a sustainable way – or it will be impossible to address all the key elements contributing to poor quality care and ensure that families have access to quality, reliable services that they need to participate fully in society.

7.
A policy shift at all levels that recognises good quality care is fundamental economically. A good health and social care system is an essential requirement for work – without good quality care services, many disabled people and carers cannot work, with consequences for families, employers, and the wider economy.

The implications for business and employers are significant. They are paying the price for poor quality care in staff attendance, stress and sickness levels and, ultimately, loss of employees. Improving the quality, supply and availability of care has been a key recommendation in many reports Carers UK has produced on employment and there are increasing calls from employers for a well-funded and well-managed care system to support families better.

The public purse could also see huge benefits from improving care quality and workplace support, with estimates suggesting that supporting carers back into the workplace could see £1 billion in additional tax revenue.26

Consumers of care
Carers UK has been working with local organisations and carers to empower them, as consumers, to raise the profile of care quality – both when it is good and when it is falling short.

The response from local organisations has been very positive, with 162 organisations ordering leaflets to distribute to carers – raising awareness of quality standards and helping carers to tell the CQC about their experiences of care. The CQC uses this feedback to inform when, where and what it inspects.

To learn more about this work, or about what you can do if you have a concern about the quality of a service, visit: www.carersuk.org/cqc

I am a qualified social worker and I am very passionate about ensuring service users and carers get good quality care and support. These leaflets will be distributed to other social workers and the commissioning team. Leaflets will also be given to service users, carers and family members.

I have recently become the Challenging Behaviour Family Development worker and will use these resources to inform families – being a family carer myself and also an expert by experience I know the value of relevant information.

What Carers UK is doing

Our work will continue to be informed by carers’ experiences, drawn from direct research, through consultative mechanisms like the National Carers Summit, and through feedback from our national Adviceline. Carers UK will:

- Continue to provide information and advice directly to carers about what they can expect from health and care services and how to raise concerns when things go wrong.
- Look at continuing to strengthen the “consumer” voice to ensure that carers feel more comfortable about raising concerns, and we will further develop our capacity to support local organisations to weave discussions about quality into their work. As part of this, we will encourage and support carers to tell the CQC about their experiences of care, to help them feed into its decisions on when, where and what it inspects.
- Help to develop a new approach to regulating and inspecting social care services as part of the CQC led Adult Social Care Co-Production Group. We will also contribute to healthcare regulation, working to shape rights systems that work for families.
- Continue to work with employers through the Employers for Carers forum to look at the relationship between services and carers’ ability to juggle work and care, and to develop good practice in workplace based support.
- Gather evidence of care quality over time, directly from carers, to improve our understanding of how changes are affecting families and their ability to manage their lives.
- Further develop evidence on the impact that good health and social care has on the economy, linked directly to demographic changes in our society, so that governments of the future can work to invest in supporting families who need care.
- Work with care providers to highlight the wider difference that care quality has on family life.
- Encourage carers to engage with commissioners to ensure that the right mechanisms are built into the commissioning of services.
- Continue to work with local authorities and others to improve delivery of social care services to carers and the people they look after.
- Ensure that quality mechanisms are firmly built in to our work on the delivery of the Care Act 2014.

As more and more of us are called upon to care for our loved ones, it is crucial that as a society we get this right.

Good quality care is a minimum requirement for ensuring that the 3 in 5 of us who will become carers[^27] are able to participate fully in society – and that employers and the economy benefit as a result – and for making sure that older, ill and disabled people are treated with dignity and respect.

[^27]: Carers UK (2001) It Could Be You – A report on the chances of becoming a carer
Appendix

Methodology: sources

The main source of data cited in this report is Carers UK’s annual survey of carers and former carers, the State of Caring Survey.

Unless otherwise stated, statistics are from the State of Caring Survey 2013, including those relating to the quality of social care services, the impact of poor care and carers’ recommendations for improving care.

2,178 carers in England responded to the State of Caring Survey 2013. Only responses from carers in England are cited here due to the different quality standards, rules and bodies in each of the four nations. Where appropriate, only responses from carers with experience of care services were used.

Data relating to experiences of health care services and the NHS, and of integration and the way health and social care services work together, are drawn from the State of Caring Survey 2014. 3,523 carers in England responded to our 2014 survey. Again, we have only used responses from carers in England in this report due to the divergent healthcare systems across the UK.

Employers for Carers is Carers UK’s membership forum for employers who want to support the people in their workforce who are carers. Its purpose is to:

- provide practical advice and support for employers seeking to develop carer friendly policy and practice and retain skilled workers
- identify and promote the business benefits of supporting carers in the workplace
- influence employment policy and practice to create a culture which supports carers in and into work.

For more details visit www.employersforcarers.org, email employers@carersuk.org or telephone 020 7378 4956.
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Carers UK makes life better for carers.
Caring will affect us all at some point in our lives.
With your help, we can be there for the 6,000 people who start looking after someone each day.
We’re the UK’s only national membership charity for carers.
We’re both a support network and a movement for change.

► We give expert advice, information and support.
► We connect carers so no-one has to care alone.
► We campaign together for lasting change.
► We innovate to find new ways to reach and support carers.

Carers UK Adviceline
For expert information and advice about caring.
T 0808 808 7777
(open Monday to Friday, 10am-4pm)
E advice@carersuk.org

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