

# Commissioning and COVID-19: advice for social care

## Understanding the impact of COVID-19 responses on citizens

**Updated: 8 January 2021**

This guide addresses the impact of COVID-19 and responses on people who use or interact with social care services including Disabled and older people, people with mental health support needs and unpaid carers. It also explores the individual impacts on paid workers. The guide will be useful for commissioners and providers as evidence to inform plans to address impacts in the immediate and longer term. It will also be of interest to community groups and anyone wanting an overview of how COVID-19 has disproportionately affected the people who use or work in the sector.

### Introduction and overview

The COVID-19 crisis has exposed existing challenges within the social care system and exacerbated exclusion, inequality and poverty for many who rely on its support. Whilst local authorities have undertaken life-saving work, people's experience of COVID-19 responses and associated restrictions has too often been lack of control, confinement, isolation, fear and stress. Many people remain distanced from the planning and decision making that affects their choices and everyday lives. Disproportionately high death rates from COVID-19 amongst older people, those living in care homes, people from Black, Asian and minority ethnic (BAME) groups, people with underlying health conditions, people with learning disabilities, as well as amongst care workers have taken a huge toll.

The exposure to risks, shortages of personal protective equipment (PPE), problems accessing food and medical help, and the negative impact of blanket policies has led many to question whether there has been sufficient value and protection of older and Disabled people's lives (by Government). These issues along with easements in legal duties, whilst rarely adopted, left many feeling like 'second-class' citizens and unpaid carers feeling abandoned. There have been increased risks of **domestic violence** [link 1](#). People face huge fears and uncertainty for the future. Many with lived experience of social care say their voices have not been properly responded to at local or national levels.

Lack of recognition and poor working conditions of the social care workforce have added to the problems. Low pay, limited sick pay, zero-hours contracts and lack of testing meant many care workers continued working, some inadvertently spreading the virus and many risking their own lives.

There have been positive stories too. There is much to learn and build on from the amazing work of Disabled individuals, communities and workers in many areas. People have connected in new ways through mutual aid, peer support and through digital links with their networks. Commissioners and providers have collaborated to ensure people do not go without essential care and support.

- An incredible effort by local authorities saw most homeless people – many of whom have mental health or substance misuse needs – allocated safe accommodation.
- There are examples of care staff in effect moving in to stay in residential homes to limit transmission.
- Shared Lives arrangements saw people isolating together in supportive households.
- Some with direct payments were able to quickly flex their support – some paying family or household members – to get the right support at the right time.

There is, however, an emerging picture, from people using social care, of a big gap between proactive, effective council responses and less responsive commissioners. Places which have long invested in partnership and relationship building and in creating capacity and infrastructure with communities and citizens, have benefitted greatly from this during the pandemic.

Commissioners need to take immediate action where it is already evident what will help, such as supporting testing, PPE supply, accessible information, risk assessments including for workers with higher risk factors. For the recovery after COVID-19, commissioners need to ensure next steps are properly co-produced with local people and informed by a full understanding of their experiences.

### Impact of COVID-19 on people using care and support services

#### Care Homes

A **Public Health England (PHE) report** [link 2](#) shows that deaths in care homes accounted for 27 per cent of all deaths from COVID-19 (20 March to 7 May 2020). In that period there were more than double the number of deaths in care homes than



expected compared to previous years, equating to 20,457 excess deaths. The figures suggest many excess deaths from other causes or an under-reporting of deaths from COVID-19. As the pandemic continues, we are a way off understanding the full impact.

Over 40 per cent of all care homes, more than 6,300 in England, reported an outbreak up to [7 June 2020](#) [link 3](#). With hospital access limited, the lack of specialist healthcare going in to care homes will have resulted in people suffering a range of health complications – not just COVID-19. For those tragically catching the virus, many may have suffered without the specialist relief and ventilation that people received in hospital. This will have taken a huge toll on relatives, care workers and fellow residents.

People living in care homes (around 400,000 people in England) have not been able to see visitors and many have faced months confined to their rooms seeing only care workers. There has been a lack of choice with people discharged rapidly from hospitals and some services not operating or not able to take new people.

Self-funders, of which there are 167,000 in England, already pay an average of 41 per cent higher care home fees than local authority commissioners. [Age UK](#) [link 4](#) reported some self-funders being hit by a 'coronavirus bill' and being asked to pay more than £100 a week on top of their usual care home fees to cover the extra costs of PPE, staff absences and vacant beds.

## People with learning disabilities (LD)

People with learning disabilities (LD) and their families have also been tragically affected. [Analysis by CQC](#) [link 5](#) revealed a 134 per cent increase in deaths of people with a learning disability or autistic adults between 10 April and 15 May compared with the same period last year. People with a learning disability are at an increased risk of respiratory illnesses, so access to testing could be key to reducing infection and saving lives.

See SCIE's [Supporting autistic people and people with learning disabilities](#) [link 6](#).

## Care and support services

Access to vital care and support has been problematic for many, with some workers off sick or isolating. Some people have had to refuse care due to fear or the need to limit footfall and reduce transmission. Many community based services closed (temporarily). It has often fallen to family and unpaid carers to bridge the gap, but many people will have gone without the care and support they need to live independently and with dignity.

## People's experiences

The section below summarises the impact of COVID-19 and the Government's response on older and Disabled people's lives. This draws largely on surveys including by Inclusion London, Carers UK, ONS plus feedback from individuals via the [Be-Human](#) [link 7](#) and other networks. It is acknowledged that much of this is based on people having digital access to resources so is inevitably weighted.

Commissioners will want to understand whether these reflect local experiences.

The summary of themes below may act as a useful checklist to benchmark and begin plans to address local issues.

- Disabled people are losing their care due to worker sickness, service closures, lack of PPE or the need to reduce contact with outside world.
- Higher burden is placed on family members and other unpaid carers, which will not be sustainable after the lockdown ends.
- People who employ their own support staff were largely left on their own at the beginning of the pandemic to deal with HR issues, source PPE and put in place contingency plans (though notable exceptions).
- Significant restrictions are placed on people in institutions, with relatives and advocates not able to visit, and remote contact not always facilitated or accessible. With the CQC operating a light touch regime for inspections, concerns are that residents are at much greater risk of abuse.
- Those who received support through day care provision, including young people who were in education, are not getting alternative means of support and are reaching crisis point.
- People feel their rights are at risk with concerns about Care Act easements, Mental Health Act detentions requiring only one doctor rather than two and blanket do not resuscitate (DNR) notices issued to Disabled people. Local authorities that implemented the easements of the Care Act did not always inform local people about the reasons in accessible ways or publish Equality Impact Assessments as required by the Department of Health and Social care (DHSC) guidance.
- Increased fees to some people funding their own care.
- Many people are experiencing distress, anxiety and isolation as a result of these issues.

## Mental distress and wellbeing

- There has been a lack of access to community support services for people who already have mental health support needs and for people who need this support for the first time.



- There are long waiting lists to access support in the community. People feel abandoned, often not knowing where to go for help. Some have waited days and sometimes weeks to get a response from the local authority.
- Due to fear of contracting the virus and the need to shield, many people have reduced their support and heavily rely on family. This is causing emotional and psychological stress with many people feeling they are at breaking point.
- Discussions of rationing resources and fears about DNR notes has caused extreme anxiety and made many people fearful that they will be left to die.
- Most support is online and with two thirds of Disabled people plus older people having barriers to access online solutions they are further cut off and face much greater exclusion.
- There is very little information in accessible formats (e.g. Easy Read, BSL), which is adding to anxiety.

## Access to other support

### ▼ Access to food and medicine

With online deliveries prioritised for people on the extremely vulnerable register, many Disabled people were unable to get deliveries for weeks (though many people shielding also struggled). Many cannot use online shopping regardless and most supermarkets did not make sufficient adjustments to enable those who could go out to shop in store.

People have either missed out or spent more money resorting to more expensive shops or ordering specialist meals online.

Food boxes do not cater for people's access and dietary needs. Some people are not able to open cans and cook meals from fresh ingredients. People may not be getting the support they need to cook due to staff shortages and this has been exacerbated by problems accessing ready-made meals.

### ▼ Access to health treatments

Many Disabled people have had routine appointments and planned surgery cancelled. There has been limited access to community healthcare. This may have significant negative consequences in the future.

The (early) NHS ban on visitors to hospital means that Disabled people who need very specialist support are not able to get it such as support to communicate and make decisions about their care and treatment.

Disproportionate restrictions were imposed in psychiatric hospitals that make people even more institutionalised. For example, cancelling leave or not implementing care plans, which help people to move towards discharge.

### ▼ Employment

Disabled people who work need help to ensure their working environment is safe and accessible. Those receiving support from Access to Work felt abandoned, as there was no communication, advice or guidance or confirmation of variation in support packages. Disabled people in work, including those continuing to shield risk losing their skilled support staff.

ONS reported on the wider [impacts on disabled people](#) <sup>link 8</sup>. Whilst not all Disabled people need or use social care, these self-reported experiences are of significance:

- Nearly 9 in 10 Disabled adults said they are very worried or somewhat worried about the effect that coronavirus (COVID-19) is having on their life. A higher proportion of Disabled adults (45.1 per cent) reported being very worried compared with non-disabled (30.2 per cent) adults. Nearly two-thirds (64.8 per cent) of Disabled adults said COVID-19-related concerns were affecting their wellbeing – feeling worried about the future and being stressed, anxious or bored.
- Over a third of Disabled adults reported spending too much time alone compared with a fifth of non-disabled adults. Almost 1 in 10 disabled adults reported often or always feeling lonely compared with 1 in 25 non-disabled adults. Spending time with members of their household was a less frequent form of coping for Disabled adults (41.9 per cent) than non-disabled adults (63.5 per cent).

More positively very similar proportions of Disabled and non-disabled adults (around two thirds) said they felt if they needed help, other community members would support them during the pandemic. Almost 8 in 10 Disabled adults and non-disabled thought people were doing more to help others since the pandemic; and Disabled adults report being as active in supporting their communities as non-disabled adults.

It is important for commissioners to build on these positives, promoting equalities and strengthening the role of Disabled and older people in their communities.

## Impact of COVID-19 on unpaid and family carers



There are **over 6.5 million adult carers** [link 9](#) (though recent figures suggest there could be in excess of 8 million) supporting a loved one who is older, disabled or seriously ill. That's one in eight adults who care, unpaid, for family and friends. Many are co-carers or with multiple caring roles, and carers are often themselves older or disabled.

Carers UK estimate an additional 4.5 million people are caring for older, disabled or seriously ill relatives or friends since the COVID-19 pandemic. Carers are facing extreme pressures and there are real fears for carer sustainability now and in the future. There will be huge challenges as more carers return to work or face financial hardship due to caring or job-losses.

The Carers UK report **Caring Behind Closed Doors** [link 10](#) found:

- Seventy per cent of carers are providing more care due to the pandemic – on average, 10 additional hours of care a week.
- Over a third are providing more care as a result of local services reducing or closing.
- Of all carers, 69 per cent are providing more help with emotional support, motivation, or keeping an eye/ checking in on the person they care for.
- Eighty-one per cent of carers are spending more money at the moment; 72 per cent are spending more on food and 50 per cent are spending more on household bills.
- Thirty-eight per cent of carers are worried about their financial situation.
- Fifty-five per cent feel overwhelmed and are worried they'll burnout in the coming weeks.
- Most (87 per cent) are worried about what will happen to the person or people they care for if they, as their carers, have to self-isolate or become ill.

There are also anecdotal reports of family carers self-medicating to cope with the extreme pressures.

More than **half of the Directors of Adult Social Services** [link 11](#) have reported an increase in people presenting to their council with adult social care needs as a result of carer breakdown, sickness or unavailability.

Carers organisations that were well embedded in the community were able to quickly link carers to practical and emotional support. Some carers have received positive support to stay in touch with services or connect with other carers – often through remote links ups such as Zoom coffee mornings. Peer support and mutual support have been vital for carers to feel less isolated. Some have received regular phone calls and practical help such as PPE or food. Some carers, in taking on extra tasks for the person they care for, have become paid employees via direct payments.

Co-production with carers and the organisations that represent them is vital to address the immediate pressure and barriers faced. Commissioners need to understand the scale of need and learn from what has helped carers and those they care for so this can inform plans.

## Disparities in the risk of dying from COVID-19

A **PHE report** [link 12](#) highlighted disparities in risk of death from COVID-19 that disproportionately affect people who use social care services and the social care workforce. Commissioners need to understand these disparities and the impact on those most affected to ensure responses address these risk factors to protect people and protect the workforce. This also points to strategic and whole-area commissioning approaches addressing impacts of poverty and inequality.

Immediate risk assessments for people using services as well as workers are needed plus longer term planning. Risk of dying from COVID is higher for:

- Older people. Age is the biggest factor with people over 80 being 70 per cent more likely to die from COVID-19 than people under 40.
- Black, Asian and minority ethnic (BAME) groups than in White ethnic groups. (Opposite of what is seen in previous years, when the mortality rates were lower in Asian and Black ethnic groups than White ethnic groups.)
- People of Bangladeshi ethnicity had around twice the risk of death than people of White British ethnicity. People of Chinese, Indian, Pakistani, Other Asian, Caribbean and Other Black ethnicity had between 10 and 50 per cent higher risk of death when compared to White British. There was a high increase in all cause of deaths among people born outside the UK and Ireland.
- People living in the most deprived areas of England experienced coronavirus mortality rates more than double those living in the least deprived areas.
- People with comorbidities – a higher percentage mentioned diabetes, hypertensive diseases, chronic kidney disease, chronic obstructive pulmonary disease and dementia than all cause death certificates. Diabetes was mentioned on 21 per cent of death certificates where COVID-19 was also mentioned.
- People working in social care had significantly high rates of death from COVID-19.
- Men are more likely to die than women.

## What has been the impact on workers?



There have been amazing examples of creativity and dedication amongst care and support workers. Some care home workers have 'lived in' to protect residents. Many have worked long hours and extra shifts to comfort residents at their most difficult time, and in the absence of family visitors. The challenges and pressures have been huge and care workers have paid a high price. The death rate amongst social care staff is double that of the general working age population.

Market shaping duties set out a commissioning role to ensure a quality, well-trained and decently remunerated workforce. Some areas have supported temporary pay increases to workers but the work overall remains poorly paid despite growing workforce shortages.

There are 1.5 million workers in social care – mainly women, a high proportion are from BAME, (one fifth are migrant) and many with real pay below the minimum wage. Twenty-five per cent are on zero-hours contracts. The lack of protection of workers meant that many could not afford not to work. [A UNISON survey](#) <sup>link 13</sup> found that 80 per cent feared having no money due to lack of contractual sick pay. Some analysts view precarious and low-paid work as contributing to a 'perfect storm' for transmission of the virus.

Factors facing workers have included:

- some workers doing shifts across multiple sites or across different companies to make up a living wage
- lack of access to adequate PPE or training to use it effectively
- workers already living in poverty and facing multiple risk factors
- high proportions of BAME front-line staff
- some workers losing their regular work as people stopped their care.

More positive experiences for workers emerged from self-managed teams, with close-knit teams already working in person-centred and creative ways to support an individual; from micro-enterprises and from Shared Lives carers thriving within the household. Some Shared Lives carers, however, faced considerable extra pressure with wider support services and local support not consistently available. A national umbrella structure, though, enabled access to networks, guidance and expert advice.

## Immediate and urgent action to support citizens

Rather than just return to business as usual and switch back on services, commissioners need to take stock of people's experiences and what they mean for current commissioning activity. These are strong messages for the immediate future as well as for longer term commissioning plans. Calls from citizens for local as well as Government action include:

- ☰ Ensure there are choices and that people – and those supporting them – realise they have choices. For example, that there are options for direct payments; to recruit your own workers; there are community and innovative alternatives to care homes; there can be flexible arrangements with providers through individual service funds, and there should be appropriate support for unpaid carers. Use this opportunity to innovate and scale what is valued.
- ⚠ Consider risk factors regarding known disproportionate death rates and plan accordingly.
- 👤 Ensure availability of PPE to social care, to people arranging their own support and to unpaid carers.
- 🧪 Testing is vital for people of all ages in all settings, for unpaid carers and for all support workers. (Though **87 per cent of directors** <sup>link 14</sup> said they are not confident about an adequate supply of/ability to access testing for unpaid carers.)
- 🏠 Ensure Disabled and older people's rights are not downgraded and social distancing measures do not result in increased barriers or reduced access to support. People still need to choose where they live, who supports them and the type of life they want. Think creatively.
- 👤 Support for people who are shielding must be more individualised, comprehensive and based on their needs, taking into account that some of those people will continue to work, look after children or other relatives.
- 💻 Technology and remote solutions need to be more inclusive. This might include provision of kits, skills and connectivity to address digital exclusion. Consider who this may still miss out and why.
- 📺 Reach people with accessible information – don't rely solely on digital.
- 👥 People with lived experience must be included in policy development at national and local level. Local authorities that co-produced their response did much better compared to others.
- 🏠 Ensure the impact of reduced services on carers and their families are closely monitored in terms of carers' health and wellbeing and ability to care in order to avoid burn-out. Appropriate support must be available as soon as possible.
- 🍲 Ensure systems are in place to properly address the basics – access to food, shopping and medicines.
- 🏠 Those unable to work because of caring need support to retain their jobs for as long as possible, as well as ongoing flexibility for carers to continue to juggle work and care.
- 🏠 Ensure that there is access to and sufficient investment in end of life care, death and bereavement services.
- 👤 The workforce needs to be protected and treated well and you need to hear directly from them. Contracts must reflect this – not just stipulate paying the legal minimum living wage. Plan for burn out as there are already massive pressures and workforce shortages.

Commissioners have an opportunity to shape immediate steps to protect lives and improve people's experiences by understanding the local experience and working with Disabled people, older people, carers and the organisations that represent them. There are considerable challenges ahead so longer term planning must be based on what will make a difference in each area.



- [Caring behind closed doors: Forgotten families in the coronavirus outbreak](#) [link 15](#) (Carers UK)
- [Latest news](#) [link 16](#) (Learning disability today)
- [Learning disability deaths](#) [link 17](#) (CQC)
- [Disparities in the risk and outcomes of COVID-19](#) [link 18](#) (PHE report)
- [Budget survey 2020: Part one COVID-19 response](#) [link 19](#) (ADASS)
- [Webinars](#) [link 20](#) (Be Human)
- [Abandoned, forgotten and ignored](#) [link 21](#) (Inclusion London)

## Support from SCIE

[SCIE's COVID-19 hub](#) [link 22](#) contains more relevant information including safeguarding, Mental Capacity Act and infection control. It can be used when working and supporting people who are isolated or vulnerable through COVID-19, and can also be shared with community groups.

**link 1** | <https://www.scie.org.uk/care-providers/coronavirus-covid-19/domestic-violence-abuse>

**link 2** | [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/892085/disparities\\_review.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/892085/disparities_review.pdf)

**link 3** | [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/891407/COVID19\\_Care\\_Homes\\_10\\_June.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/891407/COVID19_Care_Homes_10_June.pdf)

**link 4** | <https://www.ageuk.org.uk/latest-press/articles/2020/06/care-home-residents-are-being-clobbered-with-a-coronavirus-bill/>

**link 5** | <https://www.cqc.org.uk/news/stories/cqc-publishes-data-deaths-people-learning-disability>

**link 6** | <https://www.scie.org.uk/care-providers/coronavirus-covid-19/learning-disabilities-autism>

**link 7** | <https://be-human.org.uk/webinars/>

**link 8** | [https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/coronavirusandthesocialimpactsondisabledpeopleingreatbritain/2020-04-24#:~:text=Nearly%20two%2Dthirds%20\(64.8%25\)%20of%20disabled%20adults%20said%20coronavirus,more%20frequently%20report%20feeling%20lonely](https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/disability/articles/coronavirusandthesocialimpactsondisabledpeopleingreatbritain/2020-04-24#:~:text=Nearly%20two%2Dthirds%20(64.8%25)%20of%20disabled%20adults%20said%20coronavirus,more%20frequently%20report%20feeling%20lonely)

**link 9** | [https://www.carersuk.org/news-and-campaigns/press-releases/facts-and-figures?gclid=EAlaIqobChMlr83Bv6WG6gIVyrTtCh0tcwpkEAAYAiAAEgIrSfD\\_BwE](https://www.carersuk.org/news-and-campaigns/press-releases/facts-and-figures?gclid=EAlaIqobChMlr83Bv6WG6gIVyrTtCh0tcwpkEAAYAiAAEgIrSfD_BwE)

**link 10** | [https://www.carersuk.org/images/News\\_and\\_campaigns/Behind\\_Closed\\_Doors\\_2020/Caring\\_behind\\_closed\\_doors\\_April20\\_pages\\_web\\_final.pdf](https://www.carersuk.org/images/News_and_campaigns/Behind_Closed_Doors_2020/Caring_behind_closed_doors_April20_pages_web_final.pdf)

**link 11** | <https://www.adass.org.uk/adass-budget-survey-2020-part-one-covid-19-response>

**link 12** | [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/892085/disparities\\_review.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/892085/disparities_review.pdf)

**link 13** | [https://www.unisonnw.org/care\\_workers\\_vs\\_covid\\_19](https://www.unisonnw.org/care_workers_vs_covid_19)

**link 14** | <https://www.adass.org.uk/adass-budget-survey-2020-part-one-covid-19-response>

**link 15** | [https://www.carersuk.org/images/News\\_and\\_campaigns/Behind\\_Closed\\_Doors\\_2020/Caring\\_behind\\_closed\\_doors\\_April20\\_pages\\_web\\_final.pdf](https://www.carersuk.org/images/News_and_campaigns/Behind_Closed_Doors_2020/Caring_behind_closed_doors_April20_pages_web_final.pdf)

**link 16** | <https://www.learningdisabilitytoday.co.uk/ldt-news>

**link 17** | <https://www.cqc.org.uk/news/stories/cqc-publishes-data-deaths-people-learning-disability>

**link 18** | [https://assets.publishing.service.gov.uk/Government/uploads/system/uploads/attachment\\_data/file/889195/disparities\\_review.pdf](https://assets.publishing.service.gov.uk/Government/uploads/system/uploads/attachment_data/file/889195/disparities_review.pdf)

**link 19** | <https://www.adass.org.uk/adass-budget-survey-2020-part-one-covid-19-response>

**link 20** | <https://be-human.org.uk/webinars/>

**link 21** | <https://www.inclusionlondon.org.uk/wp-content/uploads/2020/06/Abandoned-Forgotten-and-Ignored-Final-1.pdf>

**link 22** | <https://www.scie.org.uk/care-providers/coronavirus-covid-19>

**link 23** | <https://www.scie.org.uk/myscie/register>

**link 24** | <https://www.scie.org.uk/myscie/login>

