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Understanding the impact of COVID-19 responses on citizens

May 2022





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About SCIE

The Social Care Institute for Excellence improves the lives of people of all ages by co-producing, sharing, and supporting the use of the best available knowledge and evidence about what works in practice. We are a leading improvement support agency and an independent charity working with organisations that support adults, families and children across the UK. We also work closely with related services such as health care and housing.

We improve the quality of care and support services for adults and children by:

- identifying and sharing knowledge about what works and what's new
- supporting people who plan, commission, deliver and use services to put that knowledge into practice
- informing, influencing and inspiring the direction of future practice and policy.

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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 affect 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 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, initial shortages of personal protective equipment (PPE), problems accessing food and medical help, and the negative impact of blanket policies 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 and abuse with incidents becoming more complex and serious. As further waves of the pandemic hit, 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 particularly in the early months 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 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, volunteers and providers have collaborated to ensure people do not go without essential care and support.

- An incredible effort by local authorities through the **Everyone In** initiative saw 37,000 homeless people who were rough sleepers – many of whom have mental health or substance misuse needs – allocated safe accommodation during the early stages of pandemic.
- There are examples of care staff moving in to stay in residential homes to limit transmission and ensure continuity of care.
- 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.
- The shift to more digital worked well and was more inclusive for some – being able to connect flexibly without the usual barriers to travelling and attending physical venues.

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

For the ongoing recovery, commissioners need to ensure next steps are properly co-produced with local people and informed by a full understanding of their experiences.

There are growing movements driving change such as **Social Care Future** campaigning for a better future based on people's intrinsic value, choice, rights, inclusion, community and belonging. **Disabled People's Organisations** are coming together with a louder, unified campaigning voice and individuals are challenging breaches of the Equality Act.

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

People living in care homes

People in care homes were hit dreadfully hard by the pandemic. Around 400,000 people live in care homes in England. During the two peak periods of COVID-19, April to September 2020 and October 2020 to March 2021, CQC recorded 39,350 **deaths in care homes** attributed to COVID-19. The ensuing restrictions on visitors and people's freedoms within homes, whilst aimed at keeping people safe, took a further toll on people's emotional, physical and mental health.

The early months of the pandemic were particularly harsh with rapid hospital discharge, difficulties accessing PPE, lack of whole-home testing for residents and staff plus difficulties using the national testing programme all adding to transmission risks.

Over 40 per cent of all care homes reported an outbreak up to **7 June 2020**. Outbreaks were initially up to **20 times more likely in large care homes**. High footfall, including agency workers, cooks, cleaners and maintenance engineers going in and out of the largest homes, is thought to have been a key factor in transmission.

The impacts on people living in care homes need to be understood so appropriate changes can be made to uphold people's rights and to ensure a better quality of life. These are some of the issues identified:

- 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.
- Residents – many of whom have dementia – experienced distress, confined to their rooms with no outside visitors for months on end.

- Poor or rushed assessments following rapid discharge from hospital made it hard for staff to understand the needs of new residents. With ongoing pressure on staffing, operational changes and limited visitors, the impact of this will have been exacerbated and ongoing.
- There was inadequate **end-of-life planning** (poor treatment and care; exclusion of loved ones and faith representatives and the unlawful use of 'Do Not Attempt Resuscitation (DNAR)' Orders).
- 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](#) reported some self-funders being hit by a 'coronavirus bill' and asked to pay a surplus on top of their usual care home fees to cover the extra costs of PPE, staff absences and vacant beds.

Visitors to care homes

Care homes implemented enhanced infection control measures and ongoing visiting restrictions to protect residents. These continued over the months and into 2022 as the country experienced new waves of COVID-19. Whilst protecting against infection, restrictions on visiting and residents' freedoms has had a hugely detrimental impact on the health and wellbeing of residents and their families. This is not to ignore the amazing ways that many care homes have creatively supported ongoing contact and virtual visits.

Research between May and October 2020 found that the **mental health** scores for family carers with relatives in care homes were significantly poorer than those of the general public and that their mental health declined further when visiting restrictions came in.

To enable **improved care home visits** through this and future pandemics, visits need to be prioritised and any changes to visiting rights must be used as a last resort and for the shortest period. Such changes should be reviewed regularly in consultation with residents, family carers and workers and be restored as soon as possible as a top priority.

People with learning disabilities

People with learning disabilities and their families have also been tragically affected. **Analysis by CQC** revealed a 134 per cent increase in deaths of people with a learning disability or autistic adults between 10 April and 15 May 2020 compared with the same period in 2019. **CQC data showed** deaths involving COVID-19 accounted for nearly a third of all deaths of people with a learning disability or autistic people in care settings between April 2020 and March 2021.

People with a learning disability are at an increased risk of respiratory illnesses, so access to testing could have been key to reducing infection and saving lives – for those living in congregate as well as for people living independently or with family. See SCIE's [Supporting autistic people and people with learning disabilities](#).

Research by [Mencap](#) following the first lockdown revealed that care packages had been halved for many people with learning difficulties. The Foundation for People with Learning Disabilities, including their members with lived experience, also describe the impact of unconscious bias and stigma, resulting in a dearth of appropriate support and advice for people and their families and friends. [The coronavirus and learning disability study](#) has been tracking people's experiences and shows, how nearly two years into the pandemic, that the

lives of adults with learning disabilities and their carers are still a long way from returning to “normal”, and the negative impact of this on their health and wellbeing.

Impacts identified by these organisations to December 2021 include:

- Young people sent home from residential schools without appropriate support.
- People remain worried to leave the house and more than one in five people with profound and multiple learning disabilities are still shielding.
- The level of support received has not returned to pre-pandemic levels.
- Some people are now paying for some services out of their own pocket.
- Some with direct payments are paying for services that they are not currently getting.
- Family carers and support staff reporting disturbed sleep, high stress, and tiredness as a result of their caring responsibilities.

Access to care and support services

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

Evidence reviewed by [TLAP](#) (Oct 2020) pointed to the impact of general confusion and anxiety of the early pandemic. There were particular issues of loneliness and isolation; financial pressures; practical issues around food shopping; increase in health anxiety; and challenges caused by changes to the streetscape. The research along with reports from Inclusion London and [ADASS](#) also highlighted barriers for people who accessed care and support and their unpaid or family carers, including:

- a challenge around communications – people not receiving useful and timely information about service changes and support available;
- concerns around accessing Personal Protective Equipment (PPE);
- cancellations of respite and day services;
- examples of changes to care packages such as support being reduced due to people not going out;
- lack of choice with some people being offered care and support such as residential care that they would not have chosen due to lack of capacity for example in home care.

[ADASS surveys](#) also show the impact on people of unmet need, the pressure on wider services and the interdependence of social care and the NHS including:

- increased demand for social care services and growing levels of unmet need, people waiting longer, and more people missing out on vital care and support;

- delays to assessments and reviews having a detrimental impact on people's lives;
- more people presenting with mental health issues; seeking help for domestic abuse or safeguarding; and more rough sleepers needing support;
- more people needing support who are awaiting admission to hospital and increased numbers requesting support on discharge;
- concerns that much of the voluntary, community and social enterprise (VCSE) sector being at risk over the next year (2022) resulting in fewer services and reduced resilience.

People's experiences

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

Not everyone experienced the pandemic in the same way and the long-term impacts will vary across different communities. People's identity, circumstances and where they live all play a part. One study found that people from Black communities are four times more likely to die from COVID-19 than people from White ethnicities. It also found that people living in the most impoverished areas are 50% more likely to die of COVID-19 than those in more affluent areas. This intersectional experience alongside its compounding disadvantages must be recognised and addressed. Commissioners will want to understand how these reflect local experiences.

The themes below may act as a useful checklist to benchmark and progress the co-production of plans with local people, communities and Disabled people's organisations to address local issues.

- Disabled people have lost their care due to worker sickness, service closures, lack of PPE or the need to reduce contact with outside world. Issues with recruitment and retention is adding to problems accessing appropriate support.
- There has been a failure to ensure the safety of older and Disabled people living in congregate or institutional settings.
- People with mental health support needs have not had access to the services they need.
- Higher pressure has been placed on family members and other unpaid carers, which will not be sustainable in the medium to long term.
- 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 there were notable positive exceptions in some areas).
- Significant restrictions have been 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, there were concerns that residents could be at much greater risk of abuse.

- Those who received support through day care provision, as well as young people in education, were not getting alternative support and many were reaching crisis point.
- People feel their rights are at risk and their lives not valued with the early use of blanket do not resuscitate (DNR) notices and the Coronavirus Act allowing for Care Act easements (now ended), and the proposed reduced protections under the Mental Health Act. 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.
- Disabled people have been differentially affected by COVID-19 due to: the increased risk of poor outcomes from the disease itself, reduced access to routine health care and rehabilitation, and the adverse social of impacts of lockdown measures ([The Lancet](#)).
- Many people are experiencing mental distress, anxiety and social isolation as a result of these issues plus hardships across all areas of life: loneliness, food poverty, financial difficulties, workplace discrimination, problems accessing healthcare, and unequal access to medicine, vaccines, and social care.

The following section looks in more detail at some of these experiences and the additional pressures that people faced and continue to face.

Access to wider support

Access to food and medicine

With online deliveries initially prioritised for people on the extremely vulnerable register, many Disabled people were unable to get deliveries for weeks (though many people shielding also struggled). Lack of digital access or not having remote payment methods, mean many cannot use online shopping and most supermarkets did not make sufficient adjustments to enable those who could go out to shop in-store. People 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; this was exacerbated by problems accessing ready-made meals.

Access to health treatments

Most Disabled people surveyed said they experienced problems or delays accessing healthcare and receiving treatment. There has been limited access to community healthcare. This has significantly impacted Disabled people's health and resulted in worsening health conditions which may have negative consequences in the future. This causes distress, limits independence and may cause irreversible damage to people's health. Remote appointments worked well for some, but not for those with limited digital access or who find such communication less effective.

The (early) NHS ban on visitors to hospital meant that Disabled people who needed very specialist support were 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, visiting and social restrictions, cancelling leave or not implementing care plans – the very things which help people to move towards discharge.

Employment

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

There was evidence of employers not complying with the Equality Act or making reasonable adjustments. There was lack of clear guidance and preparation too for people who were shielding who needed to return to work.

Disabled people are more likely to be unemployed due to the job market changes and have been the first to be considered for redundancies. Research from the Citizens Advice Bureau found that one in four Disabled people faced redundancy, rising to 37% for those whose impairment had a substantial impact on their activities.

Wider impacts

A range of other changes in response to the pandemic have had a disproportionately negative impact on those who may draw on social care. These risk undermining people's right to independent living, choice and control. It is vital therefore for commissioners to engage with communities, with individuals and user-led organisations as well as other council departments and statutory partners to understand and co-produce the holistic approaches required to improve lives.

Poverty and financial pressures. Citizens Advice report on people's desperate need for information as so many struggled to access support and advice to apply for benefits. They report on the huge financial pressures on people through COVID-19. The £20 uplift to Universal credit has now ended but had not been available to people on legacy benefits. People on lower incomes continue to be hit hard by the rising costs of food and fuel – pushing many beyond their limits.

Accessing the community and environment. Changes to streetscapes – the use of pavements for hospitality, for example, have made environments less accessible for many older and Disabled people. These are impacts that could have been reduced by engaging with Disabled people to thoroughly consider needs and the impact on access for people with a range of impairments. Mask wearing has had a particularly hard impact on Deaf people and others who rely more on non-verbal communication.

Digital exclusion. Remote information and service provision is starting to dominate, excluding those who do not have or cannot afford technology or do not have digital skills. Two thirds of Disabled people plus older people have barriers to accessing online solutions so 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 and exclusion.

Disability hate crime and targeted abuse has also increased as people have found it challenging to navigate the sudden changes to rules, streetscapes and maintain social

distancing. There are examples of verbal abuse for "jumping" queues or not wearing masks when legitimately exempted plus an increase in online abuse. Some describe a 'compassion fatigue' translating into impatience, resentment and intolerance by some people.

Domestic violence and abuse - confinement at home increases the risk of physical or sexual violence and abuse, to which Disabled children and adults are additionally vulnerable.

Mental distress and wellbeing. Such experiences **translate into an overall negative impact on wellbeing with Disabled people feeling significantly more worried about the impact of the pandemic on their lives than non-Disabled people.** Whilst not all Disabled people use social care, these self-reported (ONS analysis February 2021) experiences are of significance:

- Nearly eight in 10 Disabled adults continue to say they are worried about the effect that coronavirus (COVID-19) is having on their life.
- Nearly two-thirds of Disabled adults said COVID-19-related concerns were affecting their wellbeing – feeling worried about the future and being stressed, anxious or bored.
- Disabled people were more likely to say the coronavirus was making their mental health worse, they are feeling like a burden on others, they are feeling stressed and anxious or they are feeling lonely. They were also less optimistic about the future.
- Over a third of Disabled adults reported spending too much time alone compared with a fifth of non-Disabled adults. Almost one in 10 Disabled adults reported often or always feeling lonely.

With lockdown, some Disabled people said that their daily experience was less changed than that of other people. Lack of accessible environments, transport and appropriate support mean that many people do live their lives in a sense of perpetual lockdown.

There are positive experiences too

- 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. Most thought people were doing more to help others since the pandemic.
- Disabled adults report being as active in supporting their communities as non-Disabled adults. Community connection and local action have been recurring positive themes.
- Working at home has presented access and flexibilities that some Disabled workers have been seeking for years.
- Digital connection has also meant some Disabled people connecting with others on more of a level playing field. Creating new WhatsApp groups, zoom links with friends and building new digital connections in their communities.

Research interviews with older adults about their mental health and wellbeing during the pandemic found that many were resilient throughout social distancing restrictions. Participants described activities and behaviours that helped to protect their mental health, including adopting a slower pace of life, maintaining routine and socialising. The interviews

highlighted the importance of people being able to maintain access to essentials and ongoing social connections to help reduce uncertainty.

Of note is the self-organising of Disabled people and their allies through movements such as Social Care Future – a voice that is ‘valuable not vulnerable’ and setting out a positive future based on rights, choices and connectedness.

It is important for commissioners to build on these positives, understanding what people need and value, promoting equalities, rights 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 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. Women are still most likely to be providing care and most likely to be providing more hours of care. One fifth of women aged 45 to 54 are providing unpaid care.

Carers UK estimate that an additional 4.5 million people became unpaid carers in March 2020, meaning one in four (26%) UK adults were providing unpaid care to a relative or friend at the height of the pandemic. Carers continue to face 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 in 2020* found:

- Seventy per cent of carers were providing more care due to the pandemic – on average, 10 additional hours of care a week.
- Over a third were providing more care as a result of local services reducing or closing.
- Over 80 per cent of carers were spending more money due to the pandemic, particularly on food and household bills.
- More than half felt overwhelmed and were worried they would soon burn out.
- Most (87 per cent) were worried about what will happen to the person or people they care for if they, as their carers, had to self-isolate or became ill.

The Carers UK *State of Caring Report 2021* shows how the pandemic continues to have a huge impact on carers’ lives negatively affecting their relationships, their mental and physical health, their paid work and finances, and their emotional wellbeing. The impact has been even more pronounced on carers providing more than 35 hours of care per week, and the health impacts worsen the longer people were caring. They describe the intolerable pressure and the exhaustion carers are facing. Many are feeling more isolated, anxious and worried about the future and how they will continue to cope.

Nearly a third of carers report that they are struggling to make ends meet. A shortage of care and some services not fully opening is putting working carers' livelihoods at risk, as some carers had to reduce their working hours or even give up work altogether.

Restrictions have also had negative consequences on carers' wellbeing and carers of people with **dementia** reported difficulties in accessing formal care services and respite care. Another study reported carers of people with learning disabilities feeling powerless and coping with increased challenges in behaviour of their loved one.

Lack of access to information is a significant issue and this has been exacerbated for some who have limited digital access, particularly when support has moved online. Other carers reported that the services in their local area are not meeting their needs. This is especially true if carers are from a marginalised background or under-represented communities.

Delays in healthcare and restricted access to support services has changed people's levels of physical activity and their overall health. Seven in 10 carers say the needs of the person they care for have increased.

Disabled children and their families are at risk of developing serious mental health issues as a consequence of the pandemic on their lives. A high proportion of families and children are socially isolated to a level where their health may be impacted without intervention.

Whilst many carers and families continue to just about cope, more than half of the Directors of Adult Social Services 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 – learning from the positives

Commissioners need to understand what worked well for carers too so that they can be better supported. **Evidence of measures** implemented to mitigate the impacts on carers included the use of technology and the receipt of financial assistance and support for working carers.

Many carers were positive about the support they had received during the pandemic, particularly from local volunteering groups or from carers' networks. 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 link-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.

Digital information and engagement worked well for some carers, as it reduced travel times and meant they could access support as well as health and social care services in their homes. It also enabled some to take part in co-production without needing replacement care.

The vast majority of carers were overwhelmingly positive about being able to receive the COVID-19 vaccine for themselves and the person they care for.

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 to 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](#) in 2020 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 and help reduce these risk factors to people who draw on support and the workforce. This also points to strategic and whole-area commissioning approaches addressing impacts of poverty and inequality. A [framework](#) to assist in reducing the risks to the adult social care workforce has been published.

Risk of dying from COVID-19 is higher for:

- Older people. Age is the biggest factor, with people over 80 being 70 times more likely to die from COVID-19 than people under 40.
- Black, Asian and minority ethnic (BAME) groups (than in 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 than White British people.
- The risk of death from COVID-19 between Jan 24 and Nov 30, 2020, in England was 3.1 times greater for Disabled men and 3.5 times greater for Disabled women with than for non-Disabled men and women (The Lancet).
- People with learning disabilities living in congregate residential settings had a higher risk of death from COVID-19 than people without disabilities. Even in household settings they have an increased risk of COVID-19 death.
- 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 of COVID-19 deaths mentioned diabetes, hypertensive diseases, chronic kidney disease, chronic obstructive pulmonary disease and dementia than all cause death certificates.
- 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 'lived in' to protect residents. Many 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 communities, one fifth are migrant workers and many receive 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](#) 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 the training to use it effectively
- workers already living in poverty and facing multiple risk factors
- high proportions of BAME front-line staff who were at higher risk
- some workers losing their regular work as people stopped their care.

This has resulted in workers leaving the sector resulting in lack of capacity in services and further risks are faced as compulsory vaccinations are required in care settings.

The impact of the pandemic on the [female workforce](#) has demonstrably worsened and more women are reporting an even greater negative impact on their physical and emotional wellbeing. This is linked to the increased hours women report spending on their caring responsibilities (both in and outside of work). The impact of these responsibilities may be greater for women from black, Asian, and minority ethnic backgrounds. There were improvement in some areas, including team-working and increased feelings of camaraderie. 78 per cent of the health and care workforce are female, so it is vital that the impact of the pandemic on women is considered as part of overall recovery plans.

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

Personal assistants

Personal assistants (PAs) play a vital role supporting people using direct payments or funding their own care. Early COVID-19 guidance and responses often failed to include PAs or explain how the guidance should apply. This left some PAs without the advice they needed to provide effective safe support or to understand their rights in relation to isolating or care being cancelled.

Research found that during the early months of COVID-19 (April–June 2020) there was a fluidity of relationships with some family members working more closely with PAs; there were also tensions between PAs and family members, as well as displacement of PAs by family members. There were also PA accounts of the essential role they played supporting people who had little or no family contact or other assistance during the pandemic.

Commissioners need to encourage ongoing contingency planning and support for PAs and for staff responsible for individualised funding to ensure PAs can access advice and support for themselves or trigger back up arrangements as needed. Some areas did this well by providing, for example, parking permits, PPE and infection control training to PAs.

Views of members of SCIE's co-production network

Members of **SCIE's co-production network** have contributed to this and other guides in the series. As well as feeding in more generally, they made particular mention of:

- A concern about rates of anxiety and depression, the impact on mental health services and the long-term impact of this on people's mental and physical health.
- The loneliness and isolation of those who rely on social care and how incredibly hard it can be for people confined to their own homes. "Social Care services can end up prescribing a person's daily routine".
- How not every group was experiencing the same negatives and positives in the pandemic – we must understand the different experiences based on gender, ethnicity, class and different generations. But we need to acknowledge our commonality - it's not them and us.
- People feeling abandoned, the real experience of bereavement, carers being overlooked and the long-term impact of this on people's resilience. This can turn into a sense of anger, frustration and powerlessness. People were left wondering 'Why is it always a fight?'
- It is so important for people to be able to be part of a community, connecting and giving – everyone can contribute in some way; connections are possible, but many are still excluded and could become even lonelier. There is a worry about compassion fatigue but this needs to be turned around, to re-garner people's sense of connectedness and communal effort.

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. Duties to promote rights and equalities must be at the forefront. Plans must be co-produced. 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 ongoing arrangements for the 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 – arrangements that need to be quickly available for potential future outbreaks.
- Ensure Disabled and older people's rights are not downgraded and social distancing or other 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 so develop and implement a digital exclusion plan to close the digital divide. This might include provision of kits, skills and connectivity to address digital exclusion. Consider who this may still miss out and why. This will become the norm so people must not be left behind.
- 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 to the pandemic 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 – ongoing access to information and advice, to food, shopping and medicines. Increasing numbers may need advice on finances too or support to access benefits.
- Those who have been unable to work due to caring need support to retain their jobs or maintain their income 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 - commissioners need to hear directly from them. Contracts must reflect this – not just stipulate the legal minimum living wage. Plan for burn out as the pressures are compounded by workforce shortages.
- Urgent investment is needed in preventative, community and acute mental health services to address the increased level of mental distress. These services need to be co-produced,

be culturally competent, in line with the Social Model of Mental Distress and be appropriate to people's specific needs.

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. The approach must be holistic – thinking whole communities and a co-ordinated approach to removing the barriers people face. There are considerable challenges ahead so longer-term planning must be based on what is important to local people and what will make a difference in each area.

Further reading

- [Caring behind closed doors: Forgotten families in the coronavirus outbreak](#) (Carers UK)
- [Learning disability deaths](#) (CQC)
- [Disparities in the risk and outcomes of COVID-19](#) (PHE report)
- [Webinars](#) (Be Human)
- [Locked Down and Abandoned](#) (Inclusion London)
- [Abandoned, forgotten and ignored](#) (Inclusion London)

Support from SCIE

SCIE's [COVID-19 hub](#) 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.



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