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**COVID-19 Public Inquiry:**

**Research Report for Portfolio 3**

**The Provision of Health and Social Care Services**

**Adult Social Care**

1 March 2024, Final Version

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# 1. Background to This Report

This report was commissioned by the Scottish COVID-19 Inquiry as academic research. The focus is on item (h) from the COVID-19 Inquiry’s Terms of Reference, namely: ‘the provision of healthcare services and social care support, including the management and support of staff and the recognition, involvement and support of unpaid carers.’

This research focuses specifically on the provision of adult social care support, excluding care homes, and covering the period from 1 January 2020 to 31 December 2022.

The search strategy is provided in Annex A and a full list of the sources and references is in Annex B.

The report was submitted in draft to the Inquiry on 5th November 2023.

**Author Note**

We have no known conflict of interest to disclose. Correspondence concerning this report should be addressed to Professor Colin McKay, Edinburgh Napier University, School of Health and Social Care, Sighthill Campus, 9 Sighthill Court, Edinburgh, EH11 4BN. Email: [C.McKay@napier.ac.uk](mailto:C.McKay@napier.ac.uk)

# 2. Executive Summary

This report considers the strategic response of the Scottish Government in relation to the provision of adult social care support, excluding residential care.

Social care is largely the responsibility of local authorities, with many of these responsibilities now delegated to integration authorities. It includes home care, day services, respite care and support for carers, provision of aids and adaptations, and adult support and protection. We also consider the impact of the pandemic on hospices and support for homeless people and people affected by substance misuse.

A range of human rights are engaged in the provision of social care, including ECHR rights to life, liberty, freedom from inhuman or degrading treatment, respect for personal autonomy and integrity, and international human rights to the highest attainable standards of physical and mental health, and to equality and non-discrimination. For disabled people, these rights are further developed by the UN Convention on the Rights of Persons with Disabilities, including rights to community living, to supports and accommodations to ensure equal enjoyment of rights, and to be protected during emergencies.

We found little evidence that human rights concerns directly affected how decisions were made. Organisations supporting recipients of social care and human rights organisations have argued that the human rights of service users and carers were significantly affected.

The legislation governing social care establishes a range of duties on local authorities. Although there is a wide degree of discretion, these duties are substantive, and may not have been fully observed. Emergency legislation waived some but not all of these duties, and appears to have had a limited impact on the decisions made by public bodies.

Guidance was issued about social care services and regularly updated – sometimes so regularly as to cause significant confusion amongst those charged with implementing the guidance.

Arguably, the problems experienced in social care may be less about policy than implementation. The idea of an ‘implementation gap’ has been raised in a range of social policy areas in recent years. An example of this is the scepticism from family carers about the value of statutory carers assessments.

Most of the key decisions affecting social care users and carers were not made by Scottish Government but by local authorities/integration authorities. This reflects the historic nature of social care provision, but makes it harder to establish the basis on which such decisions were taken. It may also have meant that social care was particularly vulnerable in a crisis where decisions were largely taken at a national level.

We found little evidence that service users individually or collectively had much influence over these decisions.

Particularly in the context of plans for a National Care Service, the Inquiry may wish to interrogate what difference a more centralised and directive approach by the Scottish Government could have made to the provision of social care support.

Social care was already experiencing significant challenges because of resource constraints and demographic pressures prior to the pandemic, and this may have affected its resilience. There are also data gaps about the level of need for social care in the community, which makes it difficult to fully evaluate the impact of the pandemic.

At the start of the pandemic, the Scottish Government made commitments to maintaining social care services and support, but these turned out to be undeliverable, despite additional resources being committed. Later, as restrictions eased, the Government encouraged local authorities/integration authorities to re-open services, but this also took a considerable time to take effect. Services are still suffering from the impact of the pandemic, and levels of provision of some services appear not to have returned to pre-pandemic levels.

There were very significant reductions in the provision of social care services during the pandemic. A survey by the Scottish Parliament in November 2020 found 54% of recipients of home care saw their care either reduced or stopped completely.[[1]](#footnote-2) PHS data showed that nearly 30,000 fewer people received care at home in the last quarter of 2020/21 compared with 2019/20. Many day services were suspended, due to a combination of staff illness/isolation, lockdown restrictions, and pressures on services. The loss of day services had a particularly severe impact on people with learning disabilities.

At the same time, the number of family carers increased substantially – an estimated rise of 392,000 on top of the existing 729,000. This was partly driven by people being unable to access care support or being unwilling to do so because of fears of infection.

The harms experienced by social care users included:

* Isolation, exclusion
* A loss of independence
* A loss of continuity of care
* Harm to mental and physical health
* Increased dependence on family and unpaid carers.

Carers experienced:

* Isolation, loneliness and exhaustion
* A lack of respite
* Poorer mental and physical health
* Reduced ability to continue caring
* Financial hardship.

Carers are more likely than the general population to be women and/or themselves disabled, raising equality concerns.

The Government provided some additional financial support to local authorities and directly to the social care workforce, but there are concerns that they were not given the priority afforded to the NHS. There were initial problems accessing PPE and they were later to be routinely tested, with some evidence of higher infection than the general population. Social workers faced ethical and professional dilemmas with limited support, and care staff experienced anxiety and poor morale. The pandemic contributed to significant and ongoing issues of recruitment and retention of staff.

The pandemic encouraged the rapid expansion of remote or telecare, with mixed results. It allowed professionals to maintain contact with service users and in some cases led to efficiency gains, but was inaccessible to many people, including deaf people, people with learning disabilities, elderly people and the digitally excluded.

Hospices shifted to increased community provision reflecting the increasing number of people dying at home. Social distancing restrictions caused profound distress to people at the end of life. The lack of integration with the NHS may have contributed to difficulties accessing PPE and a lack of tailored guidance.

Homeless people and people with addictions found it difficult to access information and comply with lockdown restrictions. Many lost supports and income. Positive interventions included the virtual elimination of rough sleeping and emergency legislation providing protection from eviction.

# 3. Introduction to the Report

## 3.1 Report Purpose and Approach

This report seeks to introduce the key areas of recommended investigation for the Scottish COVID-19 Inquiry in relation to the provision of adult social care support, including the management and support of staff and the recognition, involvement, and support of unpaid carers. It identifies key events, the presence or absence of legal frameworks, the main bodies or persons involved, relevant research papers and publications, and areas for further investigation.

Our research has been conducted using a human rights lens. Whether in receipt of social care support or involved in its delivery, we are all entitled to enjoy human rights on an equal basis in all situations. A state’s commitment to fulfilling its international human rights obligations is particularly tested during times of emergency such as the COVID-19 pandemic. This applies to the full range of a person’s civil, political, economic, social and cultural rights. The rights to life and to be free from inhuman or degrading treatment cannot be limited under any circumstances. However, international human rights treaties allow states to deny the exercise of other rights during national emergencies provided this is lawful, proportionate and necessary only to the extent that the emergency requires this.

These rights requirements apply as much to the provision of health and social care as elsewhere. Our investigation concentrates on rights identified in the European Convention on Human Rights (ECHR), the UN Convention on the Rights of Persons with Disabilities (CRPD) and the International Covenant on Economic Social and Cultural Rights (ICESCR). It should be noted that none of these UN treaties allow for the presence of disability to justify the denial of rights. In particular, the CRPD, which we understand will be incorporated into Scotland’s legal framework in due course, emphasises that persons with physical and mental disabilities are entitled to enjoy the full range of rights on an equal basis with others, that support must be provided where necessary to ensure this, and that disability must never justify the denial of human rights.

In this report we start by explaining key elements of a human rights-based approach to rights during an emergency, then the impact on these in relation to adult social work and social care and the human rights framework in Scotland. The report then summarises the core public sector duties in relation to social care provision and goes on to consider the impact of the pandemic on:

1. The recipients of social care
2. Unpaid carers
3. Social care staff.

Many of the sources of evidence that were available to inform this report have a UK-wide focus. Where this was the case, we have distilled the Scotland-relevant information from these UK-wide reports to ensure relevance to the Scottish COVID-19 Inquiry.

## 3.2 Key Events Affecting the Provision of Social Care Provision

To inform each chapter of this report and to provide an overarching context within which the review is based, an overarching timeline of key events relevant to the provision of social care services during the pandemic has been created, as presented in section 3.2.1. Each of the subsequent chapters discusses specific relevant aspects of these key events, documents and related literature in depth. In some cases, dates within the timeline are not available, as these were not discoverable to the research team.

## 3.2.1 Timeline of Key Events

* 1 March 2020: First confirmed case of COVID-19 in Scotland[[2]](#footnote-3).
* 11 March 2020: WHO declared COVID-19 to be a pandemic[[3]](#footnote-4).
* 12 March 2020: Initial Government guidance advised the cancellation of all events due to have 500+ attendees and advised the public to expect mild illness lasting 4-5 days with no need to contact NHS services unless symptoms worsened. An isolation period of 7 days was advised for symptomatic individuals[[4]](#footnote-5).
* 12 March 2020: Guidance issued for those working in social or community care advising individuals who had been in contact with a confirmed case to isolate, and outlining changes to daily practice to minimise risk of infection and transmission[[5]](#footnote-6).
* 17 March 2020: NHS Scotland placed on an emergency footing for a minimum of three months under section 1 and section 78 of the National Health Service (Scotland) Act 1978 by Health Secretary, Jeane Freeman, with the intention to double ICU capacity, providing training and increasing oxygen supplies[[6]](#footnote-7).

The Care Inspectorate, the national regulator for care services in Scotland, suspended routine and on-site inspections[[7]](#footnote-8).

* 23 March 2020: UK Government issued ‘Staying at home and away from others (social distancing)’ guidance[[8]](#footnote-9).
* 23 March 2020: UK Prime Minister Boris Johnson, and Scotland First Minister, Nicola Sturgeon outlined restrictions to be placed on public life, which constituted a ‘lockdown’ state, and the consequences of failure to comply[[9]](#footnote-10) [[10]](#footnote-11).
* 24 March 2020: Scottish Parliament SPICe-spotlight reported this as the first day of Scotland entering lockdown[[11]](#footnote-12).
* 26 March 2020: Scottish Government website reported this as the first day of national lockdown[[12]](#footnote-13).
* 26 March 2020: Letter issued from Chief Medical Officer, Chief Nursing Officer and Chief Social Work Adviser which included updated guidance for social or community care, and linked to guidance for care at home, housing support and sheltered housing[[13]](#footnote-14)
* 30 March 2020: Open letter from the Scottish Association of Social Work (SASW) to Jeane Freeman MSP, Cabinet Secretary for Health and Sport, and Maree Todd MSP, Minister for Children and Young People issued, highlighting human rights concerns during the pandemic[[14]](#footnote-15)
* 30 March 2020, Joint Letter from Scottish Government and COSLA on ‘Scotland’s Social Care Response’[[15]](#footnote-16)
* 31 March 2020: Scottish Government issued information for homelessness organisations[[16]](#footnote-17)
* 3 April 2020: Disclosure Scotland suspended all fees for key workers and volunteers who are being drafted in to work during the pandemic. This was a temporary measure, initially planned for six weeks then was due to be reviewed and extended if required[[17]](#footnote-18).
* 5 April 2020: Provisions of Coronavirus Act 2020 (s16) removing some requirements to assess social care needs came into effect[[18]](#footnote-19)
* 8 April 2020: Care Inspectorate delayed the collection of continuation of registration fees due by care services until July 2020[[19]](#footnote-20).
* 9 April 2020: Joint statement issued by Scottish Government and COSLA regarding PPE use in social care. Associated guidance is issued[[20]](#footnote-21)
* 10 April 2020: Care Inspectorate introduced staff notifications system to monitor staffing levels in care services. Monitoring took place seven days per week and categorised services as green, amber or red depending on staff absences and available skills mix[[21]](#footnote-22).
* 12 April 2020: Pay rise confirmed at 3.3% for social care staff, backdated to 1 April 2020[[22]](#footnote-23)
* 17 April 2020: Care Inspectorate notifications system updated to include outbreak notifications, staff absences and staff death notices[[23]](#footnote-24).
* 20 April 2020: Scottish Government released advice for unpaid carers[[24]](#footnote-25)
* 23 April 2020: ‘COVID19: A Framework for Decision-Making’ published by Scottish Government which outlined information on lockdown and factors which must be considered in moving towards the easing of restrictions, and contains the statement ‘we must continue to provide additional support for those who need it and seek to advance equality and protect human rights in everything we do’[[25]](#footnote-26)
* 24 April 2020: Scottish parliament holds first meeting of the COVID-19 Committee, established for the duration of the emergency pandemic legislation[[26]](#footnote-27)
* 26 April 2020: Scottish Government confirmed over 22,000 health and social care workers had rejoined the workforce to support the NHS pandemic response[[27]](#footnote-28)
* 27 April 2020: Scottish Government announced Local Hubs would distribute PPE to social care services in places where supply routes have been unsuccessful. The provision of PPE was extended to cover all social care providers, unpaid carers and personal assistants.[[28]](#footnote-29)
* 27 April 2020: PVG guidance updated to remove the requirement for three-yearly updating of checks for continued PVG scheme membership[[29]](#footnote-30).
* 29 April 2020 Cabinet Secretary for Health and Sport, Jeane Freeman, confirmed that all families of frontline NHS staff who die as a result of coronavirus (COVID-19) will receive financial support[[30]](#footnote-31).
* 29 April 2020: Guidance issued for unpaid carers, social care providers and personal assistants on how to access PPE [[31]](#footnote-32) [[32]](#footnote-33).
* May 2020: Scottish Government issued initial guidance for self-directed support during the pandemic[[33]](#footnote-34).
* 3 May 2020: Scottish Government announced new measures to support those affected by drug use during the pandemic[[34]](#footnote-35)
* 6 May 2020: Scottish Government proposed an extra £19.2 million investment in the Carer’s Allowance Supplement to enable an additional one-off payment in June 2020. The Supplement would enable around 83,000 eligible carers to receive an extra £230.10[[35]](#footnote-36).
* 11 May 2020: National Wellbeing Hub is launched to look after the emotional and psychological wellbeing of Scotland’s health and social care workers[[36]](#footnote-37).
* 12 May 2020: Scottish Government confirmed an initial £50 million to help the social care sector deal with the financial implications of the pandemic.[[37]](#footnote-38)
* 12 May 2020: Letter issued from the Cabinet Secretary for Health and Sport, Jeane Freeman, to Carers Scotland regarding the Scottish Government’s main actions to improve support and advice for unpaid carers during the COVID19 pandemic[[38]](#footnote-39).
* 21 May 2020: Scottish Government published COVID-19 Route map for Scotland’s progress through and out of the pandemic[[39]](#footnote-40).
* 24 May 2020: Scottish Government announced extra financial support for social care workers in Scotland during the Coronavirus emergency.[[40]](#footnote-41) These included plans for death in service cover and enhancements to statutory sick pay[[41]](#footnote-42).
* 28 May 2020: First Minister Nicola Sturgeon announced move to Phase 1 of the route map out of lockdown. Changes, largely centred on the resumption of outdoor work and social activities and come into force from 29 May[[42]](#footnote-43).
* 29 May 2020: Move to Phase 1 of the route map out of lockdown[[43]](#footnote-44).
* 31 May 2020: Scottish Government published ‘Re-mobilise, Recover, Redesign, The Framework for NHS Scotland’ which set out how Health Boards would follow national and local clinical advice to prioritise the resumption of services[[44]](#footnote-45).
* 2 June 2020: Scottish Government announced an additional one-off Carer’s Allowance Supplement payment of at least £460.20 to be paid from 26 June[[45]](#footnote-46).
* 18 June 2020: First Minister Nicola Sturgeon announced the move to Phase 2 of the Route map out of lockdown, with changes to come into effect from 19 June[[46]](#footnote-47).
* 19 June 2020: Phase 2 of the route map out of lockdown began. Changes were focused on re-opening and scaling up, as well as updated advice for those shielding. Details included an intention to work with COSLA and partners to ‘support and (where needed) review social care and care home services’[[47]](#footnote-48).
* 22 June 2020: Care Inspectorate ended the staffing shortage notifications and no longer required care services to submit notice of staffing issues under the red, amber, green system[[48]](#footnote-49). COVID-19 outbreak notifications continue[[49]](#footnote-50).
* 23 June 2020: Announcement that routine testing of health and social care workforce would be extended as services continue to resume[[50]](#footnote-51).
* 24 June 2020: Scottish government published an impact assessment on the groups disproportionately affected by the pandemic[[51]](#footnote-52).
* 24 June 2020: Scottish Government published guidance for social care workers and employers regarding the Social Care Staff Support Fund which aimed to ensure social care staff did not experience financial hardship if they became unwell or had to isolate due to COVID-19[[52]](#footnote-53).
* 25 June 2020: Social Care Staff Support Fund went live[[53]](#footnote-54).
* 29 June 2020: Scottish Government established the Mobilisation Recovery Group, led by the Health Secretary Jeane Freeman, which was tasked with balancing the safe resumption of services which were initially paused due to the pandemic[[54]](#footnote-55).
* July 2020: Scottish Government issued further guidance for self-directed support, updated to take into account the ongoing changes of the pandemic[[55]](#footnote-56).
* 2 July 2020: Scottish Government implemented the first localised delay in the relaxation of lockdown measures due to a spike in cases in the Dumfries & Galloway region. Updates and anticipated dates were published for the remainder of Phase 2 of the route map out of lockdown[[56]](#footnote-57).
* 9 July 2020: First Minister Nicola Sturgeon announced move to Phase 3 of the route map out of lockdown. Changes due from 10 July included further relaxing of restrictions on indoor and outdoor activities[[57]](#footnote-58).
* 10 July 2020: Move to Phase 3 of the route map out of lockdown.
* 17 July 2020: Reported delays in the implementation of the Social Care Staff Support Fund[[58]](#footnote-59)
* 17 July 2020: Letter issued from the Director for Mental Health and Social Care regarding adapted day services for adults confirming that the Scottish Government is ‘in agreement’ that adapted day services should remain open or re-open to provide essential services to those in critical need. The letter confirms that the Scottish Government ‘will shortly be writing about next steps in the wider reopening of day care services, including on timescales for development of more comprehensive guidance on day services’[[59]](#footnote-60).
* 20 July 2020: Scottish Government announced a national helpline which would provide 24-hour access to mental health support for health and social care staff[[60]](#footnote-61).
* 30 July 2020: Social care worker death in service payment announced.[[61]](#footnote-62)
* 30 July 2020: Guidance on self-isolation extended from 7 days to 10 days[[62]](#footnote-63) [[63]](#footnote-64).
* 30 July 2020: During Parliamentary questions, Cabinet Secretary for Health and Sport Jeane Freeman confirmed that she, along with COSLA, had written to local authorities and Joint Boards (in April 2020) to emphasise the need for additional carer support in local pandemic response planning. This was in addition to an additional budget of over £11million. Half a million pounds had been ringfenced to provide local carer services the required remote emotional support to carers. Additional funds had been made available for young carers, and eligibility criteria for the Short Breaks Fund had been eased to make more carers eligible to apply. The Government were also working with the National Wellbeing Hub and provided additional budget (£3.8 million) to increase the capacity of NHS24 services whilst expanding the Breathing Space online support capacity.[[64]](#footnote-65)
* 2 August 2020: Scottish Government announced that homeless people and others affected by the pandemic would receive additional support from the Scottish Government’s emergency funding for communities[[65]](#footnote-66).
* 3 August 2020: Scottish Government announced up to £50 million additional funding for the social care sector which would be allocated to Integration Joint Boards to ensure sustainability of the sector throughout the pandemic[[66]](#footnote-67).

Letter issued from the Cabinet Secretary for Health and Sport Jeane Freeman, and the Minister for Children and Young People Maree Todd, to Health and Social Care Partnerships about the reopening of respite and day care services. This provided an update on national actions to support local re-establishment of respite and day care services and set out next steps in the wider reopening of adult day centres and residential respite for both children and adults[[67]](#footnote-68). In advance of further guidance to be issued, it said that ‘In the interim, all registered adult day centre services that wish to reopen can do so, subject to agreement of their approach by the local Health Protection teams and the Care Inspectorate, prior to reopening’.

* 5 August 2020: Local restrictions introduced in Aberdeen, effective immediately.
* 17 August 2020: Scottish Government issued advice for unpaid carers - for those who provide unpaid care to friends or family[[68]](#footnote-69).
* 20 August 2020: Scottish Government announced that Scotland was to remain in Phase 3 of the route map due to ongoing risk. Updated route map is published with anticipated dates for further changes to guidance and regulations[[69]](#footnote-70).
* 31 August 2020: Guidance published regarding the safe re-opening of adult social care building-based day services[[70]](#footnote-71).
* September 2020: The Care Inspectorate published ‘Delivering care at home and housing support services during the COVID-19 pandemic,’ an inquiry into decision-making and partnership working.[[71]](#footnote-72)
* 1 September 2020: restrictions on indoor gatherings and hospital/care home visiting effective immediately in East Renfrewshire, Glasgow and West Dunbartonshire[[72]](#footnote-73).
* 8 September 2020: The Care Inspectorate and the Scottish Social Services Council (SSSC) revert to previous position for pre-employment checks, meaning that employees were required to have satisfactory PVG checks and references before commencing employment. This removed the flexibility introduced earlier in the pandemic to prevent and manage backlogs and followed confirmation from care services that there have not been significant staffing and recruitment problems[[73]](#footnote-74).
* 10 September 2020: Updated route map which limits indoor gatherings published, as Scotland remains in Phase 3[[74]](#footnote-75). West of Scotland restrictions on meeting indoors were extended to include Renfrewshire and East Dunbartonshire[[75]](#footnote-76).
* 11 September 2020: Scottish Government announced local restrictions extended to include North and South Lanarkshire[[76]](#footnote-77).
* 22 September 2020: Scottish Government announced further restrictions on household visiting and a curfew of 10pm for businesses. These became active from 23 September[[77]](#footnote-78).
* 23 September 2020: Letter issued from the Cabinet Secretary for Health and Sport Jeane Freeman, and the Minister for Children and Young People Maree Todd, provided an update on the remobilisation of respite and day centres for adults and children which confirmed that stand-alone residential respite services should operate in line with Health Protection Scotland guidance for Social, Community and Residential Care settings[[78]](#footnote-79).
* 13 October 2020: Letter issued from Cabinet Secretary for Health and Sport, Jeane Freeman regarding day services for adults. Guidance on re-opening had been published on 31 August 2020 and this letter reiterates the importance of appropriate levels of support, highlights that decisions around the re-opening of services are to be made locally and emphasising the importance of communication with all stakeholders. The letter emphasises the need to consider alternative options for anyone unable to access the required support from day services[[79]](#footnote-80).
* 13 October 2020: Applications to the Self-isolation Support Grant open for low-income workers who would lose earnings as a result of testing positive or being identified as a close contact of a positive case[[80]](#footnote-81).
* 23 October 2020: Scottish Government published the five-level Strategic Framework which indicated the levels of community protection required based on different transmission levels of the virus. These were planned to come into effect from 2 November[[81]](#footnote-82).
* 28 October 2020: Scottish Government announced the NHS Winter Preparedness Plan to support health and care services over the winter, including an additional £37 million funding, and with a commitment to publish an Adult Social Care Winter plan in November[[82]](#footnote-83).
* November 2020: Scottish Parliament Health and Sport Committee published the results of a survey on ‘How has COVID-19 impacted on care and support at home in Scotland’ as part of its wider inquiry into the future of Social Care in Scotland[[83]](#footnote-84).
* 3 November 2020: Scottish Government published the Adult Social Care Winter Preparedness Plan which includes an additional £112 million investment to support the sector through winter[[84]](#footnote-85).
* 25 November 2020: Cabinet Secretary for Health and Sport Jeane Freeman announced plans to expand testing in hospital patients, health and social care staff and communities in area at protection Level 4[[85]](#footnote-86).
* 30 November 2020: Scottish Government announced a one-off £500 payment for health and social care staff[[86]](#footnote-87).
* 30 November 2020: Emergency changes to requirements to assess social care needs in s16 of the Coronavirus Act 2020 were suspended[[87]](#footnote-88).
* 10 December 2020: Letter issued from the Cabinet Secretary for Health and Sport, Jeane Freeman, recognising the contribution made by European Union (EU) and European Economic Area (EEA) citizens working in social care, and instructing those who wish to remain beyond 31 December 2020 to apply for the UK Government Settlement Scheme[[88]](#footnote-89)
* 22 December 2020: Scottish Government published ‘Dementia and COVID-19 National Action Plan to Continue to Support Recovery for People with Dementia and their Carers’.[[89]](#footnote-90)
* 4 January 2021: Scottish Government announced that mainland Scotland would go into lockdown from 5 January with a legal requirement not to leave home unless for essential purposes[[90]](#footnote-91).
* 5 January 2021: Mainland Scotland entered lockdown[[91]](#footnote-92).
* 15 January 2021: Letter issued from the Cabinet Secretary for Health and Sport Jeane Freeman to the health and social care sector to clarify that essential day service support could continue throughout the then current lockdown, and adult day centres can continue to operate ‘where they are essential for people’s wellbeing - i.e., where participants’ or carers’ health (including their mental health) and wellbeing would be significantly impacted by non-attendance’[[92]](#footnote-93).
* 22 January 2021: Additional funding of £500,000 announced to provide practical measures to support the wellbeing of health and social care staff working to tackle the Coronavirus (COVID-19) pandemic[[93]](#footnote-94).
* 27 January 2021: Guidance on access to PPE for personal assistants was updated[[94]](#footnote-95).
* 2 February 2021: Scottish Government extended criteria for the Self-Isolation Support Grant to prevent financial hardship for individuals who had to isolate due to illness or caring for someone who is isolating[[95]](#footnote-96).
* 3 February 2021: Publication of the Adult Social Care review report commissioned by Scottish Ministers (the Feeley Report). This report provided a review of issues within adult social care before and during the COVID-19 pandemic and recommended radical reforms, including a new National Care Service and that ‘Human rights, equity and equality must be placed at the very heart of social care and be mainstreamed and embedded’[[96]](#footnote-97).
* 22 February 2021: Scottish Government announced that people with underlying health conditions and unpaid carers had started to receive vaccinations[[97]](#footnote-98).

Scottish Government launched the Equality and Human Rights fund - £7 million to promote equality and tackle discrimination over the next three years[[98]](#footnote-99).

* 23 February 2021: Scottish Government published the updated Strategic Framework to prioritise the order and conditions for re-opening and the lifting of restrictions[[99]](#footnote-100).
* 26 February 2021: Scottish Government launched the Workforce Specialist Service, which offered confidential mental health assessment and treatment to health and social care professionals.[[100]](#footnote-101)
* 15 March 2021: Scottish Government launched the coronavirus online self-registration service for unpaid carers[[101]](#footnote-102).
* 16 March 2021: Scottish Government published a timetable for the easing of restrictions, including ‘Stay at Home’ regulations planned to be lifted from 2 April with messaging changing to ‘Stay Local’[[102]](#footnote-103).
* 20 April 2021: Scottish Government announce all parts of the country will move to Level 3 from 26 April[[103]](#footnote-104).
* 14 May 2021: Scottish Government announced the significant easing of lockdown restrictions with most of mainland Scotland moving to Level 2 from 17 May, and most islands moving to Level 1 (Glasgow and Moray remained at Level 3 due to high rates of cases)[[104]](#footnote-105).
* 26 May 2021: First Minister Nicola Sturgeon announced priorities for the Scottish Government as part of their first 100 days plan which included vaccine targets, convening a cross-party a steering group on COVID-19 recovery, and publishing an NHS recovery plan[[105]](#footnote-106).
* 7 June 2021: Letter from Kevin Stewart, Minister for Mental Wellbeing and Social Care emphasising the urgency of building-based day services re-opening[[106]](#footnote-107).
* 22 June 2021: First Minister announced an indicative date for the whole of Scotland to move to Level 0 as 19 July, with 9 August as the intended date for the lifting of all major COVID-19 restrictions[[107]](#footnote-108).
* 24 June 2021: the Scottish Parliament passed the Coronavirus (Extension and Expiry) (Scotland) Act 2021 which extended the application of the Coronavirus (Scotland) Act 2020 and the Coronavirus (No 2) (Scotland) Act 2020, both due to expire 30 Sept 2021. The Act also permitted the extension of secondary legislation, and denoted the parts of the Acts which would not be extended[[108]](#footnote-109).
* 27 June 2021: Scottish Government announced £8 million funding package for health and social care workforce wellbeing in both primary and social care services. This included the ongoing development of the National Wellbeing Hub, National Wellbeing Helpline, psychological interventions, Coaching for Wellbeing, digital apps, and the Workforce Specialist Service for regulated staff. Training for staff to support teach other as teams was planned and practical support like additional rest areas were provided[[109]](#footnote-110).
* 30 June: Scottish Government announce social care Personal Assistants will receive £500 payment[[110]](#footnote-111).
* 2 July 2021: Scottish Government announced additional funding of £380 million to support Health Boards with the costs of the pandemic[[111]](#footnote-112).
* 13 July 2021: First Minister announces all of Scotland will move to Level 0 on 19 July[[112]](#footnote-113).
* 19 July 2021: All of Scotland moved to protection level 0.[[113]](#footnote-114)
* 23 July 2021: Scottish Government announced changes to self-isolation rules for close contacts of COVID-19 cases. These changes provided exemptions for essential staff in critical roles, allowing them to return to work sooner if fully vaccinated; if they return a negative result on a polymerase chain reaction (PCR) test, and continue daily lateral flow testing[[114]](#footnote-115).
* 29 July 2021: Scottish Government announced £1 million of funding for nine projects supporting carers and disabled people to tackle loneliness and isolation due to the pandemic[[115]](#footnote-116).
* 3 August 2021: First Minister Nicola Sturgeon announced Scotland was to move beyond Level 0 from 9 August 2021. The legal requirement for physical distancing and limits on gatherings would be removed, but face masks and the recording of details for Test and Protect would remain[[116]](#footnote-117).
* 7 August 2021: Scottish government announced that physical distancing was to remain in place in healthcare settings beyond 9 August 2021[[117]](#footnote-118).
* 9 August 2021: Revised policy document released which removed the need for health and social care staff to isolate if they were found to be a close contact of a confirmed case of COVID-19, if they were double vaccinated, show no symptoms and return a negative PCR test[[118]](#footnote-119).
* 17 August 2021: Scottish Government launched its consultation on Scotland’s recovery which would consider whether to maintain temporary provisions made under Scotland and UK coronavirus legislation. These were due to expire in March 2022[[119]](#footnote-120).
* 25 August 2021: Scottish Government published the NHS Recovery plan which committed more than £1 billion and set out key actions for the next five years to address backlogs in healthcare and increase capacity by at least 10%[[120]](#footnote-121).
* 5 October 2021: Scottish Government announced £300 million NHS and Care Winter package to help increase capacity in hospital and community care through the winter months[[121]](#footnote-122).

Scottish Government published the Covid Recovery Strategy which set out the actions it would take to address systemic inequalities made worse by COVID-19[[122]](#footnote-123).

* 7 October 2021: Scottish Government announced £1.6 million funding to help local authorities support those affected by psychological trauma and adversity[[123]](#footnote-124).
* 15 October 2021: Scottish Government launched the £15 million Communities Mental Health and Wellbeing Fund to support adult community-based initiatives across Scotland[[124]](#footnote-125).
* 22 Oct 2021: Scottish Government published the adult social care Winter Preparedness Plan 2021-22 which set out the measures to be applied across the adult social care sector to meet the challenges of the winter season[[125]](#footnote-126).
* 2 November 2021: Scottish Government announced an additional £10 million winter funding to support the NHS, which included providing more specialists, social care workers and allied health professionals[[126]](#footnote-127).
* 16 November 2021: Scottish Government published an update to Scotland’s Strategic Framework which set out the most recent approach to managing the pandemic[[127]](#footnote-128).
* 16 November 2021: Guidance regarding the access to PPE for unpaid carers and social care providers was updated[[128]](#footnote-129).
* 16 November 2021: The Coronavirus (Discretionary Compensation for Self-Isolation) (Scotland) Bill was introduced to Parliament. Before COVID-19, health boards were required to compensate those who were asked to isolate due to an infectious disease as required by the Public Health etc. (Scotland) Act 2008. The Coronavirus Act 2020 changed this to let health boards decide whether those required to isolate received compensation, a provision which was due to expire in March 2022. This Bill would change the law so that heath boards would still have the option to compensate but would not be obliged to do so until 31 October 2022. The Bill would also allow the Scottish Government to reduce or extend this period if required[[129]](#footnote-130).
* 10 December 2021: Scottish Government letter to care services highlighting measures to minimise risk of COVID-19, including the Omicron variant, and confirming that adult based day services are not bound by guidance for household mixing[[130]](#footnote-131).
* 12 December 2021: Scottish Government announced financial support for adult care providers who may incur additional costs when employees were vaccinated during working time. This funding aimed to prevent staff from losing earnings or being forced to take annual leave[[131]](#footnote-132).
* 29 December 2021: Scottish Government announced priority PCR testing and self-isolation exemptions for essential workers[[132]](#footnote-133).
* 5 January 2022: Scottish Government announced changes to self-isolation rules in line with updated public health advice[[133]](#footnote-134).
* 2 February 2022: Scottish Government announced a new £1 million fund to improve staff wellbeing across the Adult Social Work and Social Care sectors. The fund was managed by Inspiring Scotland and opened for applications on 1 February 2022 and closed on 29 July 2022[[134]](#footnote-135).
* 3 February 2022: Scottish Government announced six-month extension to some temporary provisions made under UK coronavirus legislation including powers to make public health protection regulations[[135]](#footnote-136).
* 9 February 2022: Scottish Government announced an extension to the expiry date for statutory COVID-19 restrictions and requirements from 28 February to 24 September 2022[[136]](#footnote-137).
* 9 February 2022: The Coronavirus (Discretionary Compensation for Self-Isolation) (Scotland) Bill is unanimously passed in the Scottish Parliament[[137]](#footnote-138).
* 11 February 2022: Scottish Government further updated guidance for self-directed support to include the Self-Direct Support Framework of Standards and the ongoing changes of the pandemic[[138]](#footnote-139).
* 22 February 2022: A further update to Scotland’s Strategic Framework is published[[139]](#footnote-140).
* 11 March 2022: Scottish Government issued further updates to the self-directed support guidance[[140]](#footnote-141).
* 7 September 2022: Scottish Government guidance for social care staff and visitors to wear facemasks at all times is removed in line with latest clinical advice[[141]](#footnote-142).
* 25 September 2022: Scottish Government announced that asymptomatic testing will be paused by 28 September meaning health and social care workers will no longer be required to test for COVID-19 every week[[142]](#footnote-143).
* 19 October 2022: Letter from Humza Yousef, Cabinet Secretary for Health and Social Care, to local authorities and health and social care partnerships, outlining findings from the day services and respite care audit and the next steps for reopening services[[143]](#footnote-144).
* 5 May 2023: The World Health Organisation confirmed COVID-19 to no longer be a public health emergency of international concern[[144]](#footnote-145).
* 9 May 2023: Scottish Government confirmed that the COVID-19 Extended use of facemasks and face coverings guidance would be withdrawn from 16 May 2023 across health and social care settings[[145]](#footnote-146).
* 12 June 2023: Scottish Government published the ‘Self-directed support: improvement plan 2023 to 2027’ recognising the need for a whole-system approach to improving the delivery of Self-Directed Support (SDS) with partners across the statutory, third and independent sectors[[146]](#footnote-147).
* 15 June 2023: Letter from Maree Todd, Minister for Social Care, Mental Wellbeing and Sport to local authorities and health and social care partnerships with the findings of the follow-up day services and respite services survey[[147]](#footnote-148).

# **4. Key Human Rights Obligations Relating to Social Care in an Emergency**

## 4.1 Key Messages

* A range of treaties set out fundamental human rights, which should be delivered without discrimination, including to people with disabilities.
* These include protections for rights relating to life, liberty, dignity, autonomy, as well as to positive rights including to the highest attainable standard of physical and mental health.
* There is a positive obligation to ensure the protection and safety of persons with disabilities in emergency situations.

Restrictions to rights in emergencies must be proportionate, lawful and non-discriminatory.

* People with protected characteristics (e.g. age, sex, gender identity, disability, ethnicity or religious and cultural background) are entitled to enjoy rights to the same extent (including limitation) as others. The comparator for equal enjoyment of rights should be everyone else and not those sharing the same characteristic.
* Article 4(3) CRPD requires ‘In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.’ The question therefore arises as to the extent to which this obligation was fulfilled when making decisions about social care provision.

Various emergency legislative modifications were made, and guidance was issued, to address potential staffing and other resourcing challenges resulting from the pandemic and to ease processes to allow, where necessary, for individuals' health and social care needs to be properly met. These reduced certain safeguards but there remained an obligation on health and social care services to adhere to international human rights standards.

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## 4.2 Rights Engaged During Pandemic in Health and Social Care

Rights that were particularly engaged during the pandemic in health and social care settings were those to life[[148]](#footnote-149), to liberty[[149]](#footnote-150),to respect for private and family life/autonomy/to exercise legal capacity[[150]](#footnote-151), to freedom from inhuman or degrading treatment (dignity)[[151]](#footnote-152), to personal physical and mental integrity[[152]](#footnote-153), to a fair hearing/access to justice[[153]](#footnote-154), and to the highest attainable standard of physical and mental health[[154]](#footnote-155) and community living[[155]](#footnote-156). All of these rights must be enjoyed without discrimination based on a particular characteristic including but not limited to physical or mental disability[[156]](#footnote-157).

It is important to appreciate that the social and human rights model of disability promoted by the CRPD does not regard a person's disability as being disabling, but rather the attitudes and actions towards a person of the state and society as disabling. It is therefore imperative that any state that has ratified, and is serious about implementing, the CRPD actively prevents people effectively being disabled by such actions and attitudes. In considering human rights it is also important to consider *intersectionality –* the different and compound disadvantage experienced by a person who is subject to more than one potential form of discrimination (e.g., a member of an ethnic minority or a person with a particular gender identity who also has a disability).

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### 4.2.1 Human Rights Framework in Scotland[[157]](#footnote-158)

The ECHR is embedded in the UK (including Scottish) legal framework by the Human Rights Act 1998, requiring public authorities to give effect to its rights and allowing for such rights to be enforced through national courts and tribunals[[158]](#footnote-159). The ECHR purchase is even greater in Scotland where non-compliant devolved legislation and policy is unlawful and thus unenforceable[[159]](#footnote-160).

Other international human rights treaties which the UK has ratified also inform the implementation of Scottish health and social care law, policy and practice. Importantly, the influence of these treaties extends beyond civil and political rights, such as those mainly identified in the ECHR, to include their social, economic and cultural rights; allowing for the rights of individuals to be considered in their wider health and social care and societal context. Such treaties notably include the CRPD, the UN Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment and its Optional Protocol, the ICESCR, and the European Convention for the Prevention of Torture and Inhuman or Degrading Treatment.

The rights identified in these treaties are currently not enforceable within Scotland but, pending implementation of the Scottish Government’s stated proposal[[160]](#footnote-161) that it will introduce legislation to achieve such enforceability, they are nevertheless influential. For example, proposed Scottish law and policy must not place the UK in breach of its international obligations, which include the duty to comply with human rights treaties under international law, and can be prevented by the UK Government[[161]](#footnote-162). In addition, ECHR jurisprudence, which must be followed in Scotland, should follow United Nations human rights treaties as a higher source of international law. The aforementioned commitment to give direct legal effect to the rights identified in the CRPD and ICESCR, together with the UK’s existing international law obligation to give effect to such identified rights, reinforced by the Scotland Act 1998 provisions[[162]](#footnote-163) allowing the UK Government to prevent proposed devolved legislation and ministerial actions in Scotland which might place the UK in breach of its international obligations, are important considerations when considering measures adopted during the COVID-19 pandemic and proposed for future pandemics.

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### 4.2.2 Rights Restrictions During Emergencies

Where ordinary legislation continues to apply during an emergency it must not be interpreted or implemented as if emergency measures are in place. Moreover, even where the option to use emergency measures is available, they should be used proportionately and only to address the impact of the stated emergency. Any restrictions of rights must be authorised by law, necessary and proportionate, such proportionality crucially including non-discrimination. UK and Scottish governments recognised this when introducing the Coronavirus and Coronavirus (Scotland) Bills, each confirming that the COVID-19 measures would only be invoked if absolutely necessary[[163]](#footnote-164) and both resultant Acts contain sunset and review clauses[[164]](#footnote-165).

Article 2 ECHR and Article 11 CRPD are clear that the state has an obligation to protect life and to take all necessary measures to ensure the protection and safety of persons, including those with disabilities, in emergency situations. They acknowledge that states may introduce measures in legislation, policy and practice to address emergencies which reduce human rights safeguards. They are clear that the rights to life (which include the state obligations to both protect life and to adequately investigate deaths of persons who fall within the care of the state) or to be free from torture and inhuman or degrading treatment are always absolute and untouchable even in emergencies[[165]](#footnote-166). Other rights, however, such as the right to liberty, respect for private and family life/autonomy/to exercise legal capacity, to a fair hearing/access to justice, and to the highest attainable standard of physical and mental health and community living may be proportionally limited.

As mentioned, non-discrimination is an essential component of proportionality. Article 15(2) ECHR requires that emergency measures are ‘*…not inconsistent with its other obligations under international law.*’ This importantly includes the CRPD which both reinforces and expands the ECHR non-discrimination message and emphasises that the existence of a disability or related impairment must never justify a lower level of rights enjoyment[[166]](#footnote-167). States must ensure that the effect of restrictions, even if applied to everyone, do not disproportionately adversely impact on persons with disabilities[[167]](#footnote-168). Similarly, rights restrictions must not be justified on the basis of other characteristics, such as gender identity, age, and ethnic origin.

To overcome such inequalities, the CRPD requires the proactive support of persons with disabilities to achieve this through, for example, supported decision-making, reasonable accommodation and universal design[[168]](#footnote-169) and also active consideration of how inequalities may be overcome. The Committee on the Rights of Persons with Disabilities and the Special Envoy of the United Nations Secretary-General on Disability and Accessibility have stated that these principles apply both during and outside of emergencies[[169]](#footnote-170). No rights must therefore be limited to such an extent that an individual with mental disability or capacity issues is given fewer legal and procedural safeguards or a lower standard, of support, care and treatment than others. Additionally, whilst the right to life is particularly important - including the state's positive obligation to protect life and to take appropriate operational measures in order to achieve this - this needs to be carefully and proportionately balanced with respect for other rights. Protecting the right to life cannot of itself justify overriding the need to provide a legal basis for limiting the rights to liberty and respect for private and family life (autonomy).

The fulfilment of Article 12(3) CRPD, which places a duty on states to take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity (supported decision-making), is vital if all persons with mental and physical disabilities are to make their voice heard in social care and social support decisions on an equal basis with others. Such support may, of course, take many different forms but may include advance planning. It may also be found in peer, family or professional support, independent advocacy, clearly and appropriately communicated information and, of course, in welfare powers of attorney and other forms of advance planning[[170]](#footnote-171).

Additionally, Article 4(3) CRPD requires that 'In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.' An important consideration is therefore the extent to which this obligation was fulfilled when making social care provision decisions.

### 4.2.3 Evidence Regarding Human Rights Compliance During the Pandemic

In the view of some commentators, disabled people and those living with long-term conditions were subject to ‘*significant marginalisation, exclusion and barriers to realising their rights to live with dignity and autonomy.’*[[171]](#footnote-172)For example, *“I feel, genuinely feel like disabled people have just been abandoned, forgotten about and left to try and survive as best we possibly can.”* (ibid)

Pre-existing inequalities were further exacerbated by the pandemic, specifically for these populations. The daily lives and routines of these populations were significantly impacted by social and physical distancing, which affected the wellbeing and medication adherence of many individuals with disabilities and long-term conditions.[[172]](#footnote-173)

A study by Scherer et al. (2023) found that respondents ‘*felt invisible and ignored’* and ‘*rarely considered’* from the government’s response. This was experienced not just in the early stages but persisted throughout the pandemic:[[173]](#footnote-174)

Scherer et al. (2023) also comment on the ‘structured marginalisation’ of individuals with disabilities. They describe it as being *‘entrenched by government action and inaction [which has] exacerbated their vulnerability’*.[[174]](#footnote-175)

The Scottish Human Rights Commission (SHRC) investigated the impact of the Covid pandemic and in its summer 2020 report highlighted the need for urgent action to address immediate human rights concerns.[[175]](#footnote-176) The Feeley review of social care in Scotland also emphasised the importance of taking a human rights-based approach to adult social care. In doing so, it highlighted how pre-existing inequalities have been exacerbated by the Covid pandemic for specific populations, including older people, disabled people, people from minority ethnic communities and disadvantaged communities.[[176]](#footnote-177)

The Equality and Human Rights Commission published a report in October 2020 which examined the effect of the Covid pandemic on human rights and equality.[[177]](#footnote-178) The report also drew attention to the disproportionate impact of the pandemic on specific populations, such as older people, ethnic minorities and disabled people, as well as those who support them including paid and unpaid carers.

A report by People First in April 2020 highlighted concerns that legislation introduced early in the pandemic to preserve resources and manage the virus may not adhere to the European Convention on Human Rights or the UN Convention on the Rights of Persons with Disabilities, particularly with regard to individuals being moved without prior discussion and agreement, and individuals being given medication without consent[[178]](#footnote-179).

A report by The ALLIANCE concluded that although people recognised the need to make rapid decisions in response to the changing pandemic landscape, the lack of consultation with service users and their families regarding their rights to care caused significant distress, and left many seeking private healthcare to meet their needs. This in itself raised questions about equity of access[[179]](#footnote-180).

Sixty-one percent of respondents to the Scottish Parliament Care at Home survey noted that a number of lower and moderate care packages had been suspended in order to prioritise those in the greatest need. Others were delivered in a different way, without being completely withdrawn. Risk assessments were undertaken to identify priority cases and individuals were notified these would be reviewed within 12 weeks, however respondent attest this deadline was not upheld in all cases. Risk assessments took place collaboratively with service users and their families, and alterations to the mechanisms of delivery (predominantly changes to online/phone support) meant care could still be delivered, however there was still significant impact on the person in receipt of care.[[180]](#footnote-181)

A report by the Care Inspectorate identified the most robust protocol for safe care implantation and reduction, which involved joint working across a number of contributors from the HSCP itself, through social work, community nursing and other service providers to ensure those with the highest need were identified, after which risk assessments were undertaken to determine whether care could be reduced safely. The majority of HSCPs maintained contact with service users in case of a change in circumstances. Where partial assessments were completed under emergency legislation, most HSCPs continued to provide services, with the intention that these partial assessments would be revisited and reviewed.[[181]](#footnote-182)

This contrasts, however, with findings by the Scottish Human Right Commission report where many of their interviewees asserted their care was withdrawn rapidly and without sufficient assessments of the potential health, wellbeing, equality and rights repercussions. [[182]](#footnote-183)

The ALLIANCE report identified issues with communication and a lack of clear guidance on the differences between ‘urgent’ and ‘non-essential’ care. This information was critical to service users in understanding which elements of their care would be paused or withdrawn, and which aspects they could still access. Respondents noted that confusing, limited and interrupted communication impacted their ability to access their regular services, and many found frequently changing government guidance difficult to follow. More widely, concerns were expressed regarding accountability and transparency in decision-making, scrutiny, the impact of temporary provisions and the safeguarding of human rights during the COVID-19 pandemic under the Coronavirus Act (Scotland) 2020[[183]](#footnote-184).

# 5. The Provision of Social Care: Key Duties and Responsibilities of Public Bodies

## 5.1 Key Messages

* Local authorities have statutory duties to assess needs for and to provide adult social care services. Many are now delegated to integration authorities.
* Most of these duties were not changed during the pandemic.
* Authorities have a wide discretion in how to meet these duties, but must nonetheless fulfil the duties for their area and in individual cases.
* There must be equality in terms of accessing services, the rights to life, dignity, physical and mental health and independent living and non-discrimination in such access, meaning that a person’s characteristic (e.g. age, gender, gender identity, disability, ethnicity or religious and cultural background) must not be used to justify any restrictions of this.
* Many services were withdrawn during the pandemic. Questions this may raise for the Inquiry include:
  + Were reductions in services consistent with the statutory obligations to provide a range of social care to meet the needs of their area?
  + Were reductions in and withdrawal of services consistent with local authority duties to individuals, including under the Chronically Sick and Disabled Person Acts and Carers (Scotland) Act?
  + Were duties to consult before changing services observed?
  + How far were the human rights of service users, including their rights under the CRPD, taken into account in these decisions?
  + Could and should Scottish Ministers have used their powers of guidance and direction to ensure that adequate services were maintained?

The earlier report for the Inquiry by Farrell and Frowde on The Provision of Health and Social Care Services[[184]](#footnote-185), updated by McKay et al, summarises in Part III how social care services are organised and funded. The following section gives more detail on the nature of the duties owed by local authorities and integration authorities to people in need of adult social care support and their carers.

## 5.2 The Social Work (Scotland) Act 1968 and National Health Service and Community Care Act 1990

The main legal foundation for the provision of social work services in Scotland remains the Social Work (Scotland) Act 1968 (SWSA), as amended by the NHS and Community Care Act 1990.

Social work services are provided by local authorities who have a wide discretion as to how they fulfil their functions. However, they must perform these functions ‘under the general guidance of Scottish Ministers’,[[185]](#footnote-186) who from time to time issue statutory guidance. Ministers may also issue binding directions to local authorities.[[186]](#footnote-187)

Section 12 (1) of the SWSA states that: *“It shall be the duty of every local authority to promote social welfare by making available advice, guidance and assistance on such a scale as may be appropriate for their area, and in that behalf to make arrangements and to provide or secure the provision of such facilities (including the provision or arranging for the provision of residential and other establishments) as they may consider suitable and adequate.”*

This was framed as a broad duty to allow local authorities to do what was felt most appropriate in their area to promote social welfare. Direct services for adults, now defined as ‘community care services’ are directed at ‘persons in need’, defined in the 1968 Act as:

‘persons who

(a) are in need of care and attention arising out of infirmity, youth or age; or

(b) suffer from illness or mental disorder or are substantially handicapped by any deformity or disability’.[[187]](#footnote-188)

Support may also be given to ‘a person who is in need of care and attention arising out of drug or alcohol dependency or release from prison or other form of detention’.[[188]](#footnote-189)

Homeless people were originally mentioned in the SWSA definition of ‘persons in need’ but this reference was removed in 1977. Local authority duties to homeless people are now set out in the Housing (Scotland) Act 1987 (see below).

Section 14 of the SWSA contains a specific duty to secure ‘on such scale as is adequate for the needs of their area’, domiciliary services for households where such services are required owing to the presence, or the proposed presence, of a person in need. These are defined as *“any services, being services provided in the home, which appear to a local authority to be necessary for the purpose of enabling a person to maintain as independent an existence as is practicable in his home”*.[[189]](#footnote-190)

There is a complex boundary between adult social care and NHS care. Local authorities may, with the approval of Scottish Ministers, ‘make arrangements for the purpose of the prevention of illness, the care of persons suffering from illness and the after-care of such persons’,[[190]](#footnote-191) but these cannot include medical, dental or nursing care, or health visiting.

Nowadays, adult social care (excluding residential care) typically includes:

* ‘Personal care’, including assistance with hygiene, continence, help with dressing and preparing or eating food[[191]](#footnote-192)
* ‘Personal support’ which may include counselling
* Assistance with tasks such as laundry and ‘meals on wheels’
* Specialised aids and equipment and occupational therapy support
* Day services, often but not always in a dedicated centre, including support to develop or maintain skills and social relationships.

The NHS and Community Care Act 1990 sought to clarify the process through which adult social care was provided, by introducing a statutory framework for assessment of needs. Section 12A of the SWSA (as amended) provides:

*“where it appears to a local authority that any person for whom they are under a duty or have a power to provide, or to secure the provision of, community care services may be in need of any such services, the authority—*

*(a) shall make an assessment of the needs of that person for those services; and*

*(b) shall then decide, having regard to the results of that assessment, …*

*whether the needs of the person being assessed call for the provision of any such services.”*

A community care assessment was intended to be the gateway to social work support, although section 12A (5) provides that services can be provided without a prior assessment if the person requires services as a matter of urgency. In that situation, the community care assessment should be carried out ‘as soon as practicable thereafter’.

In 2009, the Scottish Government published, in agreement with COSLA, National Eligibility Criteria as guidance under s5(1) of the SWSA. [[192]](#footnote-193) This was intended to reinforce key principles including:

* the responsibility of local authorities to determine the provision of care services in their areas, taking account of their financial and other resources and the costs of service provision
* that the prioritisation process should target resources towards responding to people at critical or substantial risk as regards independent living or wellbeing, whilst not excluding consideration of the benefits of preventative support and less intensive care services for people at less risk.[[193]](#footnote-194)

The guidance encourages a low threshold for the *assessment* of need, which is the first part of a two-stage process.[[194]](#footnote-195) It goes on to propose that authorities prioritise need, depending on both severity and urgency, into four bands: critical, substantial, medium and low. It states that: *“Where people are assessed as being in the ‘critical’ and ‘substantial’ risk categories their needs will generally call for the immediate or imminent provision of services. Those clients are entitled to receive such services and it is expected that they will receive them as soon as reasonably practicable and, in the case of older people in need of personal or nursing care services, not later than six weeks from the confirmation of need for the service. This is the minimum expectation on local partnerships.”*[[195]](#footnote-196)

The guidance also states that: *“Councils should ensure that they have in place clear arrangements for meeting, managing or reviewing the needs of individuals who are not assessed as being at ‘critical’ or ‘substantial’ risk’”*.[[196]](#footnote-197)

We have not had time to research the matter fully but understand that, even prior to the pandemic, resource pressures on social work services were such that in many areas only people assessed as being in the critical or substantial levels of need were likely to get significant social care support.

As discussed in section 6, the Coronavirus Act 2020 provided that local authorities could choose not to undertake community care assessments, but did not remove the general duties to provide community care services to persons in need. The National Eligibility Criteria guidance was not amended.

## 5.3 The Chronically Sick and Disabled Persons Acts 1970 and 1972

The Chronically Sick and Disabled Persons Act 1970 was a private member’s bill intended to strengthen local authority duties to provide services to people with disabilities. It was applied to Scotland by the Chronically Sick and Disabled Persons (Scotland) Act 1972. It is still in force, and is important because it provides for a stronger duty to meet individual needs than the SWSA.

The effect of s2 of the 1970 Act, as applied to Scotland by the 1972 Act, is that where a local authority has duties to chronically sick or disabled persons (being persons in need) under section 12 of the Social Work (Scotland) Act 1968, and are satisfied that it is necessary in order to meet the needs of that person, the authority is under a duty to make arrangements for the provision of a list of supports, including

(a) practical assistance for that person in his home

(b) wireless, television, library or similar recreational facilities

(c) lectures, games, outings or other recreational facilities outside his home or assistance to that person in taking advantage of educational facilities available to him

(d) facilities for, or assistance in, travelling to and from his home for the purpose of participating in any services provided under arrangements made by the authority

(e) any works of adaptation in his home or the provision of any additional facilities designed to secure his greater safety, comfort or convenience

(f) facilitating the taking of holidays by that person

(g) the provision of meals for that person whether in his home or elsewhere

(h) the provision for that person of, or assistance to that person in obtaining, a telephone and any special equipment necessary to enable him to use a telephone.

Any community care assessment of a disabled person must consider the person’s need for any services covered by s2.[[197]](#footnote-198)

On its face, the wording of s2 suggests that once a community care assessment has determined that one of these needs exist, it must be provided, and not withdrawn if the need persists. We discuss below caselaw which has considered how enforceable that duty is on an individual basis.

## 5.4 Adults with Incapacity (Scotland) Act 2000

The AWIA is primarily concerned with authorising and regulating people exercising decision making powers on behalf of an adult who lacks capacity, rather than the provision of social care support. However it does set out a number of local authority functions, particularly at s10. These include

* Supervision of welfare guardians
* Investigating complaints regarding the personal welfare of an adult in relation to welfare attorneys or guardians
* Investigating circumstances in which the personal welfare of and adult who lacks capacity appears to be at risk
* Providing guardians and welfare attorneys with information and advice.

Local authorities also have specific duties in relation to welfare guardianship, including

* Where an application for guardianship is made by someone else, ensuring that a report is prepared by a mental health officer within 21 days (s57(4))
* To initiate an application for welfare guardianship where it appears necessary and no-one else will do so.

The Mental Welfare Commission reported a 30% reduction in guardianship orders granted in 2020/21 compared to 2019/20, which they attributed to the effects of the pandemic.[[198]](#footnote-199) There was a 50% increase in the following year.[[199]](#footnote-200)

## 5.5 Mental Health (Care and Treatment) (Scotland) Act 2003 (MHCTA)

The MHCTA imposes in sections 25-27 an additional set of duties on local authorities to provide services for people who have, or have had a mental disorder (which term includes mental illness, dementia, brain injury and learning disability).[[200]](#footnote-201) The Act states that these *shall* be provided for persons who are not in hospital, and *may* be provided to persons who are in hospital. The services listed include:

* Care and support services designed to minimise the effect of the mental disorder on the person, including (but not confined to) residential care, personal care and personal support
* Services designed to promote the person’s wellbeing and social development, including (but not confined to) social, cultural and recreational activities, training and assistance in obtaining employment
* Assistance with travel to enable the person to participate in these services.

These services are included in the definition of ‘community care services’ in the SWSA.

The local authority is also required to appoint a sufficient number of mental health officers – specialist social workers who operate independently in carrying out various functions under the MHCTA, the AWIA and the Criminal Procedure (Scotland) Act 1995, including authorising emergency and short-term detention and providing reports to the mental health tribunal in respect of compulsory treatment orders.

The Mental Welfare Commission published two reports on the use of the MHCTA during the pandemic, focusing on the detention and compulsory treatment provisions.[[201]](#footnote-202) These found the detentions had increased, after an initial drop in March and April 2020. There was a reduction in MHO involvement in emergency detentions, and in the provision of social circumstances reports.

## 5.6 Adult Support and Protection (Scotland) Act 2007 (ASPA)

The ASPA was introduced following a report by the Scottish Law Commission on Vulnerable Adults.[[202]](#footnote-203) The Act contains a set of legal interventions intended to protect adults at risk who are:

* unable to safeguard their own well-being, property, rights or other interests, and
* because they are affected by disability, mental disorder, illness or physical or mental infirmity, are more vulnerable to being harmed.[[203]](#footnote-204)

Local authorities have a number of responsibilities under the ASPA including:

* to make inquiries if they believe they may have to intervene to protect an adult at risk (s4)
* to liaise with other agencies when exercising protective functions (s5)
* to establish a local Adult Protection Committee to oversee the protection of adults at risk (s42)
* to visit adults at risk and to pursue various protective orders, if appropriate, including orders to allow the person’s needs to be assessed, the person to be removed from a situation of risk, or a banning order against a person putting the adult at risk (sections 7-41).

The Act was originally understood to be a relatively minor tidying up of various protective functions dating back to the National Assistance Act 1948. The number of court orders obtained is relatively modest but the co-ordination of the work of local authorities, health services, the police and others is now a significant part of social work provision for adults.

## 5.7 Public Bodies (Joint Working) (Scotland) Act 2014

As set out in Farrell & Frowde[[204]](#footnote-205) (pages 24-25), the Public Bodies (Joint Working) (Scotland) Act 2014 led to the establishment of integration authorities, responsible for ensuring that the health and social care of local populations was organised collaboratively by NHS Scotland health boards and local authorities, with services being delivered through health and social care partnerships.

Every area bar Highland has adopted a ‘body corporate’ model, with a distinct Integrated Joint Board (IJB) responsible for leading the planning of health and social care services.[[205]](#footnote-206) The IJB is required to produce a single strategic plan, and then commissions the local authority and health board to deliver services in line with the strategic plan. These are done through a structure called a Health and Social Care Partnership (HSCP). In Highland, there is a ‘lead agency’ arrangement, whereby NHS Highland has responsibility for developing the strategic plan for adult health and social care services.

The Scottish Government publishes a range of statutory guidance to support integration.[[206]](#footnote-207)

From the point of view of the service user, the duties remain the same following integration. The integration arrangements concern which public body (the local authority or the IJB/lead agency) is responsible for discharging the duty.

Under the arrangements, most local authority social work functions discussed herein are delegated by the local authority to the integration authority. Regulations set out which local authority functions must be delegated to the integration authority.[[207]](#footnote-208) Each IJB has an Integration Scheme which sets out which functions are delegated to the IJB. An example is the scheme for Edinburgh, which sets out the functions delegated by the City of Edinburgh Council at Annex 2.[[208]](#footnote-209)

The integration authority must also prepare a strategic plan for their area, [[209]](#footnote-210) setting out how they will carry out the integrated functions, and how those arrangements are intended to achieve, or contribute to achieving, the national health and wellbeing outcomes prescribed by Scottish Ministers. These plans must also have regard to the ‘integration delivery principles’ set out at s31, including that services respect the rights of service users and take account of the dignity of service users.[[210]](#footnote-211)

## 5.8 The Carers (Scotland) Act 2016

This Act was intended to strengthen the rights of and support for carers through the identification of carers’ needs for support through adult carer support plans and young carer statements; the provision of support to carers; the enabling of carer involvement in certain services; the preparation of local carer strategies; and the establishment of information and advice services for carers. Statutory guidance has been produced by the Scottish Government, which was updated on July 2021.[[211]](#footnote-212)

If the local authority identifies a person as an adult carer, they must offer the person an adult carer support plan, or provide one on the request of the carer (s6). Section 9 sets out details of what the adult carer support plan must contain, including:

* information about the adult carer’s personal circumstances
* information about the identification of the adult carer’s needs for support
* information about the support available to adult carers and cared-for persons in the responsible local authority’s area,
* information about the support which the responsible local authority provides or intends to provide to the adult carer.

Under the Carers (Scotland) Act 2016 (Adult Carers and Young Carers: Identification of Outcomes and Needs for Support) Regulations 2018 SSI 109, local authorities must identify an adult carer’s need for support through conversation with them.

Broadly similar provisions apply to young carers – see sections 12-20.

Each local authority is also required to set ‘local eligibility criteria’ by which they must determine whether it is required to provide support to carers to meet carers’ identified needs. Before doing so they must consult with carers representative bodies and involve carers (s21). These must be published and reviewed at least every three years (s22). [[212]](#footnote-213)

Where the carer has needs which meet the eligibility criteria, and which cannot be met by the support given to the cared-for person, or by services provided generally in the area, the local authority *must* provide support to the carer to meet the carer’s eligible needs, and *may* provide support to the carer to meet the carer’s other identified needs (s24). In determining what support to provide to a carer, the local authority must consider in particular whether the support should take the form of or include a break from caring (s25). Support for carers provided under s24 cannot be charged for.[[213]](#footnote-214)

This duty to meet needs for carers which meet local eligibility criteria is arguably stronger than the duties that exists in respect of cared for persons.

Although the Act talks about local authorities, duties including the setting of local eligibility criteria and preparing carer support plans have been delegated to integration authorities.[[214]](#footnote-215)

## 5.9 Staffing – Health and Care (Staffing) (Scotland) Act 2019

This Act imposes duties on anyone providing care services to ensure that ‘at all times suitably qualified and competent individuals are working in the care service in such numbers as are appropriate for—(a) the health, wellbeing and safety of service users, (b) the provision of safe and high-quality care, and (c) in so far as it affects either of those matters, the wellbeing of staff.’ [[215]](#footnote-216)

Providers must also ensure that staff are suitably trained.[[216]](#footnote-217)

## 5.10 Homelessness – Housing (Scotland) Act 1987 Part ll

Alongside the main social work legislation, local authorities have duties towards people who are homeless, or threatened with homelessness.[[217]](#footnote-218) For anyone who is unintentionally homeless, there is a duty to provide temporary accommodation until settled accommodation has been secured. If intentionally homeless, temporary accommodation should be provided for a reasonable time, alongside advice and assistance. There are also duties to provide advice and support to people who are potentially homeless.[[218]](#footnote-219)

Local authorities should also assess whether persons who are, or are threatened with, homelessness, require ‘housing support services’. These include assistance with budgeting, debt and welfare benefits, assistance with engaging with other professionals, and assisting the person to manage a tenancy.[[219]](#footnote-220)

## 5.11 How Strong are the Social Work Duties?

Local authorities and integration authorities have a wide but not absolute degree of discretion in meeting their duties to provide a social work service, at both the authority and individual level.

The core s12 duty is to provide services on a scale that is ‘appropriate for their area’.[[220]](#footnote-221) This suggests that a complete failure to provide a social work service would be unlawful, as would a service which the local authority knew (or should have known, if properly directed) was manifestly inadequate to the needs of the area.

In relation to individual service users, the duties to assess needs (when not waived by emergency legislation) are arguably stronger than the duties actually to *meet* those needs. The community care legislation introduced in 1990 always envisaged that there may be an element of unmet need, and that identification of that need would inform future planning.

The possible exceptions to this are s2 of the Chronically Sick and Disabled Persons Act 1970 and s24 of the Carers (Scotland) Act 2016. In both of these Acts, once a need has been established which falls within the scope of the legislation (and, in the Carers (Scotland) Act, the local authority’s eligibility criteria), there would appear to be a clear duty to provide services that meet the need.

It would also appear that, if an assessment has established that need, the service should not be withdrawn, without a reassessment.

Even outwith these two stronger duties, the authorities cannot simply refuse to provide a service when they know someone is in need of it. They must have regard to any assessment, and to the statutory guidance issued by the Scottish Government. That suggests that where a person’s needs appear to be ‘critical’ or ‘substantial’, there would be at least a strong expectation that the authority would do something about them.

There is some caselaw on the extent to which pressures on local authority resources may be relevant in determining whether an individual has a need which creates an entitlement to support.

In 1997, the House of Lords ruled, by a majority of 3-2, that the needs of a disabled person had to be assessed with reference to the available resources and the eligibility criteria for services could change according to the authority's financial position.[[221]](#footnote-222) Lord Lloyd dissented, saying that a need cannot be a need in one council and not another because one council has less money, and that the standard to be set for determining need is that of a civilised society, as interpreted by the social services committee. This case has never been overturned, although there was some discussion by the Supreme Court in the case of *R (on the application of KM) V Cambridgeshire County Council[[222]](#footnote-223)* about whether aspects may have been wrongly decided.[[223]](#footnote-224)

In the case of *R. (on the application of McDonald) v Kensington and Chelsea RLBC[[224]](#footnote-225)* the Supreme Court held that a local authority providing home-based community care to a person with limited mobility was entitled to withdraw the provision of an overnight carer who helped her access a commode where it had assessed that her needs could equally be met by the provision of incontinence pads or absorbent sheets. Such a decision did not violate ECHR Article 8 because it was proportionate and in the interests of other service users. It was accepted however that Article 8 could impose a positive obligation on the state to take measures to provide support.

This case was subsequently taken to the European Court of Human Rights.[[225]](#footnote-226) The Court partially upheld the complaint, accepting the judgment of the UK courts that the withdrawal of the overnight service prior to a reassessment was not lawful, and thus breached the appellant’s Article 8 rights. However, once the reassessment of needs had been undertaken, there was no continuing breach of Article 8.

In contrast, in the Scottish case of *MacGregor v South Lanarkshire Council[[226]](#footnote-227),* the Outer House considered the case of a 90 year old man with poor short term memory, restricted mobility, liability to fall and deafness who was assessed as requiring 24-hour nursing care, placed on a waiting list for a residential nursing place and informed that there might be a delay of seven or eight months due to lack of public funds. Lord Hardie ruled that once an authority determines that needs require a community care service which cannot be met in any other way, there is a duty under s12 of the SWSA to provide the necessary assistance. Resources are irrelevant to the assessment of needs but are relevant in considering how to meet the need. Placing a person on a waiting list for several months is an abdication of responsibility and *ultra vires,* as is placing on a waiting list without an exercise to assess priority.

A court ruling from Sept 2022 found that a day centre in the Scottish Borders was closed unlawfully during the pandemic. Following closure in March 2020 because of the pandemic, the centre failed to reopen because the Council had decided to change the nature of the service. The Court of Session ruled that in doing so the Council failed to consider the impact of closures on its service users, it had not adequately consulted these service users, nor had it conducted an equality impact assessment during the closure period.[[227]](#footnote-228)

Overall, then, the balance of judicial authority tends to support the view that resources are relevant in meeting care needs, even in relation to the Chronically Sick and Disabled Persons Act, but this is far from an absolute licence to authorities to withdraw services when the authority has resource challenges, including those caused by the pandemic.

The normal judicial review grounds of reasonableness and rationality would apply. In some cases, notwithstanding the wide margin of appreciation given to states, Article 8 may be relevant – and in the most extreme cases Article 3.

As we set out at section 6, most local authorities did not avail themselves of the power under the Coronavirus Act 2020 to waive their duties to assess needs. It may also be relevant to note that the stated reason for the emergency legislation was to minimise bureaucracy in meeting needs during a crisis, not to remove the duty to meet needs which were clearly apparent.

The Inquiry may also wish to consider how far the obligations under the Convention on the Rights of Disabled Persons may have been affected by any withdrawal or failure to provide services for people in need of adult social care and their carers.

## 5.12 Evolution of Government Guidance on Social Care During the Pandemic

### 5.12.1 Early Guidance

Initial Government Guidance was issued in March 2020 with a focus on advising social care staff on minimising risk of infection and transmission and notifying staff who had come into contact with a confirmed case to isolate and expect a mild flu-like illness[[228]](#footnote-229). With the NHS being placed on an emergency footing from mid-March[[229]](#footnote-230), guidance began to quickly evolve and change in response to the rapidly developing crisis. The first UK-wide lockdown was announced on 23 March[[230]](#footnote-231) [[231]](#footnote-232). This was closely followed by updated guidance for social care which included updated infection control guidance and clinical advice for ensuring the continuation of safe and effective services in various settings including community care, care at home and sheltered housing.[[232]](#footnote-233)

Initial advice for unpaid carers was issued in late April, advising individuals who provide care for a friend or family member to follow public health advice and consider who could take over their caring role should they become unwell. Unpaid carers were advised to contact social work if they were unable to continue providing care[[233]](#footnote-234).

Following issues with distribution early in the pandemic, the Scottish Government announced from 27 April that Local Hubs would resume responsibility for the distribution of PPE to all social care providers, unpaid carers and personal assistants[[234]](#footnote-235) with guidance on how to access this issued on 29 April[[235]](#footnote-236) [[236]](#footnote-237).

### 5.12.2 Lockdowns and Lifting of National Restrictions

April 2020 saw the launch of ‘COVID19: A Framework for Decision-Making’ outlined information on lockdown and the factors which would influence the future lifting of restrictions[[237]](#footnote-238). This was followed by the publication of the Scottish Government Route map out of lockdown, outlining the order in which restrictions would be gradually changed as Scotland progressed through, and out of lockdown[[238]](#footnote-239). The document describes the framework for decision making along with other key metrics including the R (reproduction) number, along with information on the Test and Protect- testing and tracking system to support isolation and minimise transmission[[239]](#footnote-240).

A move to Phase 1 took place on 29 May 2020. This largely centred around the resumption of outdoor activity and work[[240]](#footnote-241). This was closely followed by the publication of ‘Re-mobilise, Recover, Redesign, The Framework for NHS Scotland’ which set out how Health Boards would follow national and local clinical advice to prioritise the resumption of services[[241]](#footnote-242).

A move to Phase 2 occurred in mid-June with many businesses re-opening and a general ‘scaling up’ of activities and services[[242]](#footnote-243). The first localised delays to the progression of the route map came into effect in early July, due to a spike in cases in Dumfries and Galloway[[243]](#footnote-244). By 10 July the majority of Scotland had moved to Phase 3 of the route map which included the relaxation of restrictions around both indoor and outdoor activity[[244]](#footnote-245). Updated anticipated dates were published in late August and further relaxations were delayed due to ongoing risk[[245]](#footnote-246) [[246]](#footnote-247) [[247]](#footnote-248). Further local restrictions were announced throughout September[[248]](#footnote-249) [[249]](#footnote-250) [[250]](#footnote-251).

In late October, the Scottish Government published the five-level Strategic Framework which set forth the differing levels of protection required, based on viral transmission rates. These levels came into effect from 2 November[[251]](#footnote-252), however mainland Scotland entered lockdown as of 5 Jan 2021 with a legal requirement not to leave home unless for essential purposes[[252]](#footnote-253).

The updated Strategic Framework was published on 23 February 2021 to outline the proposed order and required conditions to be met for re-opening and lifting of restrictions [[253]](#footnote-254), and in mid-March a timetable for the easing of restrictions was published, including messaging changing from ‘Stay Home’ to ‘Stay Local’[[254]](#footnote-255). All parts of Scotland moved to Level 3 from 26 April[[255]](#footnote-256) and most of mainland Scotland moved to Level 2 as of 17 May (the Islands moved to Level 1, but Glasgow and Moray remained in level 3 due to higher rates of infection)[[256]](#footnote-257). All of Scotland subsequently moved to Level 0 as of 19 July[[257]](#footnote-258) and beyond Level 0 on 9 August. This ended the restrictions on social gatherings and the legal requirement for physical distancing, however the wearing of masks and the use of Test and Protect remained[[258]](#footnote-259). However, an announcement from 7 August confirmed physical distancing in healthcare settings would be maintained[[259]](#footnote-260).

### 5.12.3 Self-isolation

June 2020 brought the announcement of the Social Care Staff Support Fund, intended to ensure social care workers did not suffer financial hardship if they became ill or had to self-isolate during the pandemic. The Fund was open to social care workers contracted to deliver care and support in the social care sector[[260]](#footnote-261). From 1 October 2022 the Fund operated in accordance with the National Health Service (Scotland) Act 1978 to allow ongoing applications in order to support adherence to public health guidance related to infection prevention and control. The fund closed to applications on 31 March 2023[[261]](#footnote-262).

Initially, following a positive test, the required period of self-solation was seven days. From 30 July 2020 this was increased to 10 days[[262]](#footnote-263). This requirement remained in place until 6 January 2022 when the isolation period was reduced to seven days if other criteria were met. These additional criteria were the absence of a fever and the provision of a negative lateral flow test on days six and seven[[263]](#footnote-264). Triple vaccinated close contacts of confirmed cases did not need to isolate provided they remined well and provided a negative lateral flow test for seven consecutive days[[264]](#footnote-265).

In February 2021 the criteria for the Self-Isolation Support Grant were extended to financially support more individuals who had to isolate due to becoming unwell themselves, or caring for someone who was isolating[[265]](#footnote-266). The grant initially opened on 13 October 2020 for those in receipt of low income who would lose earnings as a result of isolation[[266]](#footnote-267). The extension to eligibility criteria opened the grant up to individuals with caring responsibilities, workers earning the Real Living Wage or less, and those in receipt of council tax reductions due to low income. The application window was also extended to within 28 days of being told to isolate, to enable a longer period in which to apply[[267]](#footnote-268). Applications closed on 5 January 2023[[268]](#footnote-269).

From 23 July 2021 self-isolation rules for close contacts of confirmed cases of COVID-19 were changed for essential staff working in critical roles, allowing them to return to work sooner if they had been vaccinated, were asymptomatic and could provide a negative PCR test. They were required to continue daily lateral flow testing after returning[[269]](#footnote-270). A policy document issued on 9 August 2021 extended this to all staff in health and social care[[270]](#footnote-271). Priority PCR testing and exemptions from self-isolation were announced for essential workers in December 2021[[271]](#footnote-272), and further changes were made to self-isolation rules in early January 2022, in line with updated public health advice[[272]](#footnote-273).

### 5.12.4 Testing & Vaccination

From June 2020 it was announced that routine testing for the health and social care workforce would be extended as services continued to resume[[273]](#footnote-274) with further expansion announced later in November 2020 across hospital patients, social care staff and communities at protection Level 4 (see above) [[274]](#footnote-275).

Vaccinations began to be administered from 22 February 2021, with the online vaccine registration portal open for unpaid carers from 15 March 2021[[275]](#footnote-276).

In mid-December 2021 financial support was made available to adult care providers who may have incurred additional costs if staff were vaccinated during working hours. The funds were intended to prevent staff from being forced to use annual or unpaid leave in order to receive their vaccinations[[276]](#footnote-277).

The requirement for all health and social care staff to wear facemasks at all times was withdrawn on 7 September 2022[[277]](#footnote-278), with asymptomatic testing ending on 28 September meaning health and social care staff would no longer be required to undertake weekly testing[[278]](#footnote-279).

### 5.12.5 Changes to Services

Guidance varied depending on the type of service being delivered (see timeline for further detail) but largely made it clear that services should communicate effectively with all stakeholders and follow the relevant respective health protection guidelines. Alternative self-directed support options should be open to anyone who could not access adequate support[[279]](#footnote-280).

As set out in Chapter 7, many services, particularly building based day services, were closed for much of the period in question. Although the Government at various stages encouraged services to re-open, this was not mandatory, and decisions were left to local discretion.

On 17 July 2020 the Scottish Government noted in a letter to health and social care partnerships that ‘a number of individuals, because of their critical needs, have been receiving important building based support as part of their care package’ and confirming that they were in agreement with this support re-opening or remaining open, provided it had been agreed with the local Health Protection team and the Care Inspectorate [[280]](#footnote-281). The implication was that most people who had used building based day services were no longer doing so at that time.

On 3 August 2020 a further letter was issued, saying that ‘all registered adult day centre services that wish to reopen can do so, subject to agreement of their approach by the local Health Protection teams and the Care Inspectorate, prior to reopening [[281]](#footnote-282).’ Guidance was issued on 31 August[[282]](#footnote-283) which said it was ‘designed to support safe re-opening and delivery of building-based day services for adults.’

The guidance noted that the majority of building-based day services for adults were closed following Scottish Government advice in March 2020 and that this had affected relationships and put pressure on carers. It highlighted that Scotland’s ‘Route Map’[[283]](#footnote-284) included “access to respite/day care to support unpaid carers and for families with a disabled family member” as part of Phase 1, but noted that ‘it may take some time to ensure the appropriate modifications are in place’ and that ‘there is no ‘one size fits all approach’.

A letter from the Cabinet Secretary for Health and Sport and the Minister for Children and Young People on 23 September 2020 provided an update on ‘guidance to support the remobilisation of stand-alone residential respite/short break facilities’, although it did not explicitly say that such services should now re-open[[284]](#footnote-285)*.*

A further letter from the Cabinet Secretary for Health and Sport on 13 October 2020 sought to ‘reiterate the importance to people who need daytime support and their families and unpaid carers of having appropriate levels of support available at the times they need it’ while recognising that risk-assessments and decisions on re-opening of services will be balancing the public health need to keep people safe from infection with the benefits for supported people and carers outlined above’ and noting that decisions should be made locally [[285]](#footnote-286).

A subsequent letter from the Cabinet Secretary for Health and Sport on 15 January 2021 confirmed adult day services could continue to operate throughout the then lockdown where they were considered ‘essential’ for the wellbeing of attendees and their families[[286]](#footnote-287).

In answer to a Parliamentary question on 17 March 2021, Mairi Gougeon, the Minister for Public Health and Sport confirmed that day centres could continue to operate in Level 4 areas during the lockdown period and had been able to do so from mid-January 2021. The Coronavirus (COVID-19) Strategic Framework confirms the move back to geographically determined levels of protection under which operations can take place in line with the tiered guidance. Although day service capacity is reduced it was emphasised that priority should be given to those in the greatest need, taking into account risk, and that those who cannot access support are involved in this decision-making process.[[287]](#footnote-288)

The initial Scottish Government guidance regarding changes to the provision of self-directed support was published in May 2020[[288]](#footnote-289), followed by updates in July and October 2020, and in February and March 2022, with a final update in June 2023.

A more strongly worded letter was issued by the Minister for Mental Wellbeing and Social Care on 7th June 2021 which said:

‘I understand how very difficult things continue to be for many people without access to day services at this time. These services are crucial to individuals with support needs, as well as their unpaid carers and families. I want to emphasise the urgency of services re-opening as soon as possible, to help people to return to their normal lives.’[[289]](#footnote-290)

In December 2020, the ‘Dementia and COVID-19 National Action Plan to Continue to Support Recovery for People with Dementia and their Carers’ was published.[[290]](#footnote-291) This set out an action plan to build upon the initial response to support people with dementia and their carers during the pandemic following the suspension of many services. The plan recognised the impact of the pandemic on this population and the anxiety and vulnerability which has grown from that. It acknowledged the worries of families and set out action taken to date and those planned for the future to support those with the illness and their families and carers, reinforcing the person-centred, human-rights based approach being taken in their care. Commitments included working with partners to evaluate the impact of the pandemic; conducting an equality impact assessment; supporting the delivery of post-diagnosis care services; and commitment to re-open or maintain services such as adult day centres, respite services, physical rehabilitation and telecare.

### 5.12.6 Winter Planning

In October 2020 the Scottish Government published the Winter Preparedness Plan to support health and care services with an additional £37 million during the winter period by doubling the number of individuals with access to flu vaccines, increasing COVID-19 testing capacity, ensuring Health Boards are equipped to deal with increased contact-tracing requirements afforded by rapid surges in case numbers, supporting key workers in health and social care by ensuring rest areas are maintained and mental health support is provided and maintaining COVID-19 Community Pathways with local assessment centres in every Health board[[291]](#footnote-292).

Following this, on 3 November 2020 the Adult Social Care Winter Preparedness Plan was published which allocated £112 million investment to support the sector through the winter months with effective infection prevention and control measures, a daily review of COVID-19 symptoms in care settings, expanded testing access for care at home workforce, free of charge top-up PPE from NHS Scotland until the end of March 2021, and additional funding to support the restriction of staff movement across care settings and the promotion of access to workforce wellbeing services for staff, third sector and unpaid carers[[292]](#footnote-293).

In October 2021 the Scottish Government published the ‘Adult Social Care - Winter Preparedness Plan 2021-22’. This accompanied the ‘Health and Social Care Winter Overview’ and set out the measures which would be applied across the adult social care sector to deal with the challenges of the winter season. The focus of the Plan was the ongoing support of the social care workforce and unpaid carers; the maintenance and ongoing provision of high-quality integrated services; and the protection of adult social care service users from COVID-19 and winter viruses[[293]](#footnote-294).

# 6. Emergency Legislation

## 6.1 Key Messages

* Emergency legislation reduced the requirements on local authorities to undertake assessments of care needs, but not the general duties to provide care.
* A minority of local authorities/HSCPs made use of the derogation from these assessment duties.
* This potentially impacted on individuals’ rights to enjoy autonomy and choice (including family life and relationships), dignity, physical and mental health and independent living on an equal basis with others.

The Coronavirus Act 2020 brought into force emergency provisions (on 5 April 2020) relating to the removal of local authorities’ statutory duties to undertake social care needs assessments and related support plans where it would be impractical to do this, or where to do so would cause unnecessary delay in providing community care services to the individual concerned. These measures related to duties:

* *To assess adult social care needs (section 12A Social Work (Scotland) Act 1968).* Where a local authority did not carry out an assessment, or only carried out a partial one, then it additionally did not have to comply with the general principles of the Social Care (Self-directed Support) (Scotland) Act 2013, which include those in section 1 requiring involving and collaborating with the person in the assessment and providing support or assistance to express their views and make an informed choice on the options available to them[[294]](#footnote-295). These emergency provisions were subsequently suspended on 30 November 2020[[295]](#footnote-296).
* *To prepare adult carer support plans (section 6 Carers (Scotland) Act 2016, regulation 2(1) Carers (Scotland) Act 2016, Adult Carers and Young Carers: Identification of Outcomes and Needs for Support Regulations 2018 (SSI 2018/109) and section 1 Social Care (Self Directed Support) (Scotland) Act 2013*[[296]](#footnote-297). These emergency provisions were suspended on 30 November 2020.
* *To assess and prepare young carers support plans (section 12(1) Carers (Scotland) Act, regulation 3(1) Adult Carers and Young Carers: Identification of Outcomes and Needs for Support Regulations 2018 (SSI 2018/109) and section 1 Social Care (Self Directed Support) (Scotland) Act 2013*[[297]](#footnote-298). These emergency provisions were suspended on 29 September 2021.
* *To assess a disabled child’s needs (sections 23(3) and 29(5) of the Children (Scotland) Act 1995 and section 1 Social Care (Self Directed Support) (Scotland) Act 2013*[[298]](#footnote-299). These emergency provisions were suspended on 29 September 2021.

A joint letter from the Cabinet Secretary for Health and Sport and COSLA issued on 30 March 2020 on Scotland’s social care support response and Scottish Government's June and August 2020 reports to the Scottish Parliament[[299]](#footnote-300) all outlined how the emergency legislation permitted local authorities to focus their resources on meeting the most urgent need with the goal of protecting those at greatest risk. Provisions could be activated and discontinued rapidly in response to local pressures. The letter, for example, stated that ‘Local Authorities will still be expected to do as much as they can to meet people’s needs, with appropriate safeguarding measures in place’[[300]](#footnote-301).

Statutory guidance[[301]](#footnote-302) was clear that the power to disregard assessment duties would only remain whilst it was absolutely necessary to protect people. The guidance stated that

‘When using these provisions, all decisions made on an individual's social care needs should be considered alongside their individual wellbeing and fundamental human rights.

To support ongoing response planning and decision-making, and to ensure that key ethical values and principles are considered throughout this challenging period, additional considerations are provided in the Ethical Framework for Adult Social Care. This sets out the values which should underpin all our decisions, which include respect, reasonableness, minimising harm, inclusiveness, accountability, flexibility, proportionality and community.’ (para 1.5)

Scottish Government surveys of Chief Social Work Officers during the periods 5 April to 16 May 2020 and 17 May to 3 July 2020 indicated that not all local authorities used the provisions[[302]](#footnote-303). The first of these reports stated that six local authorities were using the powers from 26 areas which responded. The survey covering the period 17 May to 3 July 2020 received responses from all 31 Health and Social Care Partnership areas. Of these, four reported they were using the powers, namely Dundee, East Renfrewshire, Highland and South Lanarkshire.

The Coronavirus Act 2020 and Coronavirus (Scotland) Act 2020 also introduced emergency measures in relation to the Adults with Incapacity (Scotland) Act 2000 and Mental Health (Care and Treatment) (Scotland) Act 2003 which impacted on social care delivery in terms of those subject to the Act. Apart from mention of these provisions below where they are specifically relevant to the remit of this report, details of their nature and impact can be found in our previous reports *Research Report for COVID-19 Public Inquiry[[303]](#footnote-304)* and *Scottish COVID-19 Inquiry Research (2) Lots 3.1 and 3.2: Health and Social Care.[[304]](#footnote-305)*

## 6.2 Impact of Emergency Legislation which Removed Some Duties in Social Work

An increasing divergence of devolved legislation and its implementation in the UK became apparent during the COVID-19 pandemic. Concerns have been raised regarding the process and scrutiny of the legislation; including possible changes to and effects on the workforce and the possible threat to the ability to safeguard human rights[[305]](#footnote-306).

The joint Scottish Government/COSLA letter dated 30 March 2020 confirmed that the rights of adults had not and would not change in the pandemic context, and as such it was essential that protection was prioritised on an ongoing basis during the rapidly changing pandemic context[[306]](#footnote-307). However, an open letter from the Scottish Association of Social Work (SASW) to Jeane Freeman MSP, Cabinet Secretary for Health and Sport, and Maree Todd MSP, Minister for Children and Young People, dated 30 March 2020 highlights some of these human rights concerns during the pandemic. It argued that increases in neglect and abuse are difficult to mitigate and safeguard against using without home visits, and population mental health had largely experienced decline. [[307]](#footnote-308)

Social workers expressed concerns about continuing to undertake statutory duties during lockdown, and emergency legislation which has stripped back social work duties has raised further concerns about the protection of human rights, particularly relevant to temporary amendments to the Mental Health Care and Treatment (Scotland) Act 2003 and the Criminal Procedure (Scotland) Act 1995[[308]](#footnote-309). For example, only one medical practitioner was now required to assess whether a person should be detained. SASW noted that no duty was placed upon Scottish Ministers to report the number of such mental health orders made during this emergency period, nor was there a mandate to report the assessment of human rights/person-centred options/capacity that has been made by practitioners that led to the provisions in the Act being applied[[309]](#footnote-310).

Early in the pandemic (May 2020) the British Association of Social Workers (BASW) published a report on the role of social work in the current context. This noted that emergency legislation, whilst necessary, may have long term detrimental consequences for the population, and that better preparedness could have improved the overall response. As a protective role, social work would scrutinise guidance and legislation to determine whether they align with ethics and human rights protections. Due to the non-stop nature of social work services, the report demanded that social workers be integrated into emergency planning at a local level in order to remain responsive to needs arising, to uphold rights and protect individuals from harm[[310]](#footnote-311).

The Coronavirus Act 2020 included measures to ease local authority requirements under s.13ZA of the Social Work (Scotland) Act (which authorised the provision of community care services, including residential accommodation, to adults unable to consent). These removed the need for local authorities to take into account the past and current wishes of adults who lack capacity, or the input of a guardian or power of attorney in order for action to be taken rapidly to safeguard the health of vulnerable people. This was never brought into use and expired on 29 September 2020[[311]](#footnote-312). SASW had expressed significant concerns regarding this amendment, calling it ‘a significant and deeply concerning human rights compromise’. Instead, they suggested a duty be imposed on MHOs to justify why action has been taken under 13ZA of the amended Social Work (Scotland) 1968 Act that might contravene the will and preference of the adult, or their appointed guardian or welfare power of attorney, and that this decision be reviewed within 28 days[[312]](#footnote-313).

# 7. Withdrawal of or Reductions to the Provision of Adult Social Care

## 7.1 Key Messages

* Initially the Scottish Government insisted that care packages should not be cut during the pandemic.
* This proved to be unsustainable. There were significant reductions in the availability of home care and many day services were suspended, due to a combination of staff illness/isolation, lockdown restrictions, and pressures on services.
* Staff shortages were a major problem, despite several initiatives to mitigate these
* There is evidence of increased prioritisation of services (i.e. a higher threshold of eligibility).
* The suspension of day services had a particularly adverse effect on people with learning disabilities.
* The assessed level of demand for social care services was broadly stable, although some reductions in demand were driven by service user and carer concerns about infection rather than reduced need.
* Waiting times for assessment and from assessment to delivery of care increased. The pressures on and gaps in services remained following the pandemic.
* This potentially impacted on individuals’ (i.e. people in receipt of services and carers and social care and social work staff) rights to enjoy autonomy and choice (including family life and relationships), dignity, physical and mental health and independent living on an equal basis with others.

In a response to a Parliamentary Question on 20 May 2020, the Cabinet Secretary for Health and Sport, Jeane Freeman stated that:

*“it is critical that social care support is maintained to ensure the safety, dignity and*

*human rights of people who already receive that support and along with their carers. I have already stated in the Scottish Parliament that it is not acceptable that care packages are cut during this period.”[[313]](#footnote-314).*

The Scottish Government agreed with COSLA that it would meet the excess cost burden brought about by the pandemic to ensure existing and new demands for care could be satisfied. Likewise, local authorities had been notified they should respond appropriately to the pandemic context without feeling constrained by budget concerns, as an additional £50 million had already been confirmed to assist social care cope with the pandemic pressures[[314]](#footnote-315). Further pressure was to be applied to the UK Government for additional funding for health care, local governments and the care sector to continue responding to the crisis.[[315]](#footnote-316) Notwithstanding this intention, it is clear that the prioritisation of support for people with more urgent needs was implemented widely during the pandemic. The aim of re-prioritisation was to redirect support to those with critical needs and protect them from the impact of service reductions. The implementation of this varied across health and social care partnerships.

The current chapter seeks to ‘establish the facts’ in relation to the withdrawal of or reduction in social care services, leading us to conclude that Scotland are in the same situation as The Health Foundation said of England – “*A lack of publicly available data means that we only know so much about the impacts of the pandemic on social care, and the success of policies to support the sector. Data on care provided outside care homes are limited and hard to interpret*”.[[316]](#footnote-317)

There is a significant amount of data gathered in relation to social care, but it is subject to a number of limitations. The Office for National Statistics has commented that historically, social care has not been measured with the same depth of data and analysis as healthcare due to a scarcity of funding.[[317]](#footnote-318) In 2020 the Office for Statistics Regulation published a report on Adult Social Care Statistics in Scotland[[318]](#footnote-319) which said:

‘There are gaps in the provision of statistics on social care – we don’t know how many people currently need social care and whether those needs are being met, how many people might need care in future, and we don’t know how well social care services achieve their goals of helping people to live independently and maintain a good quality of life.’

In November 2022, the Scottish Government published ‘Mapping National Adult Social Care and Care Home Data Sources in Scotland: Baseline understanding & future potential’.[[319]](#footnote-320) It identified a number of priority areas for development, including:

* Reliable indicators of who is in receipt of social care
* Good measures of social care need
* Eligibility criteria and assessment
* Unpaid care provision (described as ‘an important part of the social care sector of which very little is currently known.’)

The only source of publicly available ‘routinely collected’ data we found was provided by Public Health Scotland within their publications and related statistical dashboards - Insights in Social Care: Statistics for Scotland (published September 2020) and Support Provided or Funded by Health and Social Care Partnerships in Scotland 2021/22 (published 28 February 2023).[[320]](#footnote-321)

This social care data is provided by health and social care partnerships in Scotland for people that are fully or partially funded by the Local Authority. People entirely self-funding their care are not included. In the release, PHS caveat the figures by saying: “*The measures put in place to respond to COVID-19 pandemic will have affected the services that the HSCPs [Health and Social Care Partnerships] were able to provide over the period of the pandemic. Differences in data from previous years are likely to be affected by ability of HSCPs to provide social care services while dealing with the impact of the pandemic*.”[[321]](#footnote-322)

The headline figure is that an estimated 1 in 25 people were reported as receiving social care support and services at some point during 2020/21, compared to 1 in 20 people in the years 2018/19/20.[[322]](#footnote-323) The data available on the related dashboards allowed us to analyse changes in the number of people receiving care at home by client group from Q4 in 2019/20 and Q4 in 2020/21. In a second dataset, it was also possible to analyse changes between 2019/20 and 2020/21 for support at home, day care and community alarms/telecare. This data, however, was only available by year, not quartile.

In terms of the first dataset which explores care at home by client group, the data from Q4 in both years revealed 29,240fewer people received care at home in the last quarter of 2020/21 compared to that of 2019/20. The figure below compares the number of people receiving care at home from each local authority, whereby the majority of local authorities report a decrease in people receiving care at home. Glasgow City had the largest decrease with 5,985 fewer people receiving care at home, whereas South Lanarkshire, Dundee City and Highlands reported an increase in the number of people receiving care at home [Figure 1].

*Figure 1: Change in Care at Home by Local Authority from 2019/20 Q4 to 2020/21 Q4*

Although fewer people received care at home in this time period, the data indicates that the hours of care generally increased in 2020/21 [Figure 2]. There was an overall increase in longer care packages lasting 4+ hours, whereas there was a reduction in packages with a duration of 2-<4 hours, with 1,040 less people receiving this length of care [Figures 3 & 4].

*Figure 2: Hours of Care at Home Received from 2019/20 Q4 to 2020/21 Q4*

*Figure 3: Change in Hours of Care at Home Received (2019/20 Q4 – 2020/21 Q4)*

*Figure 4: Change in Hours of Care at Home Received by Local Authority from 2019/20 Q4 to 2020/21 Q4*

The data on client groups shows that nearly all groups experienced reduced care at home [Figure 5]. The elderly/frail represented the largest amount of people being affected with 14,048 fewer people receiving care at home, a 30% reduction [Figure 6]. Learning disability, however, had the largest decrease in care at home compared to the previous year, with a 43% reduction in the number of people receiving any care at home [Figure 7].

*Figure 5: Number of People Receiving Care at Home by Client Group*

*Figure 6: Change in Number of People Receiving Care at Home by Client Group (2019/20 Q4 – 2020/21 Q4)*

*Figure 7: Percentage Change in Care at Home Received by Client Group (2019/20 Q4 – 2020/21 Q4)*

The data shows a decrease in care at home received across all adult age groups [Figure 8]. Comparing the adult age groups, the largest reduction in the number of people receiving care at home was reported for the 75-84 age group with 8,865 fewer people [Figure 9]. The largest percentage decrease, however, when compared with the previous year was shown in the 18-64 years age group, with a 30% reduction in the number of people receiving care at home for this age group [Figure 10].

*Figure 8: Care at Home Received by Age Group*

*Figure 9: Care at Home Received by Age Group*

*Figure 10: Percentage Change in Care at Home by Age Group (2019/20 - 2020/21)*

Public Health Scotland data on ‘Support and Services’ were also analysed, comparing the following service types: care at home; care home; community alarms/telecare; day care; meals and social worker. Across all six support services, there was a reduction in the number of people receiving the following supports: care homes, community alarms/telecare, day care and meals [Figure 11]. In contrast, more people received care at home and social worker support in the year 2020/21 compared to the previous year, with 3,800 more people receiving care at home (4% increase) [Figure 12]. The largest reduction was in identified day care services with a 36% decrease in the number of people receiving this service compared to the previous year [Figure 13].

It is important to note that the ‘care at home’ findings provided in this dataset on ‘Support and Services’ differs from the findings in the previous dataset focusing on ‘Client Group’. The client group data presents a decrease in care at home. The previous dataset on client group compares the data by quartiles, specifically Q4 from each year, whereas it was only possible to compare this dataset (support and services) by year.

*Figure 11: Comparison of Service Types from 2019/20 to 2020/21*

*Figure 12:* *Change in Number of People Receiving Support by Service Type (2019/20 - 2020/21)*

*Figure 13: Percentage Change in Service Type Received (2019/20 - 2020/21)*

Data on ‘care at home’ were analysed further in this dataset and revealed that just under half of local authorities (14 authorities) had a reduced number of people receiving care at home compared to the previous year [Figure 14]. It is worth noting that data for Aberdeen City was missing for the year 2020/21, therefore the following findings are inferred from the data available. Comparing all local authorities, the largest decrease was reported in North Lanarkshire with 460 fewer people receiving care at home compared to the previous year. North Ayrshire had the largest increase of 810 additional people receiving care at home, representing a 22% increase following the pandemic [Figure 15]. Interestingly, the two largest cities in Scotland present significantly different findings regarding care at home during this time period. Glasgow City reports a 4% reduction in the number of people receiving care at home following the pandemic, amounting to 370 fewer people receiving this support. On the other hand, City of Edinburgh reports an increase of 690 people receiving care at home in 2020/21, representing an 11% increase in care at home recipients.

*Figure 14: Number of People Receiving Care at Home by Local Authority (2019/20 – 2020/21)*

*Figure 15: Change in Care at Home Received by Local Authority (2019/20 - 2020/21)*

Data on ‘day care’ were also analysed further revealing half of local authorities (16 authorities) had a reduced number of people receiving day care following the pandemic [Figure 16]. There was missing data for several local authorities in this service type, therefore the following findings are inferred on the available data. Comparing the available data, Glasgow City reported to have the largest reduction at 70% fewer people receiving day care, amounting to 505 fewer people. In contrast, Midlothian reported the highest increase with 245 additional people compared with the previous year, representing a 140% increase in people receiving this support [Figure 17]. When comparing age groups, day care had the largest reduction on the 18-64 years (-21%) and 85+ years (-46%) age groups [Table 7].

*Figure 16: Number of People Receiving Day Care by Local Authority (2019/20 - 2020/21)*

*Figure 17: Change in number of people receiving Day Care by Local Authority (2019/20 – 2020/21)*

Data for ‘community alarms/telecare’ were also analysed and reveals that just over half of local authorities (17 authorities) reported a decrease in the number of people receiving this form of support [Figure 18]. Missing data was also identified for two local authorities in this service type, therefore the following findings are inferred on the available data. Comparing the available data, Dundee City reported the largest decrease in number of people receiving community alarms/telecare following the pandemic with 885 fewer people receiving this support, representing a 15% decrease [Figure 19]. Fife reported the highest increase in people receiving this service with an additional 695 people. When comparing age groups, the 65-74 years and 75-84 years age groups saw the highest reduction in the number of people receiving community alarms/telecare, with decreases of 620 and 2,460 people respectively [Table 7].

*Figure 18: Number of People Receiving Community Alarms/Telecare by Local Authority (2019/20 – 2020/21)*

*Figure 19: Change in Community Alarms/Telecare Received by Local Authority (2019/20 – 2020/21)*

The above findings were inferred from the data available. Please note, the following inconsistencies in data were identified during analysis. The ‘Scotland (All Areas)’ and ‘All Ages’ labels provide slightly different total values to the sum of all local authority or age group labels combined. This can be seen in Tables 6 and 7 (see Annexes) when comparing ‘care at home’ under 2019/20, e.g., Table 6 (see Annex) presents the sum of all local authorities for care at home to be 89,095 people, whereas Table 7 (See Annex) presents the ‘Scotland (All Areas) sum for care home to be 89,110 people. Differences will therefore occur when analysing individual local authorities or age groups.

## 7.2 Other Sources Reporting Reductions in and Changes to Care Packages

The Scottish Parliament Care at Home survey found that 34% of individuals receiving care reported no changes in their care packages, but 33% had their care stopped entirely and 21% reported reductions in their package of care with an average reduction of 20.5 hours per week amongst respondents (reduction range: 30 minutes to 61 hours). Reductions were largely consistent across providers: local authority, non-profit and private sector care organisations, with 43-44% withdrawal and 21-24% reduction of care provision.[[323]](#footnote-324)

A BBC report in April 2020 said that, of the HSCPs that responded, the largest reductions in home-care visits were in Glasgow (34% reduction) and Inverclyde (27%). Data from Glasgow revealed that a third of the elderly and disabled population who were receiving home-care visits were no longer receiving this support. The HSCP for Glasgow stated that their staffing was at reduced capacity (40%) due to staff illness and self-isolation.[[324]](#footnote-325)

In the same report, West Dunbartonshire HSCP stated that *"any temporary changes in care as a result of this challenging and unprecedented situation are optional and are only made after consultation with, and agreement from, residents and their families, and only where the alternative was considered to be in the resident's best interests.”* [[325]](#footnote-326)

An Inclusion Scotland survey in May 2020 found that from a sample of 800 individuals with disabilities, close to 30% reported a reduction or complete cessation of care provision[[326]](#footnote-327).

The Care Inspectorate Inquiry published in September 2020 found that of 23 HSCPs surveyed, 21 reported changes to care packages, and of those 19 indicated that these changes involved reductions with varying proportions from 0.3% to 71% of people being affected by the withdrawal of services (however, some HSCPs reported small increases in care packages affecting 0.2% to 15% of their service users).[[327]](#footnote-328)

BBC Scotland’s report in April 2020 suggested that 3,700 care packages had been affected Scotland-wide following the introduction of the original legislation. This is likely to be an underestimate as eight Scottish health boards had failed to return adequate information[[328]](#footnote-329). This report stated that Glasgow (the largest social care provider in Scotland) had sent letters to 1600 service users explaining that resources had to be diverted to those most in need and that they would be unable to continue care provision, meanwhile a third of elderly and disabled service users had their home care visits withdrawn. They claimed to be operating with 60% fewer staff due to illness and self-isolation.

Glasgow Disability Alliance (GDA) issued a report in August 2020 titled ‘Supercharged: A Human Catastrophe – Inequalities, Participation and Human Rights before, during and beyond COVID-19’. [[329]](#footnote-330) It described the challenges faced by disabled individuals in living independently before the pandemic due to austerity cuts in social care. Further cuts from the beginning of lockdown in March 2020 resulted in around 2000 people in Glasgow having their support reduced or withdrawn with no advance notice and no follow up, forcing them to rely on often vulnerable family members or go entirely without any care support. GDA also highlighted the failure in many cases to address environmental health hazards.

During Parliamentary questions on 11 March 2022, the Scottish Government were asked about data on the number of complaints made as a result of the withdrawal of care packages. Humza Yousaf speaking on behalf of the Scottish Government confirmed this data was not collated centrally and therefore was unavailable, but confirmed that efforts were being made to work with HSCPs to respond to the disruption and minimise reductions in service provision.[[330]](#footnote-331)

## 7.3 Barriers to and Withdrawal of Care for Specific Client Groups

### 7.3.1 People with Learning Disability

The Fraser of Allander Institute published a summary of evidence of the impact of the pandemic on people with learning disabilities. [[331]](#footnote-332) This included a Scottish Commission for People with Learning Disabilities survey which found that 64% of respondents had seen reductions in the regular care they require to live independently.[[332]](#footnote-333) A UK online survey indicated that many adults with learning disabilities had received greatly reduced support or no support at all between March 2020 and February 2021.[[333]](#footnote-334) Day centres and respite care were closed, increasing pressure on family members who would ordinarily share caring responsibilities with paid carers.

The Scottish Learning Disability Observatory found that before the pandemic over a quarter of adults with learning disabilities (27%) and over half with severe learning disabilities (58%) used day services, but by December 2020 virtually all day services had been suspended and by August 2021 32% of all respondents, and 48% of those with severe learning disabilities had not been able to return to their day service in person or online[[334]](#footnote-335) despite services having been given permission to re-open in line with Scottish Government guidance from January 2021.[[335]](#footnote-336)

### 7.3.2 People with Dementia and Older People

Age Scotland reported demand for their helpline increased ten-fold from March 2020, primarily from older callers who were left anxious and distressed following immediate reductions in their homecare services. Age Scotland suggested that social care providers failed to adequately assess whether the families of service users were equipped to fill the gaps in provision, and in communicating clearly when and if home care packages would recommence[[336]](#footnote-337). Similarly, adults living with dementia had their care at home packages cut and were unable to access community-based care including day centres and peer support groups during the lockdown period. Such disruption may have negatively impacted their health and condition, and services being slow to resume delivery of care, particularly in cases where care restarts at a lower level of support, may have negative consequences for individuals and their longer-term health outcomes.

### 7.3.3 People with Sensory Impairment

A report by the Health and Social Care Alliance (the ALLIANCE) identified a number of barriers encountered by adults with sensory impairments brought about by lockdown restrictions and worsened by the reduction in social care support. The requirement to wear face masks reduced the options for lip reading, and there were difficulties with lip to text translation online. Similarly, the online booking of appointments and attending them online or in person without the support of care workers was challenging for many, as was the navigation of public spaces, particularly for those with visual impairments, as parking and layouts had to be altered to respect physical distancing, all of which impacted individuals’ ability to manage their lives independently.[[337]](#footnote-338)

## 7.4 Prioritisation and Changes to Eligibility Criteria

It was reported that some carers and care recipients considered the threshold for support as too high: “*What we were asking for wasn't fancy nancy. It was basic human rights*”.[[338]](#footnote-339) In April 2020, the Equalities and Human Rights Committee of the Scottish Parliament began an inquiry into which groups and individuals were disproportionately affected by COVID-19 and what the Scottish Government could change or improve to mitigate against these impacts.[[339]](#footnote-340) In its response, the ALLIANCE reported that in some cases Health and Social Care Partnerships raised their eligibility criteria for social care, making it more difficult for people to access support[[340]](#footnote-341): “*Care packages reduced to bare minimum… allocated on higher risk assessment… everyone told to get on with it*.”[[341]](#footnote-342)

One respondent shared that they felt support was being prioritised on face value and that they were “*being refused support because there are two parents*” present in their home.[[342]](#footnote-343) Alongside support being reduced and withdrawn, it was also reported that services were redirected and prioritised in a bid to meet ‘*more urgent need’*: *“…we don’t have enough people to provide that support, we’re having to refocus… having to focus on more urgent need.”[[343]](#footnote-344)*

The Scottish Human Rights Commission’s October 2020 Impact Monitoring Report [[344]](#footnote-345) argued that the reduction and cessation in home care plans during the pandemic was potentially unlawful: *“The impact of this policy and practice has had a direct and detrimental effect on people’s rights ... This includes potential unlawful interferences with people’s rights to physical and psychological integrity, and negative impacts on people’s rights to a private and family life without recourse to the normal assessment and review procedures.”* The Commission called upon the Scottish Government to develop a robust emergency decision-making framework which respected and preserved the rights of service users. A Scottish Government spokesperson noted that an additional £150 million had been allocated to social care to help the sector cope with the financial pressures of the pandemic, and asserted that it was unacceptable for some local authorities to have reduced care packages in spite of this.

## 7.5 Reductions/Delays in Assessment of Needs

The Care Inspectorate reported that almost all HSCPs encountered a reduction in demand for care due to service users and their families reducing or cancelling their care packages, largely due to fears of infection and transmission.[[345]](#footnote-346) Echoing this, the Scottish Human Rights Commission noted that many people had changed their living situation to minimise contact with the outside world in order to protect vulnerable people. In many cases this involved service users, particularly the elderly and those with disabilities, moving to live with relatives rather than continue having care workers visit.[[346]](#footnote-347)

Data from 16 local authorities confirmed that the number of new clients over age 65 who received a community care assessment remained stable year-on-year from 2012 to 2019, peaked in 2020 then declined in 2021. This may be due to resources becoming more focused on the greatest need, health inequalities, local government decision making, poverty and geographical location. This decline in community care assessments came in spite of increased spending on adult social care by Joint Boards and local authorities. There have been no national changes to guidance on eligibility criteria for assessments (see 5.2). Nineteen local authorities returned data on clients aged 18-64 but these numbers remained stable from 2019 to 2021. Similarly, new personal care clients decreased from 2018 to 2021 for older clients (based on date from 15 local authorities) but remained stable for those under 65 (based on 20 local authorities).[[347]](#footnote-348)

## 7.6 Waiting Times

Waiting times for assessments peaked in 2020 for over-65s, with 28% waiting for longer than six weeks. This coincided with the introduction of pandemic restrictions, and the level reduced to 21% in 2021 (based on data from 16 local authorities). Younger clients experienced similar increases, with 50% waiting longer than six weeks in 2020, falling to 36% in 2021 (data from 19 local authorities).

There was also an increase in time from assessment to delivery of the required service. In 2020 19% of over 65s waited more than 6 weeks (with only 45% receiving services within two weeks). In 2021 this decreased slightly to 18% waiting for more than six weeks, with an increase to 52% receiving services within two weeks (data from 15 LAs). For clients under 65 there was a decline in those receiving support within two weeks (from 68% to 56%) and an increase in those waiting longer than six weeks (from 16% to 25%) (data from 20 LAs).[[348]](#footnote-349)

Reports suggest that even by July 2023 6200 people were awaiting social care assessments to enable them to live independently, and a further 4000 had been assessed but were awaiting care package delivery. This represents a small improvement since the start of 2023, however the estimated deficit is around 40,000 care hours per week. Scottish Labour argued that this demonstrated underinvestment and chronic workforce shortages in the system, with 71% of housing and care at home support services struggling to fill vacancies by the end of 2021.[[349]](#footnote-350)

Data produced by Public Health Scotland from July 2023 has revealed that 3,964 people were currently on a waitlist for home care.[[350]](#footnote-351) Although this represents a minor improvement compared to figures at the start of the year, an estimated 40,000 hours of care is left unprovided for people requiring support.[[351]](#footnote-352)

Extended waiting times are also affecting those seeking a social care assessment, with a reported 6,253 people waiting to be assessed.[[352]](#footnote-353) A report by the Scottish Government collated data provided by Local Authorities in 2020 and found that more adults were facing longer wait times (over six weeks) for the completion of their assessment.[[353]](#footnote-354) There are reports suggesting that there was little clarity among service providers or recipients as to when access to support could or would resume.[[354]](#footnote-355) [[355]](#footnote-356) Stakeholders reported there being little available information on when day services and community activities would recommence on a local level. They also pointed out the variety in how restrictions were interpreted and applied depending on local level: “*everyone is doing their own things, people are hearing about the phases, but it’s being experienced a bit differently*” (local variation).[[356]](#footnote-357)

The need for greater consistency in Local Authority provision was raised in the Feeley review where both carers and care recipients felt that this needed to be addressed.[[357]](#footnote-358)

### 7.6.1 Displaced Demand and Accessing NHS Services

Changes to healthcare appointment delivery created challenges for unpaid carers and those for whom they care. The move to remote GP consultations reduced the numbers of carers in attendance at appointments. The reduced contact with carers may have led to slower identification of issues and slower or missed opportunities to act upon them. Many vulnerable people were advised to shield early on in lockdown, leading to their carers also having to isolate, exacerbating this lack of contact with medical care professionals for both themselves and for the individual they care for.[[358]](#footnote-359)

With GP appointments taking place online and significant delays in referrals for secondary care assessments, issues for the diagnosis and care for specific health conditions were identified. These had and will have subsequent challenges for the management of long term conditions and wider health and social care partners to the NHS. For example, a study by Brewah et al, (2022) suggested that late-stage diagnosis of motor neurone disease was likely to become more common. Such late-diagnosis was anticipated to place greater demands on social care and end of life nursing care in the community, as well as hospice and palliative care services.[[359]](#footnote-360)

Another example demonstrated the impact on third sector partners. Many third sector support organisations had to switch to online service delivery, and, as a result of 11 out of 14 Scottish Health Boards suspending pain clinics and interventions, it became clear that the organisations would have to work creatively to plug the gap in care provision. Simultaneously, referrals from GP practices to third sector organisations escalated due to the cessation of other secondary care options. [[360]](#footnote-361) The Pain Association Scotland worked collaboratively with the Scottish National Advisory Committee for Chronic Pain to ensure that adequate support was provided in an attempt to prevent treatment access becoming a ‘postcode lottery’.[[361]](#footnote-362) A report from The ALLIANCE cited a similar issue, with chronic pain sufferers being referred back-and-forth between GP and physiotherapy services with neither able to provide the necessary care. The impact of reductions in care provision in such cases has a wider reach beyond the individual service user, affecting the physical, mental and financial health of their families, in some cases leading to hospital admissions for service users as a result of challenging circumstances and support breakdowns.[[362]](#footnote-363)

The ALLIANCE found that people experienced a number of disruptions which hampered their access to healthcare services: health clinics were paused, outpatient appointments and elective surgery cancelled, face to face appointments reduced or cancelled and waiting times increased.[[363]](#footnote-364) Individuals also encountered difficulties when attempting to make appointments or access healthcare services directly, experiencing long waiting times on the telephone, being triaged away from healthcare services and told to “*wait and see what happens*”; “*I reached the top of a waiting list in March. I was supposed to have an appointment since 2019. Now I don’t know if I’m still on the waiting list. Am I on or off*?” (respondent from ALLIANCE report).

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### 7.6.2 Impact of Staff Shortages

Research found that from the beginning of the pandemic almost all local authority service providers and almost half of independent social care providers were reporting difficulties in achieving and maintain adequate staffing levels for a variety of reasons: looking after ill family members at home, or staff themselves shielding; [[364]](#footnote-365) [[365]](#footnote-366) self-isolation periods and inability to use bank staff as they were deployed elsewhere.[[366]](#footnote-367)

Almost one third of local authority care staff were ‘unwilling’ to work, an issue which was not replicated in the independent providers.[[367]](#footnote-368) Staff being placed on furlough and cuts to funding further reduced the volume of care at home that could be delivered. However the furloughed family members of some service users were able to step in to provide care support, which led to a degree of reduced demand on care at home services.[[368]](#footnote-369)

A BBC report from October 2021 said that thousands of service users across Scotland had received letters informing them that their existing care packages may be amended following the pandemic and Brexit which had caused staff shortages and interfered with recruitment. This also caused issues for other services as individuals could not be discharged from hospital without the certainty of adequate community support[[369]](#footnote-370) [[370]](#footnote-371). With demand still high for care at home, HSCPs were struggling to keep up with recruitment demands.

After staff shortages forced Glasgow day-care services to be suspended, Nicola Sturgeon called for their reopening as soon as possible, and asserted that the Scottish Government was working to increase the size of the workforce across the social care sector[[371]](#footnote-372). Social Care minister Kevin Stewart cited one home care company having lost 40% of their staff due to Brexit and arguing that the UK Government were being ‘uncooperative’ in light of requests for visas to allow European care staff to return to work in the UK.[[372]](#footnote-373)

Relevant to staffing challenges were the escalation protocols and rapid responses developed within HSCPs as discussed in a report by the Care Inspectorate. Decisions about the re-prioritisation of care, largely based on staff resources, were most often made by chief officers, but decisions with repercussions at an individual level should be made in consultation with service users and their families[[373]](#footnote-374). Feedback was mixed on the success of this protocol with many impressed by the responsiveness and assertiveness of HSCP leadership and decisions, but others left disappointed.[[374]](#footnote-375)

The SSSC, working together with the Scottish Government, COSLA, the Care Inspectorate and other partners, created a COVID-19 recruitment portal to help social care services in Scotland to recruit and deploy staff during this critical time. This system was set up for social care services and involved contacting people who had recently left SSSC’s register, asking them to apply to work in social care services if required. If care services were struggling with staffing levels, they could apply on the portal for additional staff[[375]](#footnote-376).

The Care Inspectorate, in their 2020 report [[376]](#footnote-377), acknowledged that the lack of clarity in the early stages of the pandemic with regards to shielding and furlough requirements greatly exacerbated problems with meeting staffing capacity. However, it was recognised that those who refused their usual supports and carers who stepped in to replace services, in order to minimise transmission of infection, helped significantly to maintain services during the pandemic and reduce pressure on staffing capacity. The report highlighted that some service providers witnessed a workforce reduction of more than 30% with the majority citing that this peaked in the early stages of the pandemic. To mitigate the impact of reduced capacity, many providers offered existing staff overtime and/or extended contract hours to meet the surge in demand. However, it was reported that this was not sustainable and resulted in some workers feeling exhausted with the workload. Some providers utilised the existing workforce by re-deploying staff from withdrawn services and those needing to shield and transferring them into telecare divisions, where they would provide telephone-based support. Other providers sought to grow the workforce by seeking externally commissioned service providers. Many providers hired displaced workers from other industries impacted by the pandemic such as the hospitality sector.

## 7.7 Effects on Adult Support and Protection Arrangements

Social Work Scotland and the Scottish Association of Social Work (SASW), which is part of the British Association of Social Workers (BASW), highlighted the impact of the COVID-19 pandemic on equalities and human rights[[377]](#footnote-378) with concerns around: the impact on social work practice and delivery; exacerbation of multi-dimensional and cumulative disadvantage for the most vulnerable groups of people; and systemic challenges. One such focus was changes to the provision of Adult Support and Protection Arrangements. Adult Support and Protection is underpinned by the Adult Support and Protection (Scotland) Act (2007) (ASPA)[[378]](#footnote-379) and is designed to support adults who are unable to safeguard themselves. It sits within the wider discourse of public protection[[379]](#footnote-380).

Since 2019/20, there has been an estimated 19% increase in the number of referrals for adults at risk of harm, with an increase in adult protection actions being taken following referral of 9% between 2019/20 and 2021/22.[[380]](#footnote-381) In addition, in 2021/22, there was an increase of 9% compared to the previous two years’ data for people experiencing reported harm in their own homes.[[381]](#footnote-382) It is noted that “*COVID-19 may have impacted these trends*.”[[382]](#footnote-383)

In a report published by the Institute for Research and Innovation in Social Services (Iriss) in May 2023[[383]](#footnote-384) it was noted that “*As the country takes steps to recover from COVID-19 whilst experiencing a cost of living crisis (or high inflation combined with wages that do not keep up), this may have a disproportionate impact on society’s most vulnerable and poorest households.*” When considered in light of a human rights lens, this is also of concern.

As outlined in Chapter 4, rights that were particularly engaged during the pandemic were those to life[[384]](#footnote-385), freedom from inhuman or degrading treatment (dignity)[[385]](#footnote-386), to personal physical and mental integrity[[386]](#footnote-387), and to the highest attainable standard of physical and mental health[[387]](#footnote-388); and these rights must be enjoyed without discrimination[[388]](#footnote-389). Given the observed increase in both referrals for adults at risk of harm and the increase in reporting of being referred following harm in their own homes, combined with the comparatively lagging rate of adult protection action being undertaken (although this has also risen, but to a lesser extent than referrals), this is an emerging concern. More clarity on why the growing rates of action are lower than the growing rates of referrals could be explored, e.g. were actions needed following assessment, and if actions were needed but not yet enacted, are there systemic barriers to this?

A focus on learning and improvement is central to new guidance; in particular on the application of learning reviews which shift focus to learning and organisational accountability rather than culpability. Learning reviews occur when an adult at risk of harm has died or experienced serious abuse or neglect, or where they fit either of these descriptions but have not been part of adult support and protection processes. The learning from these is hoped to inform and improve on system complexity, resource availability, emotional impact on staff, multi-agency working practices, and transparency and dissemination; ultimately improving public protection.[[389]](#footnote-390)

One area which has helped to mitigate the potential negative impact of COVID-19 on Adult Support and Protection Case Conferences is the increased use of online/virtual meetings to ensure that case conferences were maintained throughout the pandemic and lockdown periods. The Adult Support and Protection Code of Practice update, released on 28 July 2022, was explicitly informed by experiences during the COVID-19 pandemic, and now includes reference to virtual visits, interviews, and meetings[[390]](#footnote-391).

Early findings from doctoral research being carried out by Kate Fennel at Edinburgh Napier University suggest that a large proportion, possibly most, Adult Protection Case Conferences have continued to be conducted virtually post-pandemic, to encourage and facilitate attendance[[391]](#footnote-392). Further examples of learning and improvement work which may facilitate practice through supporting staff to navigate the complexities of different sources of information include the production of ‘quick guides’ outlining key features of Adult Support and Protection in light of COVID-19[[392]](#footnote-393) [[393]](#footnote-394), which facilitated transitions between areas during staff re-deployment during the pandemic.

A survey was undertaken of ASP leads on the impact of the pandemic on adults at risk of harm in the first year. The survey responses were not published but were presented at the ASP National Strategic Forum in March 2021.[[394]](#footnote-395)

Work was also undertaken in England by the Local Government Association to understand the impact of the pandemic on adult safeguarding.[[395]](#footnote-396) It found that safeguarding concerns dropped markedly during the initial weeks of the COVID-19 lockdown period, only to return to and then exceed normal levels in June 2020. There was some evidence that some forms of abuse, particularly domestic abuse, increased slightly overall and significantly within some councils, as well as psychological abuse and self-neglect.

# 8. Self-Directed Support and the Independent Living Fund

## 8.1 Key Messages

* The Independent Living Fund (ILF) is an independent body supported by the Scottish Government providing discretionary payments to disabled people to allow them to live independently.
* The ILF responded to the pandemic in a number of ways including providing guidance, making welfare calls, providing additional funding for replacement support or respite, and providing IT equipment to young people.
* Self-Directed Support (SDS) is a framework intended to give people who use social care services greater choice and control over the help they receive

Guidance on SDS during the pandemic was issued in May 2020 and updated 3 times until March 2022.

## 8.2 Background on the Independent Living Fund

The Independent Living Fund Scotland (ILF Scotland) is a Non-Departmental Public Body (NDPB) governed by a Board of directors who are appointed by Scottish Ministers[[396]](#footnote-397). ILF Scotland provides funding and support to help disabled people in Scotland and Northern Ireland to live independently. It was created by the Scottish Government following the closure of the UK Independent Living Fund in 2015. It works in partnership withHealth & Social Care Partnerships and supports over 4000 people through the following funding streams:

* 2015 Fund – providing discretionary payments to disabled people to purchase care and support to live independently.
* Transition Fund – up to £4k to help young disabled people transition into adulthood.
* Person Centred Planning Grant – helping young disabled people plan for the future
* Technology Grant – helping young disabled people to get online.

ILF funding increases the portability of care packages; it reduces inconsistency and inequality of provision for disabled people and creates a dialogue for all disabled people to challenge for their best SDS outcomes.

### 8.2.1 Impacts of the COVID-19 Pandemic on ILF recipients

Within Scotland’s ‘Mainstreaming and Equality Outcomes Report - 2020-22’, published on 4 July 2022, the ILF Scotland presented outcomes of a survey undertaken to review the impact of COVID-19 on its funding recipients[[397]](#footnote-398). Findings included:

* The loss of day services caused a loss of routine for many, leading to anxiety, stress and in some cases self-harming.
* Family carers feeling exhausted and in critical need of further support; currently unavailable due to provider services being withdrawn. Many were at breaking point mentally and physically.
* The loss of family respite services had put an enormous strain on relationships.
* Many had to take unpaid leave from work and in some instances leave a job to provide full time care and have relied heavily on ILF Scotland funding.
* The withdrawal of services has caused anxiety for young people who could no longer participate in their community.

ILF Scotland outlined their response to the pandemic:

* 4,200 welfare and wellbeing calls providing support and guidance to their recipients during the pandemic and lockdown from March 2020 – March 2021.
* £860,000 in additional funding to pay for replacement support where normal support services could not be provided, including PPE equipment, travel, etc.
* Support for carer respite in exceptional circumstances to avoid the collapse of care and the potential for the ILF recipient to have to go into a care home or hospital.
* Applied its Transition Fund policies as flexibly as possible.
* Provided young people who were digitally isolated with basic IT equipment to allow them to stay connected to friends, relatives and professional workers that were important to them.

## 8.3 Background on Self-Directed Support

The ‘Social Care (Self-directed Support) (Scotland) Act’ was passed by the Scottish Parliament in 2013[[398]](#footnote-399). The Act came into force on 1 April 2014 with a guide published by Scottish Government[[399]](#footnote-400). The Act is intended to ensure that people who are eligible for social care support have greater choice and control over how they receive these services. This means care services can be ‘personalised’ to individual needs and wishes. It focuses on five principles:

1. Involvement
2. Information and choice
3. Collaboration – working together
4. Dignity
5. A right to take part in the life of our community.

Councils have a legal duty to offer four options to people who have been assessed as needing a community care service[[400]](#footnote-401):

* Option 1 – a direct payment, which is a payment to a person or third party to purchase their own support
* Option 2 – the person directs the available support
* Option 3 – the local council arranges the support
* Option 4 – a mix of the above.

Scotland’s approach to SDS is guided by a range of policy drivers, namely *the SDS ten-year national strategy* (Scottish Government, 2010)[[401]](#footnote-402), *the SDS Implementation Plan* (Scottish Government, 2019b)[[402]](#footnote-403) and most recently the Independent Review of Adult Social Care (Scottish Government, 2021)[[403]](#footnote-404).

On 6 May 2021, the Scottish charity Iriss published an insight document reviewing the 10 years since the introduction of the SDS ten-year national strategy by the Scottish Government in 2010[[404]](#footnote-405). Within this report, Iriss summarise reports from the Care Inspectorate, Audit Scotland and the Scottish Government that suggesting ‘SDS has had teething problems since its implementation in 2014’, including:

* A limit to the extent to which people have choice and control
* Bureaucracy of processes and procedures
* Lack of transparency and recording
* A lack of the true availability of all four options
* The level of co-production
* Inconsistent knowledge across the workforce.

### 8.3.1 Impact of COVID-19 on SDS

The Scottish Government first published **‘**Coronavirus (COVID-19) self-directed support: guidance’ in May 2020, with the most recent update (V4) published in March 2022[[405]](#footnote-406). The guidance focused on the changing circumstances of the pandemic, and how SDS could be used flexibly in response to the pandemic circumstances. It includes specific information about how supported people can act as employers of Personal Assistants (PAs), and employers of family or friends as Personal Assistants.

Changes across the COVID guidance published 2020 – 2022 are listed below:

* V2 (July 2020): Updated to take into account ongoing changes of the pandemic
* V3 (Feb 2022): Updated to include the Self-direct Support Framework of Standards and the following changes responding to the pandemic:
  + Guidance name change
  + Guidance covers SDS Options 1, 2 and 4
  + Inclusion of the SDS Framework of Standards
  + Maximising flexibility of budgets
  + Enabling worker autonomy
  + People at high risk
  + Employment of family and friends as Personal Assistants
  + Social Care Staff Support Fund
  + Death in Service
  + Personal Assistants Employers Handbook
  + Self Isolation.
* V4 (Mar 2022):
  + Updated to incorporate the use of the existing powers found in section 12A(5) of the Social Work (Scotland) Act 1968. This allows local authorities to provide or arrange for the provision of support without the need for a prior assessment where a local authority considers that the need for services is a matter of urgency.
  + Minimum rates of pay for Personal Assistants employed in the delivery of adult social care

A letter released by Kevin Stewart, Minister for Mental Wellbeing and Social Care encouraged the use of direct payments to services users[[406]](#footnote-407):

*“This addition to the SDS Guidance for the Pandemic is intended to encourage practitioners to consider using the existing powers in the 1968 Act where appropriate to allow Option 1 to be used pending an assessment of social care support. I would like to see this approach being encouraged at local levels in response to ongoing system pressures, including the effects of the pandemic, and in particular, when an individual’s hospital discharge is delayed due to no social care support assessment being carried out.*

*I recognise this approach may not be appropriate for everyone or for all situations, however local authorities must enable worker autonomy, to ensure social workers and relevant practitioners are able to use their professional judgement to decide when it is the right circumstances to use this approach.”*

Although statutory guidance on SDS was updated in November 2022[[407]](#footnote-408), the only reference to COVID-19 is in relation to Death in Service payments. The guidance incorporates the Self-directed Support Framework of Standards published in 2021[[408]](#footnote-409) which were written specifically for local authorities to provide them with an overarching structure, aligned to legislation and statutory guidance, for further implementation of the self-directed support approach and principles. There is no mention of the COVID-19 pandemic within this framework.

On 12 June 2023, The Scottish Government published the ‘Self-directed support: improvement plan 2023 to 2027[[409]](#footnote-410), recognising the need for a whole-system approach to improving the delivery of SDS with partners across the statutory, third and independent sectors. The plan was developed through the National SDS Collaboration which came together in April 2022. This work included an open consultation from Jan to Feb 2023 which highlighted the following as issues to be improved on:

* ensuring people with lived experience are involved in planning services
* ensuring people who need social care support are informed about SDS and understand their rights
* ensuring access to support, including independent support and advice throughout the SDS process
* making sure SDS is included in social workers’ education and ongoing training
* ensuring leaders are informed about SDS and subscribe to the values and principles of SDS.

In April 2020 Glasgow City HSCP issued an information note on direct payments in response to some people experiencing disruption to their payments[[410]](#footnote-411). A Frequently Asked Questions guide to accompany Scottish Government and COSLA Guidance on Self-directed Support Option 1 and Option 2 during the Coronavirus pandemic was issued on 7 August 2020[[411]](#footnote-412). This included information on employing family members, flexible use of Option 1, how to deal with self-isolation and suspension of care, advice on contingency planning, access to PPE for PA and cultural considerations for black and ethnic minority staff.

# 9. Impact on People in Receipt of Social Care Services: People with Lived Experience

## 9.1 Key Messages

The combination of reductions in care support and the impact of lockdown restrictions led to vulnerable populations experiencing significant harms, including the following impacts:

* A loss of independence
* A loss of continuity of care
* Isolation and exclusion
* Negative impacts on mental and physical health
* Increased dependence on family and unpaid carers
* Reduction in use of care services because of concerns about infection, exacerbated by difficulties in accessing PPE

Third sector organisations were described as a ‘lifeline’ for many social care users.

Some groups were particularly affected, including older people and people with dementia, people with learning disabilities, and people experiencing homelessness. There is a lack of specific Scottish data on many groups with protected characteristics, and other vulnerable populations.

The apparent and suspected disproportionate impacts raise human rights questions such as whether persons were able to enjoy their rights to autonomy and choice, dignity, health, physical and mental and independent living on an equal basis with others.

Financial pressures caused by the pandemic increased the risk of homelessness.

People experiencing homelessness or with addiction issues faced the following difficulties:

* Obtaining access to information and advice
* Loss of income
* Difficulties in complying with shielding and social distancing requirements, and risk of criminal sanctions
* Restricted access to mental health support and other treatments
* Services not always able to contact people without a settled home
* Disruption to health services for conditions associated with addictions.

There were some successes including:

* Rapid rehousing projects which virtually eliminated rough sleeping in cities
* Provision of mobile phones to service users to maintain contact
* Emergency legislation protecting people from eviction.

## 9.2 Communication with Service Users

Some individuals complained about a lack of communication from care providers, particularly to notify those in receipt of care about any reductions.[[412]](#footnote-413) This theme arises in a number of reports including that by the ALLIANCE who identified a number of communication breakdowns: between services, between services and their clients, and more broadly at a public health and guidance level. This may be attributable to the difficulties faced in implementing national guidance at a local level, resulting in inconsistent availability and delivery of support, and problems with contacting and accessing services by those who rely on them. However, the majority of HSCPs communicated with service users individually, with others deploying large-scale strategies including writing to individuals and using social media to share important messages about prioritisation.[[413]](#footnote-414)

Respondents to the Scottish Parliament Care at Home survey generally said they felt well informed, however others said the amount of information and guidance was ‘overwhelming’ and it was difficult to differentiate between information for care homes, and for home care, so it was difficult for service users, their families and at times staff, to know what to expect in terms of service changes.[[414]](#footnote-415)

### 9.2.1 Understanding the Restrictions and Being Kept Informed

Another key issue was the lack of information in accessible formats. Not only does this cause feelings of isolation but more importantly it removes a person’s agency to access vital information they need to keep themselves safe and access support.[[415]](#footnote-416) In a report published by the GDA in 2020, 41% of respondent reported having difficulty accessing information in accessible formats, and as a result, 80% were not aware of any local support services they could access. This created worry and concern: *“I got a letter from the government and I’m severely dyslexic so I couldn’t read it – I panicked not knowing what it was – I thought I was in trouble.”* A respondent highlighted the importance of using visual media to convey information: *“Information isn’t available for me in a format I can understand. It needs to be clearer so everyone can understand: using pictures, info-graphics, sign language.”*

## 9.3 Being Left Without Support/Losing Independence

The survey conducted by the Health and Sport Committee of the Scottish Parliament reported in November 2020 that over half of respondents (54%) stated that their care at home support had either paused entirely (33%) or reduced (21%): Recipients of care also reported feeling “completely abandoned” in response to the closure of day services.[[416]](#footnote-417)

Those who experienced their home care being withdrawn shared the drastic impacts that lack of support can have on wellbeing and independence. Fern Adams, aged 26, shared her experience of home care withdrawal that resulted in her losing her independence and spending 23 hours a day in bed. Having to move back in with her mum, a two-hour drive away, she described difficulties in sourcing her specific medication and being left without certain medical equipment:[[417]](#footnote-418) *“Other people can control what my life looks like, so if care stops, that will affect how my life looks. If I have a fantastic care package and really good carers, I could have a really quite a good life. But I’m not in control of how that happens, or if that happens.”; “I don’t really feel I’m living at all. It’s kind of just getting through the basics of being alive from day-to-day, and that’s it.”*

GDA reported, in their 2020 report, that 47% of disabled people were concerned about losing their social care support during the pandemic.[[418]](#footnote-419)

*“Losing more independence and feeling more of a burden than usual is really hard.”*

*“My wife and I are both high risk and had to take on full time care of my mum, whilst still working. We’re doing what we can but no-one’s been in touch and we can’t cope with this indefinitely.”*

*“I was just about managing before my care was cut, just before lockdown. Now, after months with no support, I’m struggling so much I feel I have no choice but to move into a care home.”*

*“I’m terrified my care won’t be reinstated as they’ll argue I’ve ‘survived’ without it. But my mum was forced to move in with me, at the other end of the country, because they cut my care – that’s not sustainable*!”

Derek, who has chronic asthma and visual impairment, shared his experience of being a care recipient during the pandemic: *“for the first seven weeks of this lockdown, I was completely unable to identify a wholly accessible support service to help me sustain my daily living routine following the loss of my two Personal Assistants due to their own personal concerns of contracting Covid19 through their daily working schedule.”* Derek described that he needed support for daily tasks such as shopping, however the process of seeking support was “challenging mentally and physically”, as he did not qualify for initial support. He eventually found support via the council emergency social work department.[[419]](#footnote-420)

A key concern was the withdrawal and reduction of services without proper notice and the ‘trauma’ and harm this can cause: *[[420]](#footnote-421) “support stopped often without much notice and inappropriate communications…”; “support withdrawn almost overnight” … “and that was quite traumatic for people”; “...support stopped and nobody had contacted us.”*

The Scottish Human Rights Commission (SHRC) emphasised, in their monitoring report from October 2020, the human rights concerns that arise from the lack of care and called for social care support to return as a matter of urgency. Specifically, the Commission called upon the Scottish Government and the Convention of Scottish Local Authorities (COSLA) to ensure the provision of care and support returned to pre-pandemic levels.[[421]](#footnote-422)

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## 9.4 Continuity of Care

A reduction in staff numbers affected the continuity of care during the pandemic. Most notably this was “*due to a lot of staff members having to isolate due to health conditions”* and “*staff on sick leave*.”[[422]](#footnote-423)

A Scottish Parliament report (Nov 2020) found ‘continuity of care’ was important to participants:[[423]](#footnote-424) *“that services are able to continue and not be closed again’ and care services are ‘not changed and my routine is kept as normal as possible”* and *“the care service continues to be delivered according to the care plan – I would be in an impossible situation if this could not continue.”*

It is important that care plans are reviewed to ensure needs are accurately being met:[[424]](#footnote-425) *“My care plan has not changed at all in 2 and a half years but I feel my needs have changed, I’ve had no review from social work or care providers. They keep on promising to come and do it but they haven’t ever got around to it.”*

It was highlighted, however, that continuity of care is only possible if there are ‘enough staff’ and high staffing levels ‘to cover those who will need to self-isolate or quarantine.’[[425]](#footnote-426)

A report by Armstrong et al. (2020) highlighted the impact to everyday life and routines. These were described as being particularly important to disabled people and those with long-term conditions: [[426]](#footnote-427) *“For other participants with LTCs, [Long-term conditions] the change in daily routine disrupted carefully managed sleeping and eating patterns and made it more difficult for them to remember to take their medication.”*

One participant in a study reported that the disruptions in routine caused them to forget taking their medication:[[427]](#footnote-428)*“For example, this person living with epilepsy explained: I’ve also noticed that, well I use an app to take my meds, but at the time, I’ve also noticed that I’ll also sometimes forget, or I’ll just press the app to say that I’ve taken my meds, but I’ve, I might have just forgotten. I honestly can’t tell… so I think I’ve definitely forgotten a few times, or even, doubled.”[[428]](#footnote-429)*

## 9.5 Impact on Mental and Physical Health

For some individuals with pre-existing conditions, the closure of services appeared to worsen their symptoms as many individuals experienced delays in accessing appointments and/or treatment.

GDA in its 2020 report, stated that disabled people and people with long-term conditions had crucial healthcare cancelled during lockdown, resulting in a significant impact on their health. 90% of respondents in the report had concerns for their mental or physical health during the pandemic:

*“Lockdown is worsening my condition and wiping out all the work I have done to build up my health and stamina.”*

*“I’m terrified of losing care for my degenerative condition – I could lose my sight.”*

*“The stopping of non-essential services means we stopped a lot of prevention work and my long-term condition was physically a mess by the time I could re-access a services. That could have been prevented. Some of us got sicker.”*

The GDA report revealed that having a long-term physical condition makes individuals with disabilities more likely to experience mental health challenges.[[429]](#footnote-430) On mental health support more generally, the report highlighted the benefit of user-led, community-based groups: “*Being connected to GDA, Flourish House, the Mental Health Network, who understand the challenges, and check in so you know someone cares.”[[430]](#footnote-431)*

The negative effects on mental wellbeing were also discussed by participants at the Scottish Government’s Renewal Advisory Board Listening Events. Respondents reported that lockdown worsened their mental health, as a result of forced distance from communities: [[431]](#footnote-432)

*“I struggled with mental health and had nowhere to escape”*

*“I have mental health problems and lockdown made it much worse” “I often feel lonely and distressed now”*

*“There was no socialising in the community due to the lockdown which again was a strain on people’s lives in different ways. It caused depression in some people I know or made their anxiety much worse”*

Social distancing was a particular cause of poor mental health. This was reported in a study by Tomaz et al. (2021) whereby the impact of social distancing was investigated and found to contribute to feelings of loneliness having increased during the pandemic compared to pre-pandemic. Positive coping strategies included increasing online social contact with both existing social networks and reconnecting with old networks, as well as increasing contact with neighbours and people in the community.[[432]](#footnote-433) Care workers responding to the Scottish Parliament Care at Home survey noted that ideally service users had regular carers visiting. This would minimise potential cross-contamination from travelling home to home, minimising infection risk whilst also providing a level of care continuity, and also offer continuity of care/relationships with the care worker. However, this was not always possible due to staffing levels and staff felt it was essential that more robust contingency or crisis planning was undertaken to cope with future outbreaks and low staffing levels to ensure everyone is kept safe.[[433]](#footnote-434)

## 9.6 Isolation and Exclusion

These were identified across the literature as key outcomes from COVID-19 restrictions, notably social distancing measures. It was highlighted that leaving the house and engaging with communities was already much harder for disabled people, due to inaccessible environments; lack of support; and negative attitudes, and that this had been exacerbated by the pandemic:[[434]](#footnote-435)

*“Support seems to be for elderly folk, not younger disabled people like me. I’ve had really nasty reactions so I gave up trying to ask for help.”*

*“I feel I’ve been completely let down by the society that was supposed to care for me.”*

*“Some people are in total isolation and relying on care which might not be stable – we need to remind people we exist!”*

Internationally, research has demonstrated the negative effects of COVID-19 stay-at-home orders and lockdowns on people’s mental health.[[435]](#footnote-436) However, most studies have only focused on perceived negative lockdown experiences on aspects such as loneliness, psychological wellbeing, and physical health. In a cross-cultural comparison (US and UK samples) which explored both positive and negative experiences of lockdown, people were asked to indicate the ‘best’ and ‘worst’ things about lockdown for them. As a simplistic measure, there were equal proportions of positive and negative experiences reported. When explored in more depth, people reported three key themes: ‘health, self and wellbeing’, ‘being with others’, and ‘concerns with daily living’. Within these, specifically considering experiences of isolation and exclusion, this was more commonly reported by younger people, females, and people not in a relationship or living alone. People with children reported most issues around daily living and routine disruption. The most commonly reported worst thing about lockdown in this study was being physically apart from others and not being able to do routine, everyday things and activities.[[436]](#footnote-437)

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## 9.7 Reliance on Family and Increased Dependence on Carers

In a joint response to the Scottish Recovery Committee from Age Scotland and About Dementia in January 2022, it was highlighted that family and friends of care recipients were asked by partnerships and Local Authorities to help with care duties after reductions to support were implemented. Some people receiving care were told that their usual level of support would be minimised.[[437]](#footnote-438)

Recipients of care reported having no choice but to rely on family members for care and support. Some felt there was an implicit assumption to rely on family members: “*being refused support because there are 2 parents’ present in their home.”[[438]](#footnote-439)*

Despite having no choice, some individuals receiving care felt they were a burden to unpaid caregivers and felt ‘pressure’ to end temporary care arrangements and reinstate original care packages as soon as possible.[[439]](#footnote-440) Other care recipients said that they did not want to rely on family. Kate Walsh, 29, who has cerebral palsy shared that she relies on her mum for the majority of her care after she struggled to find replacement support. She said: *“I would rather have PAs [personal assistants] or carers coming in to help me because I don’t want my mum doing it”* and *“I just want to be treated like everybody else that’s 29*”.[[440]](#footnote-441) These experiences suggest that reliance on family not only puts pressure on the family member taking up caring duties but also can remove a great deal of independence from the care recipient and add strain to existing relationships.

The impact of the pandemic meant that many tasks became more complicated for recipients of care, such as shopping and socialising. This affected the independence of many recipients of care, causing them to become more dependent on their caregivers.[[441]](#footnote-442)

Some carers reported being subject to increased expectations during this time for caring duties, which often affected their ability to work from home.[[442]](#footnote-443) One participant reported that this left them feeling more exhausted, with less time for themselves: “*He has become more demanding, if he sees me around, he would call for me more often, or just call me no matter what happens just because I am here . . . He might keep asking for food every 2h . . . Or he might ask me to turn off the aircon, or fan, or lift him around.”*

COVID-19 restrictions changed the dynamic of many caring relationships. Lockdown forced parties into closer proximity for extended periods of time, which was intensified with social distancing measures. Some carers moved in to live with their care recipients, to minimise transmission of infection.*[[443]](#footnote-444)*

*“I care for my teenage daughter and am working from home most if not all of the time, so my caring role is fairly constant”*

*“It’s everyday all day now. But before I was able to go out and got a break but since the pandemic, it’s been a year since I have been out at all.”*

*“Because of the pandemic I have mostly spent the last year with my cared for person due to shielding.”*

A study by Liberati et al. (2021) focused on identifying the impact of the pandemic on caregivers’ mental health and found that most reported feelings of social isolation, which affected the quality of care they were able to provide.[[444]](#footnote-445)

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## 9.8 Reliance on Third Sector Organisations

A study by Cullingworth et al. (2022) describes third sector organisations as a “saving grace” “*providing a bulwark against the isolation of the pandemic.”*[[445]](#footnote-446)

Support ranged from meeting basic needs (such as food, prescription delivery etc.) to ensuring individuals’ human rights were defended. This support was viewed positively by individuals with disabilities who valued the role that disabled people’s organisations (DPOs) played in their lives during this time:[[446]](#footnote-447) Isla, who has dual sensory impairment, described DPOs [disabled person’s organisations] as “*they are just saving my life at the moment psychologically that lot”*; and Belinda, who has mental health issues, stated “*I would be in a bad way if they had their funding withdrawn.*”[[447]](#footnote-448)

Volunteers at helplines were described as being particularly helpful with dealing with feelings of isolation of the pandemic and a good resource to turn to: “*There’s a Mind volunteer who phones me on a Friday and has been constant through lockdown, so I’ve actually looked forward to that.”*

As a result, the third sector played a key role in helping “*create and sustain communities.”* One organisation in Glasgow attempted to call all its members at the start of the pandemic, making contact with 1,200 people within the first five weeks to carry out wellbeing and safety checks and identify needs. This resulted in help to facilitate food deliveries and providing those isolated with technology/communication devices.[[448]](#footnote-449)

Wellbeing calls were reported as being helpful: *“I must admit they have been helping me so much the last few weeks just with wellness phone calls and it has made such a difference to just talk my problems through with somebody and to actually be listened to because as a disabled person, especially with mental health problems, people don’t want to listen to you.”* (Hannah)

Provision of advocacy for disabled people’s needs was described as providing *“comfort*” (Valerie, with visual impairments, described RNIB’s initiatives). The efforts by third sector organisations were reported as transformative, as they worked with disabled people, to co-create and co-produce new services that met their needs, as defined by them.[[449]](#footnote-450)

In Scotland ENABLE, a large charity for people with learning disabilities, took a proactive approach to capturing and reviewing the needs of those needing or receiving care, seeking input about what their needs are and how they can be met. In addition, ENABLE representatives hosted a phoneline to provide individual emotional support and facilitate a range of online peer activities. [[450]](#footnote-451)

Participants in the study shared positive experiences when recounting the role the sector played in their lives:[[451]](#footnote-452) *“… without the work that the third sector have done, in supporting our members and supporting the wider community, we’d have been on our knees.”*

The responsiveness of the third sector and the vital role it played in the lives of disabled people is in direct response to the reported lack of support provided via statutory services. Where statutory services failed, the third sector stepped in to support people:[[452]](#footnote-453)

*“Arthur, a man with a physical impairment and mental health issues, described his role in providing peer support through his affiliation with a local organisation: ‘So, lots of people that haven’t been getting support have been washing up on my doorstep … I’m hoping to solve little problems before they become major issues … I don’t begrudge the help I’m giving to people … My anger and upset is towards the statutory organisations, not towards the people I’m helping.”*

*“When one couple has gone from 21 hours [of] … professional support a week down to less than an hour, it takes a lot for peer support to make up that kind of difference”*

Many stakeholders shared that they had given up on government services and instead found more support and comfort from third sector services: “*I’ve been reliant on … the community initiatives” (Jason);* and *“The people that are helping out most are the charities, they’re catching people falling through the net” (Caitlin)*

There was an implicit reliance on third sector organisations to step up and meet the demand from those in need. The Cullingworth et al. study (2021) revealed that DPOs were contacted by Local Authorities to fill the gaps in support for disabled people.[[453]](#footnote-454)

There was shared criticism towards the inadequacy of the state’s response, particularly the challenges with accessing support and communicating with statutory workers. Participants described phone lines constantly being busy and a lack of clear information on when services would resume.[[454]](#footnote-455)

A study by Hutcheon and Steiner (2022) investigated the role of community-led organisations in promoting the health and wellbeing of disadvantaged populations after the pandemic.[[455]](#footnote-456) It was found that increased social networks, sense of belonging, and fewer instances of social isolation and loneliness had the largest effect on improving the social wellbeing of service users. Increased attention to social wellbeing led to wider positive mental and physical health impacts, such as decreased likelihood of depression and increased mobility.

Some international examples of mitigating systemic challenges include innovations in ongoing communication with service users to reduce social isolation and help protect their mental health; collaborating with emerging mutual aid organisations to further support community social work; and practical and pragmatic steps to assure peoples’ safety and reduce risks of harm[[456]](#footnote-457). Critiques of neoliberal approaches from the international social work community suggests looking for alternatives to resource distribution and service provision[[457]](#footnote-458). Relatedly, suggestions have been made that Modern Monetary Theory may be able to address this, and that ‘COVID-19 has highlighted that the health and survival of society is dependent on the provision of care and the structures providing it’.[[458]](#footnote-459)

## 9.9 Difficulties Accessing Supplies and PPE

A qualitative study by Pearson et al. (2022) found that accessing supplies was a key problem for many disabled people. The sudden lack of support resulted in them having to make their own arrangements. In Glasgow and London, disabled people’s organisations became the main source for supplying PPE after the local HSCPs/LAs were unable to offer this for disabled people using home care services, with this being cited as an example of how home care was excluded from policy planning related to the pandemic, as was evident from the absence of support from statutory services, which hindered independent living as a wider policy goal.[[459]](#footnote-460)

A study by Glass et al (2023) revealed ‘the unequal distribution of societal risk during the pandemic, exacerbated by a legacy of precariatisation and individualisation in the labour market and welfare reforms. Although the state acted to mitigate risk and financial hardship during the lockdown, it was often voluntary and community organisations that filled the gaps left by the inability of the state to reach effectively into rural areas.’[[460]](#footnote-461)

The Pearson study found that many disabled people felt that they had to ‘negotiate their own risk’ by either trusting PPE, if they could access it, or limit who was safe to enter their homes.[[461]](#footnote-462) Negotiating this risk and attempting to avoid contact with the virus often became too complicated and many recipients of care relied on family and other informal carers. A study by Shakespeare et al. (2021) built on these findings, and reported that many participants felt anxiety around who was entering their home, for fear of contracting the virus, therefore caregivers were replaced by people ‘already within their social bubble’.[[462]](#footnote-463)

## 9.10 Impacts on Particular Groups

### 9.10.1 Impact on Vulnerable Groups

Whilst there is no consensus on what ‘vulnerability’ means in a health and social care context[[463]](#footnote-464), one broad ranging definition which encapsulates the changing nature of vulnerability across a person’s timespan is proposed: “everyone can be vulnerable and this will vary depending on the context, the situation and across the person’s lifespan.”[[464]](#footnote-465) Consensus exists among social work academics, practitioners and service users, that some people were disproportionately more vulnerable to the impact of the COVID-19 pandemic. Specifically, these groups could be broadly divided into two categories. The first category includes people with any combination of protected characteristics [[465]](#footnote-466) such as people with disabilities [[466]](#footnote-467) and people from ethnically diverse communities [[467]](#footnote-468). The second category includes those who were vulnerable due to their life situations and needs such as adult mental health populations [[468]](#footnote-469), people experiencing homelessness[[469]](#footnote-470), the Roma community[[470]](#footnote-471), people subject to domestic and/or gender-based violence, and social work students [[471]](#footnote-472). Situations arising where a person belongs to both categories suggest even greater risk.

This list is not exhaustive as to date there is only limited evidence available on a Scottish-specific context during the COVID-19 pandemic. Relevant omitted populations include Scottish rural communities, people involved with the criminal justice system and people who misuse substances[[472]](#footnote-473). International research extends this list to include forced migrants[[473]](#footnote-474), and black poor women[[474]](#footnote-475). Conversely, positive effects of the pandemic may be seen in identifying otherwise hidden and vulnerable populations and therefore being better equipped to review and improve service provisions.[[475]](#footnote-476)

### 9.10.2 Older People and Dementia

The UK-wide perspective suggests specific barriers to engaging remotely with people with advanced dementia due to the nature of the condition[[476]](#footnote-477), and there were calls for further investigation into the experiences of women living with domestic violence during this period. Of specific interest are the forms of support both groups drew on during the national lockdowns, and how they coped with the crisis.[[477]](#footnote-478) The Scottish Government’s Dementia Action Plan (Dec 2020) reported that the reduction and withdrawal of services had a big impact on individuals’ confidence and independence: [[478]](#footnote-479)

*“I’ve lost confidence. I want to go out independently but I can’t. I want to do the right thing but I don’t know what the right thing is, so I’d rather do nothing than get it wrong.”*

*“The Scottish Government champions independent living for older and disabled people within their community. Living in the right home with the right support can be the key to enabling people to live safely and independently at home.”*

In their consultation response to the Health and Sport Committee in September 2020, Age Scotland cited care recipients who shared their experience of having their support services withdrawn.[[479]](#footnote-480) Complete withdrawal of support resulted in individuals being “*left to cope on [their] own.”* - *“We heard from a woman (aged 87) who lived alone and had been recovering from a broken arm after falling in the shower and now struggled with dressing and washing herself. Previously her package of care included a daily visit, however, with no explanation she was informed that her service would be stopped. Although her family could help with shopping, they were not confident providing personal care. The abrupt removal of her care package meant this woman had been left to cope on her own, despite being too anxious to use the shower due to a previous fall.”*

Charities such as Age Scotland criticised increasing waiting times for assessment or receiving a service, stating that it is *“wholly unacceptable for so many older people to spend weeks in limbo”* whilst they are seeking help. They reported that their helpline was inundated with calls from care recipients and their families concerned about the waiting times. There was concern that the extended wait times would affect the health, wellbeing and recovery of many individuals needing support. Evidencing this concern, a committee briefing paper presented to Scottish Government identified that between December 2019-January 2022, there were 11,817 excess deaths recorded. Of these, 94% were caused by COVID-19 directly or indirectly (i.e., as a contributing factor), meaning that there were an additional 709 excess deaths recorded in this time-period which were not caused directly by COVID-19.[[480]](#footnote-481)

The CEO of Age Scotland, Katherine Crawford, stated that “*the longer people wait for care, the more acute their needs become*”, therefore, “*urgent action is required from Government, councils and policy-makers”* to ensure people receive the care they are entitled to.

Access to dementia support services before the time of COVID-19 was mostly described as a difficult process. Long waiting lists and poor communication between the various services led to delays in accessing support. The impact on delayed access to support was described, mentioning fears of long-term social isolation.

*“we did eventually manage to access our Link Worker, it took another twelve months after his diagnosis to get that. I've been fighting to get some support for his meals since September 2019 and we are about to get the support just before Christmas when there was a change in the occupational therapist and then of course we had the Christmas rush and he put on to the waiting list... my father was again on the waiting list to go and join a day centre with him, we are extremely worried and concerned about him becoming socially isolated” Female carer (spouse), 52 years old.*

*“Within the past year probably we’ve been engaging with Social Services to try and engage my Dad and get him some support and support for myself and my aunt but that’s been a* slow *process just trying to you know build up trust in relationships and assess how that’s going to work” Female carer (daughter), 40 years old.[[481]](#footnote-482)*

### 9.10.3 People with Learning Disabilities

Research into the impact of emergency legislation on people with learning disabilities during the pandemic identified four principal areas of concern[[482]](#footnote-483). There was a notable absence of this group from consideration in the national response strategies; social care services/packages were removed at very short notice, impacting service users and their families; many experienced profound social isolation due to disruption of day services (such as book clubs and drama groups); and there was a lack of vaccine support and associated efforts to prioritise this group despite their susceptibility to the disease. Consequently, questions were raised regarding the extent to which the human rights of people with disabilities were upheld under the circumstances.

A longitudinal study by Flynn et al. (2022) investigated access to support during the pandemic from the perspective of individuals with learning disabilities.[[483]](#footnote-484) Data supports claims that people with learning disabilities who received care pre-pandemic stopped receiving or received drastically reduced support during the pandemic. There were indications of increasing access to some services and supports between Wave 2 and 3, but this was not universal.

Individuals with intellectual disabilities are believed to be at a greater risk of contracting the virus[[484]](#footnote-485). The daily lives of this population were also shown to be greatly affected, as the routines and structure that many rely on were disrupted due to restrictions.[[485]](#footnote-486)

A report published by Armstrong et al. (2020) identified that many respondents with learning disabilities led reasonably isolated lives pre-pandemic, and therefore the social distancing requirements exacerbated this: “*Participant: It was quite hard because you didn’t get to see anybody, the only person I had seen was your support staff and that. Researcher: So, do you have friends or family that you usually like to spend time with? Participant: I've not really got any, any family.”[[486]](#footnote-487)*

In an extreme case, the Scottish Human Rights Commission shared the experience of an older man with a learning disability who was found “catatonic in bed” with low bodyweight due to lack of social care.[[487]](#footnote-488)

The issue of accessible information is particularly pertinent to people with learning disabilities. Without information in accessible formats, people with intellectual disabilities, may have difficulty understanding the reasons for certain restrictions and the changes to their daily lives.[[488]](#footnote-489)

### 9.10.4 Homelessness, Alcohol and Drug Addiction

The COVID-19 pandemic created new problems and exacerbated existing problems for people impacted by homelessness[[489]](#footnote-490), alcohol and drug addiction. Many such individuals have multiple morbidities or compromised immune function and are therefore additionally vulnerable [[490]](#footnote-491) [[491]](#footnote-492) due to increased likelihood of severe disease and/or death[[492]](#footnote-493) [[493]](#footnote-494). Specific risks included:

* Difficulties accessing alcohol
* Challenges with managing new pandemic rules such as the wearing of masks in shops
* Loss of income from street begging/pan handling to purchase alcohol
* Restrictions on using cash rather than credit/debit cards
* Sharing alcohol
* A street drinking culture making social distancing and/or self-isolating difficult Potential increased intake of non-beverage alcohol (i.e., hand sanitiser or rubbing alcohol) [[494]](#footnote-495) [[495]](#footnote-496) [[496]](#footnote-497) or illicit drugs being used as a substitute[[497]](#footnote-498) [[498]](#footnote-499) [[499]](#footnote-500) [[500]](#footnote-501)
* Physical distancing and self-isolation contributing to even greater social isolation, marginalization, and loss of social networks.[[501]](#footnote-502)
* Phone and online support offered some benefits to older adults but there were also disadvantages.[[502]](#footnote-503)
* Access to alcohol rehabilitation services.

#### **9.10.4.1 Homelessness**

The majority of services that support people facing multiple disadvantages, such as people experiencing homelessness (PEH) faced pressure to rapidly adapt services to meet needs during the COVID-19 pandemic. In Scotland, there were a number of changes made to service landscapes and included: PEH were rapidly rehoused in hotels[[503]](#footnote-504); individuals no longer had to use the local choice-based lettings system for new social housing tenancies[[504]](#footnote-505); the Coronavirus (Scotland) Act 2020 included a provision to protect all renters from being evicted from their accommodation during the pandemic.

The ‘Everyone In’ scheme which was deemed to reduce the number of rough sleepers and provided access to ‘wrap-around support’ ended after the first national lockdown. After the first lockdown, those at risk of homelessness such as those affected by the financial impact of the pandemic and individuals coming out of prison were housed depending on the procedures of their local authority.[[505]](#footnote-506) The negative financial implications of the pandemic led to increased demand for housing services. People already receiving low incomes were further negatively impacted due to loss of jobs or reduced income due to the furlough scheme.

#### **9.10.4.2 Emergency Accommodation**

Rapid rehousing in hotels for PEH allowed people to self-isolate effectively[[506]](#footnote-507);

However, the pitfalls of emergency accommodation include a lack of essential facilities and inadequate living conditions, peer pressure, abuse and increased prevalence of drugs and alcohol, the regular witnessing of death, and feelings of re-traumatisation and of being isolated and trapped[[507]](#footnote-508).

Access to mental health support was restricted during the pandemic and was the service most affected. Many of their clients were suffering due to isolation, lack of social interactions and worsened financial issues during the pandemic.

#### **9.10.4.3 Alcohol Addiction Services**

The pandemic presented a number of challenges for alcohol addiction services. These included:

* Staff not being aware of existing protocols for service delivery.
* Restrictions of provision of substance use hospital liaison services because of staffing issues associated with workforce rotation, phone advice and staff redeployment to acute services.
* Reconfiguring services to accommodate the need for physical distancing.
* Individuals’ reluctance to approach services[[508]](#footnote-509)

Additional problems have been identified for people who use drugs (PWUD) during the pandemic, e.g., the inability to shield or isolate oneself due to not having safe housing; difficulty with social distancing; poorer access to resources to protect health (e.g., PPE); potential medication shortages and/or disruption to health services such as hepatology appointments[[509]](#footnote-510); criminal justice sanctions resulting from breach of lockdown rules ( with the likelihood of fines being issued 12 times higher in deprived areas)[[510]](#footnote-511). To address the increased risk of harm in the context of COVID-19 there has been a call for rapid changes to substance use services and treatment[[511]](#footnote-512) [[512]](#footnote-513)[[513]](#footnote-514).

#### **9.10.4.4 People Who Use Drugs (PWUD)**

Scotland responded to COVID-19 by funding enhanced social services for people with drug addiction. In some places, the public health imperative to contain COVID-19 has bolstered housing for PWUD[[514]](#footnote-515) (e.g., the Simon Community in Scotland implemented a rehousing project which virtually eliminated outdoor sleeping in Edinburgh and Glasgow within 72 hours). Community-based organisations also conducted in-person street outreach to maintain contact with PEH or who were otherwise hard to find.[[515]](#footnote-516)

People experienced difficulty in accessing statutory alcohol and drug rehabilitation services (e.g., difficulties securing face-to-face appointments, a reliance on virtual meetings, with little outreach or follow ups provided when requested, a lack of communication and consistency).

Healthcare workers’ confusion over COVID-19 rules resulted in feelings of insecurity, powerlessness, and stress in a dysfunctional manner which had clear implications for therapeutic relationships. Technology problems also adversely impacted on service quality and communication[[516]](#footnote-517)

Further adaptations included weekly prescription collections for individuals supported by addiction services instead of daily collections reducing the time burden for PEH collecting opioid substitution therapy. Closing day centres removed a safe space for individuals to socialise and reduced the capacity for donations.

In addition, participants described that access to illicit substances such as street heroin and methadone by PEH was hindered during the pandemic, which led to a higher demand for the drug and alcohol services.

Many described that the lack of face-to-face contact made the support individuals received less effective as many struggled with remote forms of communications.

One study looked in detail at the experiences of a drop-in service in Edinburgh for people who are, or at risk of being, affected by homelessness. [[517]](#footnote-518)

Whilst staff had made an effort to gather client contact details before the lockdown occurred, they were still left without a means of contacting some. A major early development was the distribution of smartphones with data to clients who either did not have telephones or who had no means of accessing the Internet. This was made possible through a range of funding sources. The distribution of telephones allowed staff to remain proactively in contact and offer emotional and practical support to clients and allowed the groups, which were a major aspect of the centre, to occur online. For some clients this was the first time that they had had access to a smartphone. There were initial concerns, external to the service itself, that clients may lose or sell these telephones, but this largely did not materialise.

By early May, after the initial period of crisis support and intervention, both staff and clients described a more settled pattern of service provision. Staff were able to provide practical and psychological telephone and online support to clients. As individual situations became more settled over the course of lockdown staff were able to move from crisis intervention to support focused on emotional and psychosocial needs.

The continued provision of harm reduction services over this time was beneficial to existing clients and those who had previously accessed other services which had closed.

# 10. Impact of Telecare and Other Remote Means of Providing Support

## 10.1 Key Messages

The pandemic led to a rapid acceleration in the use of telephone and online technology replacing face to face meetings in health and social care.

This led to significant efficiency benefits in some areas, including routine follow-ups and specialties where there was no requirement for physical examination.

Virtual and online support was sometimes used in innovative ways as an important means of maintaining contact and keeping busy.

Helplines were valuable supports to many service users.

Remote support was problematic for a number of groups, particularly:

* Deaf and hard of hearing people, who could not easily use telephones
* People affected by digital poverty or with low levels of familiarity and comfort with digital technology, including many older people
* People with learning disabilities or dementia.

Other problems included:

* Limitations on support by family carers, who could not be present during calls
* Variable technical competence by health and care staff, and variable technical quality of the remote access mechanisms
* Ethical issues around delivering a diagnosis without the usual support mechanisms
* Deterioration in mental health from service users unable to access face to face support.

This potentially impacted on individuals’ rights to enjoy autonomy and choice (including family life and relationships), dignity, physical and mental health and independent living on an equal basis with others.

The COVID-19 emergency gave governments reason enough to remove regulatory blocks to rapidly purchase and use newly-developed technologies, especially bespoke software for supporting video consultations use of which significantly increased as a result[[518]](#footnote-519).

The use of remote support played a significant role in slowing down the transmission of the virus via the “social gap” or social distancing that was made possible by the reduction of person-to-person contact[[519]](#footnote-520) thus protecting people who were at greater risk of developing the disease (e.g., elderly people and those with underlying diseases) and built on the previous NHS Near Me initiative.

In March 2020, when the COVID-19 outbreak reached Scotland, most routine and non-urgent care in both primary and secondary care was halted. Space and staffing were repurposed to support the pandemic response[[520]](#footnote-521). Rollout of the Near Me video service was accelerated via a 12-week scale-up plan, led by a rapidly-assembled national implementation team within the existing Technology Enabled Centre (TEC) Programme. Staff were drafted in from across Healthcare Improvement Scotland, the Scottish Access Collaborative (a government programme to sustainably improve waiting times for non-emergency procedures) and the Care Inspectorate. They prepared guidance and resources for deployment of video consultations across a range of health and care settings and built links with other key government departments[[521]](#footnote-522).

Between March 2020 and June 2020, the number of video appointments increased 50-fold, from about 330 to 17,000 appointments per week nationally, and over 50 clinical specialties introduced video consultations for the first time[[522]](#footnote-523). Whilst many general practices introduced the Near Me service model, most used it infrequently and ad-hoc, so that general practice as a whole accounted for only 23% (81,822/362,828) of all video consultations in Scotland. Amongst hospital and community specialties, the services accounting for most video activity were psychiatry, psychology, and community mental health (36% of all hospital and community care activity 94,876/260,547), physiotherapy (9%, 22,909/260,547) and paediatrics (8%, 20,354/260,547)[[523]](#footnote-524).

## 10.2 The Advantages of Telecare and Other Remote Support During the Pandemic

Prior to the pandemic, almost all new consultations in secondary care were face-to-face, in order to establish a clinical relationship, undertake a full physical examination and conduct baseline assessments[[524]](#footnote-525). Video consultations were used primarily for routine follow-up of chronic, stable conditions, especially to convey test results and affirm that the patient remained asymptomatic. Video was noted to be very useful where there was no requirement for formal physical examination: examples include psychiatry, psychology, counselling, respiratory medicine and speech and language therapy, where visual, non-verbal communication was important and personal protective equipment might interfere[[525]](#footnote-526). Because of pandemic restrictions, GPs considered telephone communications adequate for most problems in known patients, since they felt they rarely needed to rely on visual assessment or physical examination. Video was sometimes considered crucial for visual assessment to exclude rare but potentially serious acute problems such as infection[[526]](#footnote-527).

## 10.3 The Disadvantages of Telecare and Other Remote Support During the Pandemic: Digital Exclusion

Many deaf and hard-of-hearing patients found remote consultations by telephone impossible, while those able to lip-read or use the chat function often welcomed the option of video. Hard-of-hearing patients and staff were greatly handicapped by the requirement to use face coverings in face-to-face settings, making a video consultation a more attractive option[[527]](#footnote-528). A lack of familiarity and low digital literacy explained some patients’ reluctance to use video even in the absence of a relevant disability or co-existing condition. Whilst the pandemic provided impetus for upskilling, it was difficult for clinicians or support staff to estimate a patient’s likely capability prior to the consultation, and making decisions based on age, gender or social stereotypes felt unprofessional[[528]](#footnote-529) . However, older patients and those assumed to be unfamiliar with digital technology (e.g., those in manual and outdoor occupations) were often offered telephone calls rather than video calls[[529]](#footnote-530). That being said, failed attempts at video consultations to patients affected by digital poverty (e.g., no smartphone, no webcam, limited data package) were reported as common and frustrating.

In addition, during the pandemic, shielding and physical isolation measures limited the availability of carer support. The quality of video consultations with care home residents also depended on care workers’ varying technical knowledge and skill[[530]](#footnote-531) .

The morality of offering patients a diagnosis over a video consultation was also questioned[[531]](#footnote-532) in light of the ethical implications of offering a diagnosis without the usual support of specialist nurses or other appropriate persons. This was exacerbated given that family members were banned from visits under Government guidance and therefore were unable to offer moral support or a more simplified explanation to their loved ones[[532]](#footnote-533). Moreover, healthcare staff levels of telecare/telemedicine competence varied thus impacting on the quality of care provided[[533]](#footnote-534). Care recipients have expressed concerns over the accuracy of online assessments in comparison to traditional in-person assessments[[534]](#footnote-535), with blended online and in-person approaches being reported by the ALLIANCE as being preferred.[[535]](#footnote-536)

Carers with limited digital skills or who are not readily able to access online resources have found it challenging, despite additional funding for technology. [[536]](#footnote-537) [[537]](#footnote-538) Whilst some carers have found online sessions easier and quicker to access than in-person alternatives, others have experienced them as a barrier, particularly those with disabilities or those who live in busy environments with large families who have insufficient privacy for the delivery of appointments and sessions.[[538]](#footnote-539)

The barriers of implementing telemedicine formats also largely depend on accreditation, payments systems, and insurance. Furthermore, some physicians are concerned about technical and clinical quality, safety, privacy, and accountability. This rapid deployment of virtual care, whether publicly reimbursed or sold by commercial platforms, has raised concerns regarding equity and the exacerbation of systemic and structural inequalities in accessing and using health care services[[539]](#footnote-540) .

Additional difficulties were identified in Scotland for individuals for whom English is not their first language[[540]](#footnote-541). Problems also arose for those who did not have access to technology or the internet [[541]](#footnote-542). For example, despite efforts to make information accessible by providing easy read’ versions, these were often only available online, thus excluding those who did not have digital access[[542]](#footnote-543). The GDA reported that 60% of their respondents felt they were digitally excluded and therefore received less information than others: *“Services have closed – everything is moving online now and I don’t have internet.”*[[543]](#footnote-544). People with learning disability were disproportionately impacted[[544]](#footnote-545). Staff supporting people with learning disabilities reported that isolation was a key concern for this group due to poverty and digital exclusion, but also the lack of face-to-face support that people with learning disabilities required to learn new skills to adapt to online social communication.[[545]](#footnote-546) That being said, there are examples of proactive attempts to ensure information was accessible to all[[546]](#footnote-547) and funding being directed to close the digital exclusion gap*[[547]](#footnote-548)*. Helplines have also been well received by some stakeholders as an effective source of support which is accessible to the majority: “*If I hadn’t had the Alzheimer Scotland Helpline, and specialist help, I wouldn’t have managed.”[[548]](#footnote-549)*

## 10.4 Lived Experience of Remote Support

Illustrating how the transition to virtual forms of support was not accessible for everyone, May, who is deaf, shared her experience of feeling *“left out and anxious due to […] communication difficulties”.* She explained that she has poor speech recognition and therefore digital communication methods were difficult: *“To just phone isn’t an option for me because my speech recognition is so poor I cannot understand what is being said to me unless I can lip read. Speech to Text software for Apps and video-conferencing helps. I am finding keeping in touch a constant struggle.”[[549]](#footnote-550)*

Virtual/online replacements have also been reported to cause deterioration of mental health for some individuals: *“I can’t have face to face contact with the mental health nurse I work with so we can only have short phone conversations, which don’t provide as much support and my mental health including anxiety and paranoia has deteriorated*.”[[550]](#footnote-551)

Janice, who has a chronic respiratory illness, shared her experience of being a care recipient during the pandemic. She states that she was “fortunate”, as she still had access to support during this time, albeit virtual support: *“My nearest Carers Centre in South Ayrshire has closed its doors to general public in compliance to guidelines but they firstly called to let me know they would still be only a phone call away if need be. I also received a further message when the social distancing, vulnerable groups guidelines were issued. They phoned to ask permission for a designated member of staff to be allocated to me if I need some assistance and not to hesitate in letting them know.”[[551]](#footnote-552)*

Broadfoot et al.’s findings support these doubts around the suitability of virtual support for all groups; particularly individuals with dementia. They acknowledged that such technology allowed ‘more patients to be seen’ but that video consultations were no substitute for face-to-face consultations, especially for complex patients such as those with dementia or those uncomfortable with technology [[552]](#footnote-553). Interestingly, one contributor to the Broadfoot report supported the use of face-to-face consultations and argued that they were essential for people with dementia: *“Lack of hospital visiting meant a loss of knowledge and benefits of carers for people with dementia – all patients have dementia. Restrictions on carers and service provision was terrible as they can’t say how you are. People with dementia are not good at using Teams.”[[553]](#footnote-554)*

In contrast, other unpaid carers have shared positive experiences and have found benefits to virtual and online methods of support[[554]](#footnote-555). For example, “*video chats / activities daily, and this has been fantastic for our daughter as she can still see all of her friends and it breaks up her day.”*[[555]](#footnote-556)

There is concern, however, that virtual and online methods of support delivery will replace in-person support altogether. Stakeholders here stress the importance of physical connection and in-person experiences- not only for wellbeing but also to reduce the impact that COVID-19 restrictions have caused so far: “*I’m just hoping all these services eventually do come back and they come back sooner rather than later because my Dad hasn’t been out.*”[[556]](#footnote-557)

Further evidence is needed to examine the efficacy of virtual communication and assessment of needs, as well as the suitability of different methods for different groups[[557]](#footnote-558). A study by McKenzie et al. found that the quality of life of care recipients was not always negatively impacted to the extent the majority of the research suggests. Staff in this study reported that they were able to maintain the quality of life of their care recipients by responding proactively to resources available at the time. For many workers in care and support this involved utilising online technology to ensure the people they support had access to social connection and participated in meaningful activities[[558]](#footnote-559). A key theme of the study was that support had been “*adapted rather than impacted”; “say a person has an art session or a cookery session, that’s normally out in the community, they’ve created that structure at home”.* Staff/carers were ‘getting creative’ with their delivery of support and making previously mundane tasks into more meaningful activities. Staff also reported that they recognised the importance of social relationships on a person’s quality of life and therefore actively tried to ensure this was maintained for their care recipients*.* This was often facilitated using online technology: *“So we are looking at different ways we can get family involved…now that we have Skype and we have clients who’ve bought iPads and things and tablets”.*

Finally, a study by Giebel et al. reported that few dementia services attempted to adapt to COVID-19 restrictions by offering alternative methods of support, such as virtual platforms *[[559]](#footnote-560).* Where adapted forms of support were applied by the people living with dementia, it was frequently highlighted that these adapted services were of lower quality and did not compare to face-to-face contact.

# 11. Impact of COVID-19 Restrictions on Unpaid Carers and their Ability to Provide Care

## 11.1 Key Messages

The Government offered additional financial support for carers – although this only benefited the minority of carers who receive Carers Allowance.

The number of unpaid carers and the amount of care they gave increased very substantially during the pandemic.

Causes included increase in need, reduction in other support, and withdrawing from services to avoid infection.

Among the harms caused to unpaid carers were:

* Isolation, loneliness and exhaustion
* Lack of respite or breaks from caring
* Negative impacts on mental and physical health
* Fears and anxiety, particularly over possible transmission of the virus to the cared for person
* A diminished capacity to continue caring responsibilities
* Financial hardship

Equality and human rights issues include:

* Most carers are women
* Carers have a higher prevalence of disability compared to the general population
* An apparent disproportionate impact on black and minority ethnic carers

Legislation to introduce a right to a Carer’s Assessment had a limited impact.

Support from third sector organisations was viewed very positively when it was available.

## 11.2 Increased Caring Responsibilities and Number of Unpaid Carers

Unpaid carers make up the majority of the caring workforce in Scotland, with more unpaid carers than paid across health and social care combined.[[560]](#footnote-561) Data shared by the Scottish Government indicated a sharp rise in the number of unpaid carers in the early stages of the pandemic. An estimated 392,000 people have become unpaid carers as a result of the COVID-19 pandemic. This is in additional to the existing 729,000 pre-existing unpaid carers in Scotland, making the total approximately 1.1 million.[[561]](#footnote-562)

It has been estimated that the number of unpaid carers in the UK increased from 9.1million to 13.6million since the beginning of the pandemic[[562]](#footnote-563), with the estimated increase in Scotland at around 400,000 additional carers at the height of the pandemic.[[563]](#footnote-564) Reporting by the ONS in April 2021 identified that close to one third of unpaid carers (31%) lived with someone who was sick, disabled or over the age of 70 during the pandemic, as did 90% of those providing more hours of care (50hrs+). Such unpaid carers were more likely to avoid physical contact with others outside the household (92%) compared with non-carers (92% vs 88%). Fewer carers, however, had avoided contact with elderly or vulnerable populations (presumably as these were the people they were caring for). [[564]](#footnote-565)

Research by Carers UK suggested that 39% of unpaid carers were providing more care due to a reduction or withdrawal of local services as a result of the COVID-19 pandemic.[[565]](#footnote-566) It suggested that, by taking on the burden of care, unpaid carers have saved the UK economy an estimated £193 billion each year during the pandemic. [[566]](#footnote-567) Restrictions imposed as a result of the pandemic resulted in some caring responsibilities being transferred to informal carers. Of these unpaid carers, women are more likely than men to provide caring responsibilities and are twice as likely to have to change their working patterns to accommodate their caring roles.[[567]](#footnote-568)

A report by Carers UK found that with the announcement of lockdown measures carers immediately increased their care hours, with 87% of carers still providing additional care six months later. The average increase was around 10 hours per week, with 45% saying this was due to local care and support services being reduced and day services being closed or running on a vastly reduced capacity.[[568]](#footnote-569) [[569]](#footnote-570) Close to three quarters of carers (72%) stated they were concerned about how they would cope if ongoing or further restrictions were put into place.[[570]](#footnote-571) As many as seven in ten carers stated that the needs of the person they care for had increased, therefore increasing the care burden on them,[[571]](#footnote-572) [[572]](#footnote-573) and many noted that lockdown restrictions had contributed to the deterioration in the condition of the person they care for. [[573]](#footnote-574)

Carers UK found that over 80% of unpaid carers were spending more money during the pandemic predominantly on grocery and household bills[[574]](#footnote-575), and reporting by the ALLIANCE called for non-financial support to be added along with the increased Carers Allowance Supplement. The ALLIANCE urged collaborative working with the Scottish Government and carer services to ensure the demands on carers were not unreasonable, that funding and spending were transparent, that the Carers (Scotland) Act 2016 was better implemented, and that social care day services were restarted.[[575]](#footnote-576)

## 11.3 Caring Role has Intensified/Additional Responsibilities

The Carers Trust reported that unpaid carers experienced an increase in their workload, either because they have moved to live with the person they provide care for, or because they are spending longer hours with them, whilst minimising contact with others as a safety precaution.[[576]](#footnote-577) A survey by Carers Scotland found that the majority of respondents had increased their caring responsibilities since March 2020 and 77% reported feeling exhausted and worn out.[[577]](#footnote-578) More than a third (36%) of unpaid carers who provide care for a family member or friend in Scotland felt unable to manage their caring responsibilities.

Respondents to both ‘Caring behind closed doors’ surveys (2020) issued by Carers UK found that closure of services during the pandemic in response to restrictions was the reason that they were providing increased hours of care. A report investigating racial inequalities found that this was the case for 35% of white carers and 47% of black, Asian and minority ethnic carers.[[578]](#footnote-579) In response to the lack of support for unpaid carers during the pandemic, only a small number of carers felt optimistic about receiving adequate support in the upcoming year: only 14% of white carers and 10% of black, Asian and ethnic minority carers. In a bid to address the inequalities here, Carers UK and Carers Trust (funded by the COVID-19 Support Fund) created the ‘Making Carers Count’ project which aims to gather experiences from traditionally under-represented groups of carers.[[579]](#footnote-580)

The nature of the COVID-19 pandemic brought a lot of uncertainty and change, which in turn increased the level of support many individuals required. Unpaid carers were left to meet these intensified levels of need. [[580]](#footnote-581)

*“Due to increasing frailty and illness of the person I care for, the caring element time has increased substantially.”*

*“Physical and cognitive status of both parents who I look after has deteriorated due to covid pandemic, becoming more housebound and no day care.”*

*“I am spending more time caring because my parent can no longer go to groups in the community, I am spending more time with her because I want to give her lots of mental stimulation and to ensure she has daily exercise.”[[581]](#footnote-582)*

Data from the Understanding Society COVID-19 Study (April 2020) found that shopping was identified as the most common support provided in April 2020, followed by preparing meals.[[582]](#footnote-583) The lack of support for unpaid carers further intensified these caring responsibilities: [[583]](#footnote-584) *“Lack of external support being available has been a major factor in care needs intensifying.”*

The fear around transmission caused many unpaid carers to replace and take on the responsibilities of paid carers, to limit the risk of the virus. Such precautionary measures placed additional pressure on unpaid carers: [[584]](#footnote-585)

*“The person I care for doesn’t want carers coming into their home so consequently I’m caring more.”*

*“My son was advised that carers were needed else where by people living in supported accommodation – which we understood. We also did not want to increase his risk by having carers coming into the house.”*

*“I need to shield my daughter as much as possible. I am also high risk so carers at home would not be an option.”*

Some families chose to deliver care in order to “*reduce the number of people entering”* homes for safety reasons.[[585]](#footnote-586)

## 11.4 Pressure to ‘Step In’/Replacing Other Services

A Scottish Parliament report by the Health and Sport Committee (November 2020) found that a number of family carers felt they were left with no choice but to increase they care they provided, without receiving any help or support from services, and at times very little or no communication was received from care providers to notify them of changes in provision, or to provide any guidance.[[586]](#footnote-587) The same report found evidence to suggest that the de-prioritisation of care for some individuals occurred on the basis that they had family who could step in as carers.[[587]](#footnote-588) This was echoed by Age Scotland and About Dementia in their response to the COVID-19 Recovery Committee of the Scottish Parliament into Excess Deaths in Scotland where they also highlight that many local authorities and HSCPs asked friends and family to provide care due to support cuts for dementia service users.[[588]](#footnote-589)

A report by Carers UK highlighted several changes in the delivery of care by unpaid carers for many. They noted that face to face caring reduced, and the use of online mechanisms or telephone calls had increased for some carers, particularly those who provided emotional and social care rather than physical. Ninety percent of carers in their report said their care hours had increased but their care delivery had changed. The most commonly cited reasons for this were increased needs of the person they care for (46%); local authority care decreasing (29%); the person they care for not wanting paid carers in their home (7%); and caring for more people (5%).[[589]](#footnote-590)

The following two studies also reported changes in caregiving responsibilities as a result of the COVID-19 pandemic. First, Sousa et al. (2021) explored relatives’ experience of caring for people with end stage renal disease during COVID-19.[[590]](#footnote-591) Second, Lightfoot et al. (2021) explored family carers’ views of how caregiving for older adults and people with disabilities has changed during COVID-19. They found that caregiving tasks changed in the following ways: less social stimulation, changed schedules, more practical caregiving.[[591]](#footnote-592)

Family members have reported feeling pressure to *“step in*” and “*left to get on with it*”[[592]](#footnote-593) A large number of respondents/family members reported that they had to increase the amount of care they provided, and feeling that unpaid carers and family members were forced to *“provide all the care*”. Some shared their experiences of being the sole carer: “*100% of the care, 100% of the time*.” Others shared feelings of isolation and having no other option: “left to get on with it” and provide care “without any help or support”: *“No care package was available for the person I am caring for due to the onset of Covid. I had to take on sole carers role/responsibility due to this.”* [[593]](#footnote-594)

Some respondents said families provided care because “*no support was offered to them*” and there was no communication from care providers.[[594]](#footnote-595) A common feeling was that it was implicitly assumed that family members would provide care: *“I feel like people were kind of left to get on with it. If I didn’t have family then I don’t know if I’d be here.”*

Support provided by statutory services, local organisations and other sectors providing paid carers or day care had to pause their services in response to the COVID-19 restrictions. This created a gap in support which unpaid carers met.[[595]](#footnote-596) Many individuals may have unknowingly taken up supportive and caring roles during and after the pandemic without recognising themselves as an unpaid carer. As a result, these individuals perhaps are not actively seeking support available to them. It was highlighted that for some individuals there may be a stigma associated with accessing carers support which means they do not receive this aid.[[596]](#footnote-597) Carers UK published a report in 2022 on the experiences of black, Asian and minority ethnic carers during and beyond the COVID-19 pandemic, which found that unpaid carers from these populations experienced more pressures, specifically financially and economically. This was before the added stresses caused by the current cost of living crisis. [[597]](#footnote-598)

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## 11.5 Support for Carers

Data from the Scottish Parliament in July 2021 states that despite an increase of around 400,000 carers during the pandemic, resulting in over one million carers Scotland-wide, only around 83,000 carers with a ‘more intensive caring role and lower financial resilience’ were in receipt of the Carers Allowance.[[598]](#footnote-599) Firstly the Coronavirus (Scotland) (no.2) Act 2020 allowed a double payment of the Carers Allowance in June 2020 to those in receipt. This was followed by the Carers Allowance Supplement Bill (July 2021) which allowed another double payment in December 2021 to help cover the costs of caring over winter.[[599]](#footnote-600) [[600]](#footnote-601) Carers Scotland also called upon the Scottish Government to ring fence future funding for use by carers facing financial hardship.[[601]](#footnote-602)

Peer support groups have been important for carers to feel less isolated. Some received regular phone calls and support to stay in touch with services, others attended coffee mornings virtually and some received food and PPE deliveries. [[602]](#footnote-603) However, this is far from being the case for everyone – The Carers Trust reported that 36% of carers had accessed support from local care centres, 12% through charities and 9% were supported by GPs and primary care, but 42% had accessed no support at all. [[603]](#footnote-604) Some carers reported that their local authority was no longer able to meet their needs and provide adequate support, particularly for carers from marginalised or minority groups [[604]](#footnote-605). The Carers Trust also highlighted a number of cases where aftercare for difficult diagnoses, including dementia, had been curtailed [[605]](#footnote-606) [[606]](#footnote-607) and others where long-term psychological support and been reduced or withdrawn as a result of reductions in service provision [[607]](#footnote-608).

It was also recognised that a number of relatives who are acting as carers would not necessarily recognise themselves in an unpaid carer role and therefore may be unaware of the help and support which should be available to them. There can be stigma attached to asking for help and support in some minority communities which may act as an additional barrier, and families from these communities are liable to take on additional caring duties when local authorities fail to provide paid carer support in line with cultural requirements[[608]](#footnote-609).

Carer support services worked to respond flexibly to maintain contact with unpaid carers throughout the pandemic. However, the withdrawal of adjacent services made it difficult to refer unpaid carers for the support they require and are entitled to, and communication with statutory services was complicated by online security measures, which resulted in delays. More widely, carer support workers expressed concerns about their key partnerships in the community and how the pandemic may impact carer referrals and signposting in the future.[[609]](#footnote-610)

## 

## 11.6 Lived Experience of Unpaid Carers

There is agreement in the literature that there is an overall lack of recognition for unpaid carers and that measures should be put in place so that there is not such a disproportionate reliance on unpaid carers in the future. Stakeholders felt strongly that “*this should not happen again!”* and unpaid carers should “*not to be left to manage entirely on (their) own.*”[[610]](#footnote-611) A key theme from stakeholders was the feeling of isolation and being abandoned.

This was reflected in the responses from a survey conducted by the Health and Sport Committee at the Scottish Parliament. [[611]](#footnote-612) Despite many family members and friends stepping in to replace the lost support, many family members were unable to meet these obligations. Age Scotland shared a response from a family member who was unable to replace the care her mother had lost, as she needed to self-isolate due to a health condition. The care provider had withdrawn the support because the family member lived close by, not realising they were not in a position to care:[[612]](#footnote-613)

*“Her mother has important medication requirements and timings that she is unable to manage on her own, and previously received four daily visits as part of her care package. Just prior to lockdown the caller was informed from the service that they would no longer assist her mother as she had family living nearby who should step in to provide this help instead. While strictly speaking this was correct, the family member was self-isolating due to underlying health conditions and other family members were either receiving care themselves or did not live nearby, therefore, not in a position where they could replace the critical level of care her mother previously needed.”*

The lack of support provided suggests an implicit assumption that unpaid carers will *“pick up the slack of other services with little to no support”.* [[613]](#footnote-614)

Respondents to a survey issued by the Health and Sport Committee at the Scottish Parliament in 2020 reported that unpaid carers facing “*increased work load should have received additional financial support”*. [Unpaid carers] *“need a full time wage. We are under-seen and under-valued”* and should “*not to be left to manage entirely on (their) own.”* Some families chose to deliver care in order to ‘reduce the number of people entering’ homes for safety reasons*.*[[614]](#footnote-615) [[615]](#footnote-616)

A systematic review of the qualitative literature on the experiences of unpaid carers of people with long-term conditions during the COVID-19 pandemic identified that caregiving demands had increased for carers during the pandemic, and informal carers faced negative emotions such as fear and uncertainty.[[616]](#footnote-617)

In April 2021 eligibility for vaccination changed for carers and unless other criteria applied, preferential/priority vaccination was no longer available. Carers who provided primarily emotional support by telephone/videocall were asked to wait to be vaccinated. Only carers between the ages of 16-64, providing face to face support, not as part of voluntary or contract work were eligible for priority vaccination[[617]](#footnote-618).

Some carers felt that their responsibilities had been ‘blurred’ and their role changed as a result of the COVID-19 pandemic, with their role having expanded as a result of withdrawal of certain services.[[618]](#footnote-619) There was a common feeling that by helping to fill the gap in support compliantly, unpaid carers have become taken for granted and become “victims of [their] own success”: *“We’re not getting any external support. We have tried but we have been told that as a family we are doing a great job – I feel like we are victims of our own success. We have thought about getting carers, but mum doesn’t settle with new people in the house… caring, while being rewarding, takes its toll in lots of different ways. It’s had a massive impact on all our lives.”* [[619]](#footnote-620) (Carer from England cited by Care Quality Commission)

## 11.7 Lack of Respite

Carers Scotland published a survey in 2021 which reported that 71% of unpaid carers had not had any breaks from their caring role during the pandemic.[[620]](#footnote-621) Of those who got a break, over a third (36%) revealed that they had to use the time to catch up on housework and practical tasks, and just under a quarter (24%) needed to use the time to attend their own medical appointments.[[621]](#footnote-622)

Research from Carers UK’s State of Caring report (2021) found that over half (55%) of unpaid carers who relied on day services no longer had access or had reduced access.[[622]](#footnote-623) The same report also revealed that unpaid carers were less optimistic about the support they would receive in the upcoming year with only 13% of carers feeling confident they will receive appropriate support in the next 12 months: “*I’m scared for the future and I don’t know what will happen to us in 12 months’ time. We’ve been together for 47 years, but his illness is progressing. It’s heart-breaking to see someone you love deteriorate but it’s made worse when you don’t have enough help to care for him practically. Unpaid carers are on our knees with exhaustion and we need help.”* (carer to her husband with advanced brain disease).

According to the survey conducted by the Health and Sport Committee at the Scottish Parliament (2020), unpaid carers report the *“lack of respite [as] very hard emotionally and mentally*” and is essential to help them have *“chance of a break”.* [[623]](#footnote-624)

*“I had little space for personal recharge and found trying to get help during pandemic exhausting on many levels. I felt this was unacceptable and very frustrating.”*

There was agreement that greater support is needed for unpaid carers to protect them from ‘burnout’ and so they are “*not left to care 24/7 without a break*” [[624]](#footnote-625) Respite support in all its forms was impacted and reduced as a result of restrictions. This included more formal opportunities for respite such as breaks and overnight stays, as well as informal respite such as work, school or hobbies. [[625]](#footnote-626)

*“I have no respite. I used to access support such as therapy, college, peer support, and the pandemic took absolutely everything away from me.”*

*“I was a mess emotionally and had to fight to get some sort of respite restored but this only happened in January. And I have been reminded constantly that I can only access respite as an emergency so almost made to feel guilty for asking for respite.”*

*“I asked for support from social services when I was in crisis due to one of the people I care for having Covid and all I was offered was access to PPE - which I was grateful for but there was no break or respite from the additional workload.”*

A study by Willner et al. (2020), which focused on the UK more generally, found that the level of support provided also differed depending on the type of support being provided. It was reported that carers of those with intellectual disability received less social support, despite having greater mental health needs.[[626]](#footnote-627)

In contrast, many carers reported positive experiences about the level of support they had received during the pandemic, specifically from local volunteering groups or from carers' networks. Being well rooted in the community helped some carers’ organisations quickly set up practical and emotional support. For example, carers reported being connected with other carers as a way to share peer support, which often took the shape of Zoom coffee mornings. This peer support was described as vital in feeling less isolated. [[627]](#footnote-628)

The Carers Week charities called upon the Scottish Government to re-open support services for unpaid carers and allocate funding for respite breaks.[[628]](#footnote-629) It was reported that 69% of unpaid carers are concerned about the future and maintaining their caring responsibilities without a break, and one in four unpaid carers report not having had a break in five years. The need for more consistent respite was addressed in the Feeley review, which recommended that the Carers Act be amended so that carers be given the right to respite.[[629]](#footnote-630)

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## 11.8 Impact on Physical and Mental Health

The Carers UK report ‘Caring Behind Closed Doors’ in 2020 found that the COVID-19 pandemic left a devastating psychological, financial and practical impact on unpaid carers. Specifically, more than half of respondents felt overwhelmed and were worried they would soon burnout.[[630]](#footnote-631)

As support services reduced, the burden of care increased for caregivers. Carers reported feeling concern and ‘burden’ to protect recipients of care from the negative impact of COVID-19 measures, particularly on mental health. Some unpaid carers felt that the restrictions had contributed to the worsening of care recipients’ symptoms and/or condition, which in turn had intensified their own caring role.[[631]](#footnote-632) Factors such as social isolation and lack of routine were highlighted as key contributing factors towards the deterioration of mental health.[[632]](#footnote-633)

The Scottish Mental Health Tracker Survey collected questionnaire data between 28th May and 21st June 2020. It found that over a third (36%) of adults reported an elevated level of psychological distress. In terms of more specific symptoms experienced, just over a quarter of adults reported depressive symptomology and almost one in five (19%) identified as having anxiety symptomology of a level that indicated possible need for treatment. Overall, the survey found that some groups reported higher than average prevalence of mental health problems, for example young adults (18-29 years), women, individuals with pre-existing mental health conditions, and individuals from lower socio-economic backgrounds. Interestingly, this reflects the demographics most representative of unpaid carers.[[633]](#footnote-634)

Findings from the Carers UK report on Black, Asian and Minority Ethnic carers reveal that only a third (33%) of this population felt that they were able to manage their health and wellbeing during the COVID-19 pandemic. Respondents shared that their mental and physical health had deteriorated as a result of the pandemic; 62% and 63% respectively.[[634]](#footnote-635)

*“Carers have been left behind. As a carer, the impact of this situation has made me feel like I am not a valued member of society” – Mixed race carer*

*“I feel overwhelmed and anxious. My eating disorders have returned and I feel like it’s going to impact me and my family for a long time.” – Pakistani carer*

A study by Gamble et al explored whether the COVID-19 pandemic affected the well-being of carers of people with dementia living in the community, and their ability to cope with their caring responsibilities. The results found that, compared to the pre-pandemic group, those in the pandemic group appeared to cope better and had more stable self-rated competency and role captivity. They did not differ in terms of well-being or quality of life.[[635]](#footnote-636)

Increased caring responsibilities, including longer hours and more intensified needs, have impacted the physical and mental health of unpaid carers.*[[636]](#footnote-637)* A report by Carers Trust Scotland indicated that half of unpaid carers reported their own mental health to have declined since pre-pandemic, with 34% rating it as ‘much worse’. Over half agreed they were more stressed, tired or lonely, and more anxious or worried, with some of the potential reasons for this again being down to the withdrawal of services and the lack of time away from caring responsibilities - 82% of carers in this report had been unable to take a break from caring since March 2020.[[637]](#footnote-638)

These additional pressures have resulted in increased feelings of isolation, loneliness and being undervalued, which according to accounts of lived experience places unpaid carers at a higher risk of developing anxiety, depression and mental exhaustion.[[638]](#footnote-639)

*“My own physical health has become significantly worse during the pandemic which is also impacting on mental and emotional health.” [[639]](#footnote-640)*

*“I feel totally alone and the impact of caring has made my mental health decline rapidly”*

*“I am exhausted, feel very ‘down’ most of the time … my physical ailments have gotten worse and I now need the strongest of pain relief every day as I have to be active to make the person that I care for safe and supervised. It seems endless, with only terrible alternative options.”*

*“Mentally at times I’ve felt unable to cope during the pandemic. I was due to have a hip replacement before the pandemic. The physical side of caring has been unbearable at times.”*

*“Isolation/lockdown has had a huge negative effect on my life. Mentally and physically. I can’t go anywhere or see anyone other than the person I am caring for.”*

*“I am more stressed, and no physical activity, so I feel lonely and low all the time.”*

*“big impacts are on physical and mental health… people were struggling and worried about breaking down.”* [[640]](#footnote-641)

*“a huge mental health impact on carers and…. psychological pressures, increased stress and social isolation.”*

‘Celia’ shared her experience of being an unpaid carer during the pandemic. She describes that *“the burden of care I felt, which was already at the sharp end before, has become a knife edge”.* She continues that *“I hope the Government will now look at the unequivocal evidence as to just how much unpaid carers hold together the threads of society’s holes in social care.”[[641]](#footnote-642)*

A report by the ALLIANCE found that unpaid carers had experienced considerable distress at having to provide additional care for loved ones with little or no access to support, respite or day care, which had taken a toll on their mental health and on their ongoing ability to provide the required care.[[642]](#footnote-643)

The following studies found that carers experienced high levels of emotional distress as a result of the COVID-19 pandemic:

* Maćkowiak et al. (2021) explored the experiences of people with dementia and informal carers during COVID-19. Experiences identified psychological response of uncertainty and anxiety, social isolation and adaption and coping.[[643]](#footnote-644)
* Ciopolletta et al. (2021) explored the experiences of family carers of people with dementia during the COVID-19 pandemic and the impact on their lives. Experiences identified included practical difficulties with everyday care and time needed in care routines, emotional stress and difficulties reaching out for help.[[644]](#footnote-645)
* Giebel et al. (2021) explored perceptions of public health restrictions for carers of people with dementia during the pandemic. The study identified feelings of frustration and burden.[[645]](#footnote-646)
* West et al. (2021) - explored the impact of COVID-19 on people with dementia and carers from black and minority ethnic groups. The study identified feelings of fear and anxiety, as well as lifestyle changes (shopping, eating patterns, isolation and identity, community and social relationships).[[646]](#footnote-647)

Summarising and confirming these findings, a survey conducted by Carers UK in May 2020 revealed the top three challenges that unpaid carers face: (i) managing stress and responsibility (71%); (ii) adverse effects on physical and mental health (70%); (iii) inability to take a break from caring duties (66%).[[647]](#footnote-648) Specifically in Scotland, the majority of carers surveyed (77%) said they were exhausted, with 65% saying they had been unable to take any breaks from caring during the previous six months.[[648]](#footnote-649)

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## 11.9 Unpaid Carer Loneliness and Isolation

A study by Grycuk et al. (2022) explored levels of care burden, loneliness and social isolation among caregivers of people with long-term physical and brain conditions in English-speaking regions worldwide, comparing pre and post COVID-19 outcomes.[[649]](#footnote-650) The study found that all caregivers experienced a significant increase in burden, loneliness, and isolation after the COVID-19 pandemic (compared to pre-covid). Caregivers of people with both physical and brain conditions were reported to be most ‘burdened’ and measured highest on loneliness and isolation. This increase in care burden in caregivers was reported as a potential barrier to their ability to provide care.

Wormald et al. (2023) investigated the differences between carer groups, in the context of loneliness and burden of care.[[650]](#footnote-651) The study found that 65% of those caring for people with an intellectual disability experienced increased burden, and 35% of carers of people with an intellectual disability experienced more feelings of loneliness. The predictors for loneliness included feeling burdened by caring and worsening mental health, and the predictors for feeling burden encompassed age, poor mental health and feelings of loneliness pre-pandemic. These findings suggest that the impact of the pandemic had greater impact on those already struggling with caring duties pre-COVID.

A study reporting on longitudinal data from the UK Household Survey produces a comparison between carers and non-carers in the context of wellbeing. The study found that the mental health of home-carers was more significantly affected compared to non-carers.[[651]](#footnote-652) Similarly, a study compared formal and informal care by investigating the differences in how restrictions/disruptions affected psychological distress among older individuals.[[652]](#footnote-653) *‘Findings show that the disruption of informal and formal support represents a significant risk factor for psychological wellbeing in older adults and increases their risk of depression.’*

In a report by Carers Week in 2022, it was reported that unpaid carers were still struggling with the aftermath of the pandemic.[[653]](#footnote-654) An estimated 4.68 million unpaid carers were concerned for their own physical and mental health and 2.2 million carers were concerned about their ability to cope financially. [[654]](#footnote-655) In their response to the Feeley review, Carers of East Lothian comment that individuals with caring responsibilities have needed significantly more emotional support as a result of the pandemic and they have witnessed increased demand for counselling services from this population.[[655]](#footnote-656)

The demand for care is increasing, with more care and support being provided now compared to at the height of the pandemic. One in five of the UK’s adults (approx. 10.58 million people) now provide care and support to a relative, friend of neighbour because of chronic illness. Therefore, there is an urgency to address these gaps in support to prevent further damage to the health and wellbeing of carers.[[656]](#footnote-657)

In response, Carers’ Week charities urged Government to take action and suggested a 12-month plan to direct more support for unpaid carers, specifically to address lingering issues from the pandemic.[[657]](#footnote-658) Several charities supported the call for action put forward by Carers Week in 2022: Carers UK, Age UK, Carers Trust, MND Association, Rethink Mental Illness, Oxfam GB, The Lewy Body Society. Specifically, they support taking action towards a recovery and respite plan aimed at meeting the needs of carers including: investing in their mental health support; prioritising carers’ leave; more support directed at ensuring basic needs are met (food, energy costs etc.) and prioritisation in the vaccination programme.[[658]](#footnote-659)

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## 11.10 Fears Over Transmission

The fear of infection was also a central concern, both the risk of catching COVID-19, transmitting it and not being able to continue their caring duties.[[659]](#footnote-660) A systematic review of the qualitative literature on the experiences of informal carers of people with long-term conditions during the COVID-19 pandemic identified ‘fear’ as a key theme, specifically that carers reported felt afraid of infecting their family members and were anxious, even when taking all the necessary safety precautions.[[660]](#footnote-661)

*“I’m worried about the person I care for catching the virus, worried I might catch it and pass it to her, worried I might catch it and be too ill to help her.”*

*“The stress of trying to avoid catching Covid and passing it onto my two disabled sons, who live in different cities has been overwhelming.” [[661]](#footnote-662)*

‘Fear’ was a recurrent theme among informal carers. A systematic review found that fear specifically originated around infecting recipients of care, which in some cases caused anxiety. These feelings of fear persisted even with adherence to safety precautions.[[662]](#footnote-663) *“Let’s say that right now it is even more difficult because we are always feeling the panic of transmitting her the virus. As soon as we see that she has a temperature or she is more* *agitated, then we immediately think, ‘It must be this [COVID-19].’ We are always in apprehension.”*

A common concern was that their care recipient would be hospitalised and that they would not be able to visit due to strict ‘no visitation’ restrictions in place: *“I didn’t want him to go to hospital”.[[663]](#footnote-664)* Similarly, others changed the location they provided care due to the fear of not being able to visit. “*The caregiver is not following through with placing him in a nursing home because she is afraid she will never see him again’*”[[664]](#footnote-665)

Many sources have raised concerns about the disproportionate number of women in unpaid caring roles. Close the Gap, a Scottish policy advocacy organisation working on women’s labour market participation, highlighted unpaid care (both paid and unpaid) as a gendered issue.[[665]](#footnote-666) Data from 2020 reveals that 61% of unpaid carers are women. With 78% of carers reporting having to provide more care since the start of the pandemic, women are disproportionately affected.[[666]](#footnote-667)

A report by Carers Week (2020) raised concern about the mental and physical wellbeing of this population, adding that caring responsibilities add additional strain on relationships, finances and employment.[[667]](#footnote-668) Unpaid carers have to face a balancing act between support and risk. Many experience moral injury and stress around these decisions, as they want to cause the least amount of harm. [[668]](#footnote-669)

Some unpaid carers did note that they did not feel traditional respite options in the form of stays away were safe due to the risks of coronavirus. In general, many unpaid carers are very worried about passing coronavirus to the person(s) they care for: [[669]](#footnote-670)

*“I’m worried about the person I care for catching the virus, worried I might catch it and pass it to her, worried I might catch it and be too ill to help her.”*

*“The stress of trying to avoid catching Covid and passing it onto my two disabled sons, who live in different cities has been overwhelming.”*

*“[Respite] is not something that we have actively sought nor indeed would want given the risk of increased exposure to the virus.” [[670]](#footnote-671)*

## 11.11 Impact on Welfare Factors (Financial, Employment, etc.)

Research shows that women are more likely than men to have caring responsibilities and are twice as likely to have to change their working patterns to accommodate their caring roles. As a result, women will suffer a disproportionate economic impact. [[671]](#footnote-672) The Office for National Statistics (ONS) found that a higher percentage of unpaid carers are disabled (32%) compared to non-carers.[[672]](#footnote-673) This group is therefore also at risk of suffering disproportionate economic impact, and impact on their own health and wellbeing.

Carers UK, in their 2022 report, found that carers with lower household incomes were more likely to provide higher amounts of care (over 20 hours per week), which in turn places additional stress on finances and employment.[[673]](#footnote-674) An earlier report (2021) by Carers UK highlighted the importance of support for unpaid carers to enable them to continue working. One in five unpaid carers said that if support did not improve or become more affordable, then they would be forced to reduce their employment hours.[[674]](#footnote-675) Some carers had to give up working commitments or reduce their working hours to accommodate their caring duties. This was more prevalent for unpaid carers. *[[675]](#footnote-676)*

A report published in 2021 highlighted the financial and economic challenges that younger unpaid carers are more likely to face. The COVID-19 pandemic only exacerbated these hardships with many unpaid carers facing redundancy, having to work fewer hours or facing a reduction in their household income due to the furlough scheme.[[676]](#footnote-677)

Carers UK, as part of their ‘Making Carers Count’ project with Carers Trust, called for a £1.5 billion investment to support social care over the next three years. A focus of this investment would be ensuring carers can remain working alongside their caring responsibilities and ensuring support is accessible.[[677]](#footnote-678) In a bid to address this issue, it was suggested in the Feeley review that the carer’s access to employment be considered as a routine part of the assessment for support.[[678]](#footnote-679)

Being an unpaid carer was no longer a sustainable option for some: *“I’m a taxi driver with severe asthma, caring for my high risk wife and mother – but I’ve had to go back to work because we’ve run out of money. It’s terrifying, but we’ve got no choice.”*[[679]](#footnote-680)

Many unpaid carers were reportedly paying for the provision of paid care themselves in order to get a break from their caring duties: “I had nothing for 6 months… I had to pay for a private carer out my own pocket and I’ve spent thousands”[[680]](#footnote-681)

It was reported that unpaid carers face significant financial hardship, with Carer’s Allowance and other benefits such as Universal Credit or Child Benefit not necessarily providing an overall income that allows their household to live free from the risk of poverty. [[681]](#footnote-682)

The amount of time carers spend supporting others may adversely affect their employment outcomes as well as their income. Before the pandemic, 38% of carers reported they had given up work to care and 21% had reduced their hours. [[682]](#footnote-683) Research found that young carers and their families’ financial difficulties had worsened with some household members being made redundant, having to work fewer hours, or facing a reduction in their income due to the furlough scheme. Some family members had to put in more hours of care to cover the lack of support services available during the pandemic.[[683]](#footnote-684)

A report by the Fraser of Allander Institute, which investigated the care of adults with learning difficulties, revealed that over half of the unpaid carers who took part in the survey shared were below or on the poverty line, due to factors affecting their ability to work.[[684]](#footnote-685) It was also revealed that the support provided by each unpaid carer in the sample ‘saved the taxpayer £114,000 per year’, with a total time of unpaid care ranging from 8-16 hours plus additional care through the night (for residing with their care recipient).[[685]](#footnote-686)

## 11.12 Carer’s Assessments

Local authorities had the option to suspend carer’s assessments as a result of COVID-19 emergency legislation between 5 April 2020 [[686]](#footnote-687) and 30 November 2020 [[687]](#footnote-688) (for young carers, until September 2021) [[688]](#footnote-689). Experiences from carers suggest that there was minimal, if any dialogue with family members on their ability or needs to provide support[[689]](#footnote-690): “*There was no real assessment of whether that informal carer was in a position to offer the kind of support the person needed…”*.[[690]](#footnote-691)

Many carers reported feeling disappointed in the carer’s assessment process. Some who shared their experience reported that it feels like a “*tick box exercise”* with little tangible outcome or benefit. [[691]](#footnote-692)

*“I had to give up a career due to my caring role. I did a carer’s assessment but there was absolutely nothing in terms of additional support or resources for me for my family. It was just a tick box exercise. I just assumed that’s what a carer’s assessment is.”* (unpaid carer)

*“There’s no point having a carer’s assessment. Mine was completed and I qualified for extra support but there isn’t any replacement care available. I was given a massage voucher, but I can’t take time away from my family to use it.”*

The ALLIANCE reported from their engagement sessions: *“We are hearing repeatedly from unpaid carers that carers assessments are not being undertaken, that they feel undervalued and their human rights as people are being ignored. Unpaid carers are relentlessly providing care, night and day, with many paying for provision themselves in order to get a break from their caring responsibilities.”* [[692]](#footnote-693)

It was felt there is a need for more transparent and visible help, with access to a wider range of services that help unpaid carers not only in their supporting role but also help facilitate them to live a fulfilling life themselves.[[693]](#footnote-694)

# 12. Impact on Social Care and Social Work Staff

## 12.1 Key Messages

* Social workers faced many ethical and professional dilemmas with limited guidance.
* The wellbeing of social workers decreased significantly in 2020-21, having improved in the previous two years.
* Social work education moved almost completely online, which presented significant challenges to people entering the profession.
* The Scottish Government provided increased pay and other financial support to social care staff at various points during the pandemic.
* Guidance to social care staff was updated very frequently, contributing to confusion and anxiety.
* Some social workers reported working ‘outside the rules and restrictions’ to provide a more humane service
* Social care staff experienced a range of negative impacts including anxiety, poor morale and feeling under-appreciated.
* There is a lack of data on levels of infection of social care staff, but evidence of a higher level of deaths and long Covid than the general population.
* Routine testing was introduced later for non-residential social care staff than other clinical and care staff – January 2021.
* Social care staff were prioritised in the vaccine roll-out, but there is evidence of vaccine hesitancy.

PPE was initially provided to social care staff through a different route than the NHS, and there were widespread concerns about difficulties in obtaining appropriate PPE. This potentially impacted on the rights of social care and social work staff to life and physical and mental health.

* There continue to be significant staffing and recruitment issues within the sector.
* There are human rights questions as to whether the rights of social care workers were disproportionately affected, and whether enough was done to ensure their need for the support at the time and subsequently were and are being met.

On 23 March 2020, the Scottish Government announced[[694]](#footnote-695) that “*the Scottish Government will meet additional costs to increase support and staff capacity in social care*”. However, on 23 January Government 2023 the Daily Record reported that the Scottish Government had written to all Integrated Joint Boards asking for return of “*surplus covid reserves*”[[695]](#footnote-696). The article quotes Labour MSP Jackie Baillie saying: “*The Government must drop these reckless plans to reduce health board budgets and let local health and social care bodies use this funding to deliver the social care services we desperately need.*” The Feeley Review highlighted that workforce planning needed to be addressed. The COVID-19 pandemic highlighted the difficulties in deploying and maintaining appropriate staff levels when there is urgent national need. Currently, there is no national oversight of workforce planning in Scotland and employers include local authorities and third and independent sectors.

The Scottish Government and Scottish Social Care Services Council acted quickly to re-register social care staff who had left or retired[[696]](#footnote-697) however a number of services still reported difficulties in recruitment, training and retention of staff. The SHRC noted ‘*the disparity between the skilled and demanding nature of social care roles and the relatively low pay available for these*’ [[697]](#footnote-698). Evidence gathered by Audit Scotland described how around one quarter of staff leave within the first three months of employment[[698]](#footnote-699), with 88% of social care providers agreeing recruitment and retention had been problematic, to the extent that 53% of those organisations said they would refuse requests for new care packages[[699]](#footnote-700). Staff also complained that due to shortages 78% of care at home workers did not have time to deliver care to the standard they feel was required, and 73% noted they had been expected to undertake training in their own time,[[700]](#footnote-701)

Despite the reduction in care provision, many staff reported hours of work remaining the same or increasing (71% of respondents). Workloads also increased for staff not providing face to face care. Reasons for this included training in PPE use and infection control, completing and updating service user risk assessments, reporting and attending regular meetings for updates and changes to delivery. This along with higher rates of staff absences increased pressure and demand on staff members.[[701]](#footnote-702) This Chapter will discuss these issues in more detail, beginning with issues around regulation and moving towards more person-focused concerns later in the Chapter.

## 12.2 Governance and Regulatory Oversight: Changes made by Care Inspectorate to their Oversight and Regulation of Social Care Services During the Pandemic

The Care Inspectorate (CI) registers and inspects a wide range of care services in Scotland. Its roles include the inspection of care services, the evaluation of service quality, supporting service improvement, dealing with complaints and carrying out enforcement action. The CI register and inspect over 2,500 support services (including care at home) and housing support services, used by approximately 86,000. This is twice the scale of residents in care homes (40,000) and number of care homes (1900).

From 17 March 2020 the CI suspended their routine and on-site inspections[[702]](#footnote-703) and from 03 April 2020 they introduced a staff notification system which monitored staffing levels twice daily, seven days per week, and assigned a category to the staffing levels and skills mix available to services: green to indicate sufficient staff and skills mix; amber to indicate the staffing levels are stretched; and red where there were no longer an adequate level of skills mix to meet the needs of service users[[703]](#footnote-704).

Additional notification categories added from 17 April 2020 included outbreak notifications where services notified the CI of individual COVID-19 cases in service users; staff absences using a weekly notification template to report staff who are self-isolating, shielding and those unable to work due to stress; staff hospitalisations and deaths were also required to be reported[[704]](#footnote-705). Requirements for staff reporting ended on 22 June 2020[[705]](#footnote-706) but outbreak notifications continued[[706]](#footnote-707).

On 16 April 2020 the CI issued an update on their support activity, which stated “*At this extremely challenging time, we will support services in their need to apply flexibility and judgement around staffing to ensure the safety and wellbeing of people experiencing care. We recognise that services will need to be creative and make use of a wider range of resources, including potentially staff from other public services and volunteers.*”[[707]](#footnote-708)

From 27 April 2020 the requirement for individuals to complete three-yearly updates for their PVG scheme membership was suspended[[708]](#footnote-709). This follows the earlier suspension (3 April 2020) of Disclosure Scotland fees for key workers and volunteers who were drafted in to support services during the pandemic[[709]](#footnote-710). However, from 8 September 2020, in light of registered care services not reporting significant staffing and recruitment challenges, the CI and the SSSC elected to remove this flexibility and revert back to requiring full pre-employment checks[[710]](#footnote-711).

In their report on the learning from COVID-19 the CI state that their scrutiny during that period was led by intelligence and based on risk[[711]](#footnote-712). To some extent this may explain the care home focus much of their work seems to have had. To a large extent it appears that the CI role for non-residential care services (for older people) may have been limited to providing advice and guidance. For example, their work to facilitate service user access to NHS Near Me is reported only as being for care homes. Moreover, a table in the report sets out the contacts by service type, but does not make explicit whether they reached out to these services, or responded to a request, or the extent to which an individual service made numerous contacts.

## 12.3 Impact on Social Work Service Delivery

### 12.3.1 Changes to Provision across the Timeline

Initial Scottish Government guidance on 13 March 2020 advised the cancellation of large events scheduled to see 500+ attendees, however smaller events were permitted to continue (SASW events continued during this period). The public were advised to expect mild illness lasting 4-5 days with no need to contact NHS services unless symptoms worsened[[712]](#footnote-713). An isolation period of seven days for symptomatic individuals was advised.

However, an update was published on 15 March 2020 for those working in social or community care advising individuals who have been in contact with a confirmed case to self-isolate and advising against the use of bank or agency staff wherever possible. Staff were advised to comply with infection control protocols at all times and were directed to move appointments with confirmed positive COVID-19 cases to the end of their working day, if these could not be avoided/rescheduled. Only essential staff should attend, and PPE should be worn, and immunosuppressed or pregnant staff should not provide direct care to infected individuals. Staff were further advised of the occupational risk of contraction and warned to be vigilant for respiratory symptoms developing during potentially a 14-day incubation period. In the case of these developing they advised to contact their GP or occupational health department in line with local policy[[713]](#footnote-714).

The first ‘lockdown’ commenced on 23 March 2020, and saw social workers leaving offices to work remotely from home and engaging with service users via mobile phones or online. Until the government passed the emergency legislation (the Coronavirus Act, 2020 and The Coronavirus (Scotland) Act 2020) for practitioners including social workers, service providers were initially lacking guidance and taking their own initiatives to assure safety of all involved while continuing service provision. Some of the early guidance re-affirming the long-established social work values in the newly emergent context came from Scottish-based academics, offering professional directions and mitigating uncertainty[[714]](#footnote-715). Noteworthy is the founding of the free, online*, Social Work 2020 under COVID-19* Magazine, on 19 March 2020. This was an outlet for social work practitioners, academics, service users and students to discuss the realities of social work in the pandemic [[715]](#footnote-716).

A report by BASW from January 2021 which surveyed 1119 social work staff across the UK found that 77.7% felt that lockdown restrictions had impacted their capacity to protect vulnerable people, and just over half (52.5%) agreed they had encountered difficulties in safeguarding access as a result of limited in-person contact.[[716]](#footnote-717)

Explicit challenges of the first wave of the pandemic included but were not limited to: providing social care/work at a physical distance, negotiating home/work boundaries, managing emerging risks and considerations of long-term implications of COVID-19 for social work practice [[717]](#footnote-718)

The second wave of the pandemic revealed the importance of professional judgment which, unlike in pre-pandemic circumstances, could not always be discussed with colleagues, and therefore allowed for greater autonomy in decision-making. This however comes with greater responsibility for the decisions made[[718]](#footnote-719). Reportedly, some social workers felt unsure about the robustness of decisions they made in the absence of peer-review [[719]](#footnote-720).

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## 12.4 Impact on Social Workers

A number of challenges have been identified around staff wellbeing during the pandemic,[[720]](#footnote-721) specifically: working conditions, uncertainty around social work practice when implementing emergency legislation, and how to resolve emerging ethical dilemmas. Such dilemmas were challenges to their ethical identity and involved navigating changing expectations of the profession; relationship building via virtual means; balancing service user rights, needs and risks against personal risk to social workers and others; responding to service users’ needs with limited resources and having to prioritise these with limited assessment available; tensions between organisational policies and procedures and social workers’ and service users’ autonomy; and managing self-care in unsafe environments [[721]](#footnote-722). Challenges relating to the use of information and communication technologies (ICT) included the blurring of professional boundaries, searching for service users’ information online, and covert use of ICT without professional discussion and/or guidance [[722]](#footnote-723).

Responses to these challenges include ‘ethical confusion’ - where the social worker did not know what to do; ‘ethical distress’ - when the social worker knew what the right action would be, yet was unable to carry it out due to organisational constraints; ‘ethical creativity’ - invented new viable solutions, and ‘ethical learning’ - through reflection for betterment of future social work practice [[723]](#footnote-724)

However, this challenging period afforded staff some opportunities including finding creative responses to social distancing, opportunities for professional and personal development, greater freedom to apply professional judgement, changing of organisational culture by placing higher value on relationships over normally risk-averse-administratively-driven approaches, more creative methods of social work education and revival of social work activism[[724]](#footnote-725). Further social work actions comprised the promotion of solidarity and social justice through advocacy, lobbying politicians, translating government policies to easy-to-understand documents and innovating social work methods to include games in virtual environment[[725]](#footnote-726). International research has also emphasised the pivotal role played by social workers in mitigating social isolation of service users during the pandemic [[726]](#footnote-727) and recognised how communication technologies in social work practice became an adjunct to face-to-face interactions [[727]](#footnote-728).

In the UK, social workers’ mental well-being and the quality of working life increased significantly from 2018 to 2020 due to increased support, reprioritisation of workload, moving to home working and associated greater flexibility of working hours.[[728]](#footnote-729) This is in stark contrast to the report of significantly decreased mental wellbeing and the quality of working life from 2020-2021 of health and social care professional groups deploying negative coping strategies[[729]](#footnote-730) [[730]](#footnote-731).

Particularly disadvantaged were newly qualified and early career social workers in Scotland, due to under-developed professional networks in times of home working, which meant less support, impacting their confidence, competence and their professional identity[[731]](#footnote-732). Furthermore, some had their final placement concluded early which affected their sense of readiness for social work practice and some research projects were also adversely impacted[[732]](#footnote-733). The same study further suggests limited provision during inductions and absence of continuous and consistent support. In relation to people receiving services, newly qualified social workers found building meaningful relationships remotely challenging. Consequently, a small number resorted to working outside of the emergency regulations.[[733]](#footnote-734) No specific examples were given in the paper to support this important point, but it was clarified that these changes were enacted to try to provide more *humane* and *socially just* practice. This is a potentially important area which could be explored further via primary research.

Suggestions for post-pandemic recovery include strengthening social work’s capacity to address structural issues in practice, addressing gaps in social work education, new and updated standards and guidelines, professional clarity and expert supports, and governmental support. [[734]](#footnote-735)

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## 12.5 Governance and Regulatory Oversight of Social Work

On 20 March 2020, in response to the draft Coronavirus Bill, SASW National Director Alistair Brown called upon the Scottish Government to recognise social work as ‘key workers’ and noted that the Scottish Government had the opportunity to enhance the workforce by registering final year students, those who had retired and those on career breaks to bolster staff resilience as demand increased. School closures and home working were expected to increase demand for social work services, particularly for vulnerable individuals and those in abusive domestic situations who may require additional support. [[735]](#footnote-736) However, a later open letter to Ministers[[736]](#footnote-737) (30 March 2020) highlighted the importance of managing such cases of registration carefully, with an emphasis on safeguarding, establishing clear lines of accountability and ensuring particularly complex cases are assigned to the most experienced staff.

Following a Scottish Government letter issued on 30 March 2020 [[737]](#footnote-738), which confirmed that social care support workers were to be regarded as ‘keyworkers’ delivering essential services during the pandemic, SASW noted that social workers needed to be made aware of the implications for registration if they were unable to meet timescales, duties and legal compliance during this period.[[738]](#footnote-739)

The SASW response to the Coronavirus Bill also described social work as a priority group who needed to receive adequate PPE for their work alongside the NHS in supporting vulnerable individuals[[739]](#footnote-740). This is echoed in an update by SASW from 25 March 2020 where they highlight the issue of inconsistent access to necessary PPE[[740]](#footnote-741), and the open letter of 30 March 2020 where again PPE is highlighted as an issue, along with childcare for workers and the need for consistent protocols around home visits and community care.[[741]](#footnote-742) A report by BASW from January 2021 confirmed that 63.5% of social work staff agreed that PPE availability and access had improved since the early pandemic, but the report cautions that this still did not equate to staff having sufficient access or supply.[[742]](#footnote-743)

Social work education as an infrastructure upholding the social work practice experienced profound development during the COVID-19 pandemic. Following the implementation of emergency legislation, higher education was forced to rapidly move learning and teaching almost exclusively online. However, the digital inequalities between students and teachers became apparent. The differential access to information and communication technologies, and variance in strength and reliability of internet connections raised questions around access to digital education as well as about the balance between in-person and remote teaching and learning[[743]](#footnote-744).

Scottish student perceptions of blended learning indicated four key findings[[744]](#footnote-745). First, the real-time interaction with academic staff was important, as was the opportunity to ask questions; second, a sense of community cannot be easily replicated in virtual environments and the onus was placed on academics to ensure regular opportunities for in-person meeting on campus; third, practice and academic assessments were affected by the enactment of emergency legislation which caused considerable anxiety amongst students who were required to gain practical learning experience to satisfy professional standards; and fourth, moving to a virtual environment was interpreted as an opportunity for professional growth as the same strategies would likely be applicable in social work practice.

The impact of teaching and learning from home was emotional and physical, requiring the development of coping strategies to adjust to new realities[[745]](#footnote-746). This included problem-oriented strategies aimed at instrumental support from colleagues to address arising challenges. Likewise, emotion-oriented strategies such as gaining mental distance from work, accepting unchangeable situations and focusing on positive experiences had been reportedly effective. This was not true for avoidant coping mechanism, which had overall negative effect and come at a cost.

An example of social work students on placements applying the learning from a bespoke Mindfulness-Based Social Work and Self-Care (MBSWSC) programme to their social work practice reported how switching from an avoidant- to an approach-oriented coping strategy allowed them to alleviate any negative thoughts or feelings they were experiencing[[746]](#footnote-747).

Five final year social work students in Scotland graduating amidst the pandemic reported feelings of both connection and disconnection in relation to environment around them, to others and to themselves[[747]](#footnote-748). They highlighted the impact of their professional and personal identity on their experience. Notably, clear disparities were identified between data entries of black and minority ethnic participants and their white counterparts. The student’s transition to a professional identity was sought through reflection and ritual in the absence of formal ceremony. Similarly, the impact of the pandemic did not spare the doctoral students, whose research was severely methodologically challenged due to emergency legislation [[748]](#footnote-749),

Under-reported, however, remain experiences of students and teachers protected by the Equality Act 2010, those with caring responsibilities, international students, along with students whose personal circumstances became challenging due to change in their socio-economic circumstances, such as loss of income and student poverty, and/or rapid change in physical and/or mental health and/or impact of grief/s.

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## 12.6 Guidance and Support Available to Social Care Staff

### 12.6.1 Guidance

The first guidance was issued on 26 March 2020 as part of clinical guidance for the management of clients accessing care at home, housing support and sheltered housing. The guidance was aimed at local authorities, Health and Social Care Partnerships (HSCPs) and registered providers, who support and deliver care and support to people in their own homes.

Adult social care providers and their staff were informed of the required public health measures that should be taken to prevent and manage COVID-19 through Scottish government published guidance ‘COVID-19 – information and guidance for social, community, and residential care settings’.[[749]](#footnote-750) This guidance covered the provision of care/support in a range of settings and, of particular relevance to this report, where care is provided to individuals in their own home or in adult social care building-based day services. Between January 2020 and December 2022 fifteen versions of this guidance were issued[[750]](#footnote-751).

The constant changes to policy guidance and public restrictions created feelings of uncertainty, fear and ambiguity for both recipients of care and care providers. In some cases, guidance was updated several times in a short space of time, which created stress for individuals trying to negotiate their care and for caregivers to ensure they were compliant with regulations. *[[751]](#footnote-752)*

For staff, the information could also overwhelm. Due to the number of different forms of social care support, it was not always clear to staff which guidelines were relevant to which roles.[[752]](#footnote-753)

For winter 2020-21, guidance was issued around the delivery of services. In order to reduce transmission, digital service delivery was recommended wherever possible. Staff were offered and advised to receive the seasonal flu vaccine, and staff cohorts were to be created, to minimise infection transmission and enhance continuity of care. Providers were expected to be able to demonstrate that they have made every effort to limit staff movement. This was to be supported by an additional £50 million of funding to help facilitate this temporary staff restructuring.[[753]](#footnote-754)

Guidance issued in April 2020 directed that all in-person contact with service users should be risk assessed in advance to include the potential impact for the safety of all attendees, infection control and the physical context of the meeting, including whether adequate measures such and physical distancing could be maintained, and whether individuals in the meeting location were vulnerable or symptomatic. For essential visits to individuals who were symptomatic, staff were advised to adhere to all infection management protocols including hand hygiene, physical distancing and the wearing of PPE. Importantly, as above, essential visits should continue, but staff were to adhere to all guidance in order to keep themselves as safe as possible. [[754]](#footnote-755) This guidance became more detailed as the pandemic progressed.[[755]](#footnote-756)

Guidance from January 2022 emphasised that social work staff who had come into close contact with a positive case of COVID-19 were exempt from self-isolation rules under certain conditions.[[756]](#footnote-757) These conditions included being permitted to leave isolation on day seven if a negative Lateral Flow Device (LFD) test was obtained on days six and seven, and they did not have a fever. From 17 January 2022, fully vaccinated staff who had come into contact with positive cases were to take daily LFD tests for seven days but did not have to isolate provided they test negative and remained well.

Staff were strongly urged to continue with asymptomatic LFD testing every working day, along with a weekly PCR where required. The same guidance reminded staff of the importance of vaccines and boosters, as vaccine status affected which guidance must be followed and when a return to work was viable. Importantly, when staff returned they were still not to work with the most clinically vulnerable groups for the remainder of what would have been their ten-day isolation period. In an outbreak situation, local Health Protection teams were able to override exemptions.

Notably, employers need not demonstrate that they were in an extreme situation before asking staff to return, and responsibility of doing so rested with line managers. Where staff met the outlined conditions they were expected to return. In a survey by BASW from January 2021, 30.7% of respondents said that they had felt under pressure to work whilst unwell and 22.3% disagreed that their employer had accommodated them early in the pandemic when they were advised to shield.[[757]](#footnote-758)

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### 12.6.2 Emotional and Psychological Impact on Social Care Staff

Social care workers reported feeling under-appreciated during the COVID-19 pandemic. For example, a BBC news article published on 7 April 2020 carried the headline *“Coronavirus: ‘I’m a frontline carer but feel undervalued’”*[[758]](#footnote-759). The article outlined the story of a social care worker not allowed to access the Tesco shopping hour restricted to access for frontline workers because they didn’t have an NHS badge. Tesco and Iceland claimed they were unable to accommodate independent sector social care workers and could only manage to offer the benefit to NHS workers. Donald MacAskill of Scottish Care is quoted in the article as saying “*we are still seeing ignorance and under-appreciation of social care workers*”.

A report published by Health and Social Care Scotland in July 2020 highlighted that social care staff often felt under-appreciated during the pandemic, despite their very challenging roles[[759]](#footnote-760). The morale of workers in the care sector has been affected as a result of staff shortages and problems with maintaining workforce levels, which in turn affected the mental wellbeing of workers in this sector.[[760]](#footnote-761)

It was reported that many staff members experienced anxiety when the pandemic and subsequent restrictions were initially announced: *“I think initially …everybody went into sheer panic.”* Participants in the study highlighted that their roles, by entering people’s homes, were placing them at risk. This, in turn, caused staff to worry about transmitting the virus to close ones and family members: *“From the staff point of view, we’re having lots of issues of people’s own sort of worries about their safety, their family’s safety”.* Interestingly, the report found that expressions of fear mostly related to transmitting the virus, not contracting the virus: “*the staff were frightened in case they brought something into the homes and one of our service users became poorly”.[[761]](#footnote-762)*

A report by Sanders (2020)highlighted the impact of ‘moral injury’ on health and social care workers, as a result of the pandemic (moral injury, being the potential for psychological distress arising from actions or omissions to act which have the potential to become a moral or ethical infringement). The report applies this to the context of social care, where workers may experience guilt as a result of potentially carrying and/or spreading the virus, or the impact of lack of resources. The report highlights that these symptoms can develop into more serious difficulties, such as depression or PTSD. [[762]](#footnote-763)

Findings from cross-sectional online surveys, completed by a total of 4,950 UK Social Care and Social Workers found that working conditions and well-being measures were found to be significantly worse during Phase 2 (November–January 2021) than Phase 1 (May 2020 - July 2020), with worse psychological well-being than the UK average in Phase 2. It was also found that in January 2021, feelings about general well-being, control at work, and working conditions predicted worsened psychological well-being[[763]](#footnote-764).

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### 12.6.3 Levels of COVID-19 Infection Within the Social Care Workforce

Websites including Public Health Scotland, the Scottish Government and the Care Inspectorate were searched with an aim to locate data on the numbers of social care staff infected with COVID-19 over the course of the pandemic. However, these searches did not yield this information.

It was noted during these searches that on The Scottish Government site named “Coronavirus (COVID-19): data: definitions and sources”, within the section “Published data on COVID-19 and the health and social care workforce”, categories included “Number of NHS staff absent for COVID-19 related reasons” and “Number of staff absent in adult care homes due to COVID-19” and that there was no equivalent category for other social care staff not working in adult care homes[[764]](#footnote-765).

To determine if it was the case that specific infection data for this sector had not been collected, we contacted Public Health Scotland who replied: “*Unfortunately, we are unable to identify social care workers in our data sources and have therefore been unable to produce data on social care worker specific rates of infection.*” .

The lack of access to these statistics makes it very difficult to determine the true impact of COVID-19 infection on the social care workforce. However, even if available such statistics would be unlikely to reflect the true number of COVID-19 infection rates within social care staff, because some positive cases will have not taken a test and many will have been asymptomatic. One study estimated that as many as 30% of COVID- 9 infected individuals are asymptomatic but are 75% as infectious as those with symptoms[[765]](#footnote-766). With the absence of regular asymptomatic testing for social care staff until January 2021, these cases would have gone undetected[[766]](#footnote-767).

English data suggests that social care staff have been at higher risk of dying from COVID-19 than others of the same age and sex.[[767]](#footnote-768)

A high level of COVID-19 infection within social care staff in Scotland can be inferred from the high rates of Long COVID reported within this group. A report by the COVID-19 recovery committee published in April 2023, stated that as a proportion of the UK population, the prevalence of self-reported Long COVID is greatest in people aged 35 to 69 years, females, people living in more deprived areas, those working in social care, those aged 16 years and over who were not working and not looking for work, and those with another activity-limiting health condition or disability[[768]](#footnote-769).

Individuals working in care faced an increased risk of contracting the virus during the pandemic. Subsequent data on death rates revealed that social care staff specifically had a high death rate compared to other occupations in Scotland.[[769]](#footnote-770) The difference in death rates between paid and unpaid carers remains unclear.

Data from 30 July 2021 reported that 31 social care staff had died from COVID-19 and that 19 eligible claims have been made and subsequently paid from the ‘Coronavirus (COVID-19): Social Care Worker Death In Service Scheme’, which provides a lump sum payment of £60,000 to the dependants of these individuals[[770]](#footnote-771).

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### 12.6.4 COVID-19 Testing for Social Care Staff

Early in the pandemic, testing for COVID-19 was initially carried out exclusively using the only test available at the time which was the lab-based PCR test. In March 2020, the capacity of NHS testing in Scotland was only 700 tests a day and testing was restricted to suspected cases of COVID-19. Guidance for NHS Boards issued 24 March 2020[[771]](#footnote-772) outlined that where testing capacity is available, after testing of critical patients, frontline staff would be tested to enable their return to work and reduce working days lost to COVID-19 isolation. The guidance indicated this testing was applicable to all key worker roles and that social care workers should have the same access as all other frontline healthcare workers:

*“The Scottish Government has decided not to create a static hierarchy of key worker roles or organisations for NHS Boards to use in prioritising who should be tested. Instead, at the current time, testing prioritisation should focus on supporting critical service delivery in health and social care services (including children’s services).”*

In order to better monitor and control infection spread in high-risk settings, the Scottish Government introduced weekly asymptomatic testing for care home staff on 25 May 2020[[772]](#footnote-773). If a positive case was detected, all staff and residents were then tested. From July 2020, this weekly asymptomatic testing was extended to all hospital staff working in long term care wards.

Regular testing of other social care workers was not introduced until 10 months later, with the publication of ‘Guidance on coronavirus testing for the care at home sector’ on 15 January 2021.[[773]](#footnote-774) By this time self-test LFD tests had become available, in addition to lab-based PCR tests. The guidance is broken down into sector areas as follows:

* *Care at home services:* LFD or PCR – Because of the diverse nature of care at home services some services will use LFD tests while others will use PCR. LFD – twice weekly test with follow up PCR test if LFD is positive. PCR – once weekly.
* *Personal assistants and adult day centres and day care services:* LFD tests – twice weekly with follow up PCR test if LFD is positive.
* *Sheltered housing, housing with multiple occupancies:* LFD tests – twice weekly with follow up PCR test if LFD is positive.

In addition to online documents and posters, online training workshops were delivered. While LFD results are delivered instantly after the test is run, PCR tests require lab analysis. Given that transport time and lab turnaround would have affected when PCR results were delivered, it is likely that result return time varied across the country depending on lab services available in the area.

Asymptomatic testing in Scotland was not at any stage mandatory for health and social care workers. Commentary on this issue included from UNISON Scotland who wrote “*In its worst conceivable form, mandatory testing could compel workers to undergo repeated, intrusive procedures along with repeated sharing of sensitive personal data, all compelled by the threat of disciplinary action and the loss of human rights associated with work. The combined effect of a bad policy would be hard to justify.*”[[774]](#footnote-775)

At the same time, though, UNISON Scotland called for “routine testing of workers without any symptoms”. A BBC News article from November 2020[[775]](#footnote-776) reported that although the Scottish Government had announced on 23 October 2020 that wider staff testing would be rolled out, no timescale was provided. Carer Kathy said she was *“very, very angry”* that this had not yet been implemented and queried *“Why are we not getting tested when we are working with vulnerable people?”*.

The GMB Union called for the immediate roll out of testing, with Shona Thomson of the GMB Union quoted in the same BBC article as saying *“Our workers out there are terrified. I’ve got workers on the phone every day. They are crying because they have vulnerable people in their own households who they are trying to protect and they are having to go out into the community as well to do their job.”*

Within the same BBC article, the Cabinet Secretary for Health and Sport, Jeanne Freeman, was quoted as saying *“Before the end of November I will go back to parliament and set out for MSPs the whole delivery plan to roll out routine testing to asymptomatic people in those different groups. At the point when I set that out to parliament, we will be giving dates for some of these groups – and that will include home care workers – about when we will begin to deliver that testing.*[[776]](#footnote-777)” She is also reported to have said: *“Responding to suggestions that some care workers feel “forgotten”, I am genuinely very sorry that they feel like that. I have certainly not forgotten them. They have always been in my mind as a group that we needed to be able to offer testing to as soon as I had the capacity to do that*[[777]](#footnote-778).”

An article published in the Herald Scotland on 13 January, 2021[[778]](#footnote-779) reported that the GMB Union was balloting home care workers in Glasgow for strike action on lack of confidence in workplace testing. A union representative was quoted as saying *“They were failed on PPE at the outset of this pandemic, they have been left waiting 10 months for workplace testing, and some are already encountering problems getting their first vaccine.”*

An update from the Scottish Government on their testing strategy in March 2021[[779]](#footnote-780) reported that: *“Care at home staff began routine testing for adult services from the 18 January (adult day centres/day services, care at home, personal assistants, and sheltered housing/housing with multiple occupancy). This was implemented by the end of February – one month ahead of the planned full roll out date”*.

The Scottish Government announced on 15 September, 2022 that asymptomatic testing of social care staff would end with immediate effect[[780]](#footnote-781).

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### 12.6.5 Vaccination of Social Care Staff

Social care staff were included in the Joint Committee on Vaccination and Immunisation (JCVI) Group 2, which included in full: *“Patient-facing, frontline healthcare workers; non-clinical but patient facing staff in secondary or primary care/community healthcare settings; laboratory and pathology staff; social care staff directly involved in the care of their service users”*[[781]](#footnote-782).

While vaccine hesitancy has been widely reported among some health and social care staff, little is known about this amongst social care workers[[782]](#footnote-783). There is evidence, however, to suggest that some in the social care group in Scotland were reluctant to take up the booster vaccine. A more recent study reported that as many as one in six healthcare workers in Scotland were unsure about whether to get vaccinated[[783]](#footnote-784).

Towards the end of 2021, the uptake of the booster vaccine was found to be lower amongst social care workers at 47.7%, compared with 72% of frontline workers. This statistic led the then Health Secretary Humza Yousaf to issue a request on 12 December 2021, urging social care staff to get the booster, in light of the emergence of the Omicron variant[[784]](#footnote-785). Also announced within this release was that “Scottish Government financial support is available for adult care providers who incur additional costs if employees are vaccinated in working time – so staff can do so without losing earnings or having to take annual leave.”

There were reports of social care staff having difficulty with accessing vaccines. For example, on 30 July 2021, The Scotsman published findings of a Public Health Scotland survey of 7000 health and social care staff that “6 per cent of social care workers said they found the vaccine difficult or very difficult to access in their organisation”[[785]](#footnote-786).

The introduction of vaccination led to an updated policy framework, which from 9 August 2021 removed the need for health and social care staff to isolate when a close contact of a COVID-19 positive individual, provided they are double vaccinated, show no symptoms, and return a negative PCR test.[[786]](#footnote-787)

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### 12.6.6 Personal Protective Equipment

Access to personal protective equipment (PPE) for workers engaging in face-to-face contact with patients was a critical component of infection control during the COVID-19 pandemic. PPE items included gloves, gowns, aprons, masks, eye protection and hand sanitiser[[787]](#footnote-788).

Guidance for carers and those working in social care on how to access PPE was first published by the Scottish Government on 29 April, 2020 and last updated on 16 November, 2021[[788]](#footnote-789). Also on 29 April 2020, guidance was also issued to personal assistants[[789]](#footnote-790).

On 8 April 2020 the GMB Union accused the Scottish Government of forcing carers to work with insufficient PPE, expressing concern that guidance recommended home care staff only wear a mask when the person that they were caring for was suspected of having COVID-19 and they were coming within two metres of them[[790]](#footnote-791). The union claimed this was a change to the original guidance issued to the whole of the UK and had left Scottish home and social care workers at greater risk. This led to further discussion between the unions, the Scottish Government and COSLA, and to amended guidance for carers that they could wear masks whenever they felt it was appropriate.

At the start of the COVID-19 pandemic, social care workers were not provided PPE through national procurement by NSS (NHS National Services Scotland), which at this point only sourced PPE for hospitals. Instead, PPE for the social care sector was sourced by care providers through private providers. This led to uncertainty over who was responsible for the additional provision of PPE to social care workers in the early stages of the pandemic[[791]](#footnote-792).

On 25 April 2020 The Scottish Government announced that local hubs would distribute PPE supplies to the whole social care sector, where normal supply routes had not been successful. The aim of the hubs was to extend PPE provision to all social care providers, and unpaid or family carers and personal assistants.

An Audit Scotland Briefing report on PPE, published in June 2021, reported that social care and primary care were later added to the NHS remit, with 48 hubs established across Scotland where care at home workers, unpaid carers and personal assistants could access a week’s worth of PPE, and an emergency response phone line being set up[[792]](#footnote-793). Audit Scotland noted that PPE stocks fell to very low levels in April 2020 with only 0.3 days’ worth of stock of long sleeve gowns, one day of FFP3 masks, and two days of visors. While stocks did not run out, there was concern that health and social care workers found it challenging to access PPE. For example, an article in the Scottish Daily Express quoted Aamer Anwar, a solicitor acting for the Scottish Covid Bereaved group, as saying *“Each minister so far has said there were no problems and no shortage but quite honestly that doesn’t match to reality. We know that medics, nurses, health professionals, social care workers were literally crying out for PPE”*.

Furthermore, healthcare staff themselves expressed concern at the quality of the PPE issued to them. On 8 April 2020 a BBC News article reported that over 100 medical professionals had signed a letter to Scottish Government expressing “grave concern” about their PPE, including that aprons and masks were too thin and eye protection not sufficient[[793]](#footnote-794)

A study conducted by Cardiff University, published in April 2020 – a UK-wide study that included Scotland – reported that *“Evidence from care workers shows how lack of PPE is a safeguarding issue and there are fears too about maintaining basic hygiene due to reported shortages of soap and hand sanitiser”* and *“our analysis of survey results reveals that across social care and support settings, workers are experiencing a severe lack of PPE”*[[794]](#footnote-795).

There appeared to be initial misunderstanding about how to access PPE and what sort of protective measures were needed in certain situations*: “…I think there was initially some real misunderstandings about the sorts of support situations that go on within people’s own homes and the fact that social care would need particular access to bits of PPE that wasn’t part of their everyday ordinary supplies and there were real difficulties accessing [it]…”[[795]](#footnote-796)*

Safety was a key factor driving decision making. Staff reported having to constantly *“balance the health and safety of staff and the individuals we support.”* [[796]](#footnote-797) Staff were furloughed, or Care at Home providers had their funding ‘reduced’. According to a Care Inspectorate Report, published in September 2020, there was a lack of clear guidance for social care staff early in the pandemic regarding infection risk to themselves and their families, who should be shielding, and which staff could be furloughed. This report suggested that this was detrimental to staffing levels. However, as the pandemic progressed absence rates declined. This may have been attributable to staff confidence in guidance and testing, and the adoption of more robust risk management protocols.

For similar reasons, a number of service users and their families chose to decrease or withdraw from care because of concerns for safety.[[797]](#footnote-798)

The Health and Sport Committee at the Scottish Parliament highlighted the need for quality communication so ‘*people are kept well informed of the situation’* as there were instances of ‘no contact’ between some services and service users. In particular there have been calls for more *‘clear concise guidance’* so people are aware of the roles they need to carry out in future pandemics.[[798]](#footnote-799)

Accessing PPE as a carer was repeatedly highlighted as a key issue during the early stages of the pandemic. The lack of PPE affected the way that carers could perform their care tasks. A report drew on findings from a UNISON survey, highlighting the challenges with PPE, specifically it being unavailable and/or unsuitable. A respondent to the survey (carer) summarised their experience with PPE as: “*We have very little PPE, we are forced to tend to clients in a rushed way, making it difficult to follow correct infection control measures.*”[[799]](#footnote-800)

Care providers reported that the main difficulties with accessing PPE were due to suppliers prioritising NHS customers and the rise in prices for equipment.[[800]](#footnote-801)Access to PPE improved during the pandemic, as supply was addressed and national PPE hubs were created to manage this. *[[801]](#footnote-802)* Local hubs were used to organise distribution of PPE to all social providers from the national stock, meaning unpaid and family carers and personal assistants were no longer excluded.[[802]](#footnote-803)

## 12.7 Staffing, Recruitment and Retention

The long-standing effect of the pandemic is clear on recruitment and retention of staff in the care sector. It was reported in early 2022 that care workers did not feel *‘adequately supported or rewarded’* during and after the pandemic[[803]](#footnote-804), which contributed to difficulties in retaining staff levels and unmet vacancy levels[[804]](#footnote-805). An estimated 88% of social care providers during this time reported that recruitment was challenging. A report by Audit Scotland revealed that close to a quarter of staff leave within the first three months of starting and the GMB reported that 78% of home care workers felt they did not have enough time with clients to ‘*deliver compassionate and dignified care’* [[805]](#footnote-806).

One of the issues identified was the lack of investment directed towards the workforce. Many social care workers reported that the pay needs to improve, as workers currently feel undervalued and underpaid. Some workers reported that they have to rely on financial support because the pay is not enough: *“I have four part-time jobs, two in social care... I rely on working tax credits at the end of the month”* [[806]](#footnote-807).

The Scottish Government, responding to concerns about funding for social care, stated that they have *“increased the pay for social care workers by more than 14%”* over the last couple of years,[[807]](#footnote-808) that they are investigating how they can *“plan for, attract, train, employ and nurture the workforce, working with COSLA on consistency of improved pay and conditions […] and ensure a career in social care is attractive and rewarding”,*[[808]](#footnote-809) and that they are committed *“to increase spend[ing] in social care by 25% by the end of this Parliament, an increase of over £840m.”*[[809]](#footnote-810)

# 13. Hospice Services

## 13.1 Key Messages

* Deaths at home increased during the pandemic, partly because people avoided in-patient settings because of visiting restrictions.
* Hospices increased their community services.
* Hospices had mixed experiences in shifting to digital access to services.
* Hospices experienced difficulties accessing PPE, together with staffing shortages and a loss of volunteer support.
* There was a lack of tailored guidance for hospices.
* The social distancing and visiting restrictions caused profound distress, particularly at the end of life.
* The pandemic had a negative impact on fundraising, which is essential for many hospice services.

The Scottish Partnership for Palliative Care registers 52 palliative care services across Scotland. Hospices provide palliative and end-of-life support to over 22,400 people via inpatient, home care and day services, each year.[[810]](#footnote-811) The need for these services appears to be increasing year on year and is expected to rise as a result of our ageing population.[[811]](#footnote-812) It is estimated that there will be an additional 100,00 more people dying in the UK in 2040, with a projected increase of 14% (up to 10,000 more people) requiring palliative care.[[812]](#footnote-813) Following existing trends, the majority of these deaths are anticipated to take place in the community.[[813]](#footnote-814) Evidence indicates that currently one in four people do not receive the palliative support they need. [[814]](#footnote-815)

Unlike other health and social care services, hospices did not receive tailored guidance, which caused confusion and misunderstanding amongst staff, carers and care recipients.[[815]](#footnote-816) The rules and measures around visitation were particularly unclear, resulting in weak enforcement in some areas. Many felt that the measures being implemented compromised the service model of hospice care, namely: a strong commitment to person-centred and holistic care for both care recipients and their carers. Depriving social contact with loved ones at the point of end-of-life caused immense emotional distress for all parties, particularly family and friends. Many felt that the restrictions affected their ability to provide “*best care*” and witnessed care recipients not having dignity at the end of their life by being unable to be with loved ones and lack of touch.[[816]](#footnote-817) This influenced many to choose to die at home to maintain contact with loved ones: *“One of the reasons why I wanted to keep [my mother] at home and not into the hospice because at the hospice there were [visiting] restrictions.” (Carer)* [[817]](#footnote-818)

The COVID-19 pandemic highlighted the importance of social relationships and connections for mental wellbeing and recovery; they are particularly valuable during end of life care.[[818]](#footnote-819)

## 13.2 Impact of Restrictions on Recipients of Care and their Families

The surge in demand for palliative home care meant that many individuals went without the support they needed or in some cases had to endure a long wait.[[819]](#footnote-820) At a time when in-person contact with friends and family is the upmost priority, many individuals’ facing end-of-life care did not have this option and instead experienced isolation and loneliness during their last days. The strict social distancing measures caused profound distress to all parties involved, causing many to choose to die at home.[[820]](#footnote-821)

Many carers reported that the reduction or withdrawal of support for end-of-life care was challenging, as they were often left to carry this out alone with little or no support. There were calls for: *“Better communication for patients following a cancer diagnosis, better shared care as no one was reviewing my mother’s medication for brain mets [metastases] and her condition was deteriorating.” [[821]](#footnote-822)*

Social distancing measures also resulted in many carers and family members not being able to attend appointments due to hospital restrictions. The lack of involvement in their treatment caused concern: *“For me, I worry that I don’t have enough information regarding the cancer my husband has and how to deal with the emotions and symptoms confidently. COVID-19 prevents me from going into the oncology office during appointments, so I am doing research via support groups.”[[822]](#footnote-823)*

For the majority of carers and family members, their bereavement experiences had a long-lasting impact and there was limited support in place to help with this, despite new technological initiatives: *“I haven’t been offered, you know the I mean [hospice], nobody’s offered anything. We might have had one wellbeing call and then that was it. So no. But it is something that I think probably that we that we will explore” (Carer).* Others agreed that support would have helped:“*And I think if I had had more support . . . then maybe that would have helped me and my family with their grieving process, there’s a lot of unanswered questions… I don’t know if you’ve ever had a child but you know when you have a birth debrief, I think almost like a death debrief.” (Carer)*

A study by Bradshaw et al. (2022) found that the imposition of visitation restrictions caused moral distress for palliative carers and staff. Measuring a UK sample, the study found that the inability to fulfil the wishes of their care recipients at the end of their life was distressing to staff and carers. The inability to say goodbye to loved ones was highlighted as the biggest challenge of the social distancing restrictions.[[823]](#footnote-824)

This has also impacted the provision of bereavement support in both creating more need for this support and exacerbating existing demand. These services also transitioned to a virtual mode of delivery. This was met with mixed opinions, as practitioners reported feeling more stress delivering this support virtually compared to in-person.

Findings from the study suggest that bereavement care should be considered an integral part of health and social care provision.[[824]](#footnote-825)

During the pandemic, there was a collaborative effort between hospices and other health and social care providers to meet the increased level of need. This involved adapting services and delivery of care in new ways that comply with COVID-19 measures.

## 13.3 Change in Service Delivery: Shift Towards Community Care

Since the start of the pandemic, there has been a noticeable shift in the location people choose to die, with the majority of non-COVID-19 patients being cared for and dying in the community, [[825]](#footnote-826) The reasons included the strict visitation rules and fear of infection transmission.[[826]](#footnote-827) Data from 2020 reported that almost a third of deaths took place at home, resulting in over 4000 more deaths at home compared to previous years.[[827]](#footnote-828) Data from a Marie Curie report in July 2022 compares rates of deaths occurring at home against socioeconomic status. The report reveals that individuals living in the most deprived areas were at an increased chance of dying at home, however post-pandemic data showed an increase to home deaths across all socioeconomic groups with the largest increase those living in least deprived areas.[[828]](#footnote-829)

Palliative care services played a vital part in the pandemic emergency response.[[829]](#footnote-830) The social distancing measures imposed strict rules on visiting in care facilities, which resulted in many individuals opting to receive their support at home. To meet this increased need for care at home and in the community, hospices increased their community capacity and adapted their services in the following ways: rapid response services, virtual wards, and providing out of hours support.[[830]](#footnote-831)

Many hospices increased the level of care they provided by offering an increased out-of-hour service. These services, in some cases, operated 24 hours a day throughout the week to ensure people were able to manage their pain and symptoms.[[831]](#footnote-832) Although this proved beneficial to care recipients and their carers by ensuring support was available when needed, it also presented logistical issues such as staffing challenges and added further pressure to existing issues with PPE, medicine and equipment access. A study conducted by Hasson et al. (2022) investigated these services and findings suggested that these logistical issues likely could have been addressed with more integration with wider healthcare providers.[[832]](#footnote-833)

The Strathcarron Hospice@Home Service in Forth Valley is an example of a hospice provider adapting to a community model of care. This service provides practical and emotional support to the care recipient and their family. It was found that patients receiving care under the service experienced significantly fewer bed days compared with those not receiving community care. Not only does this minimise pressure on acute services, but also feedback from the service reported high levels of satisfaction from carers and families.[[833]](#footnote-834)

## 13.4 Change in Service Delivery: Adapting to Digital Technologies

Hospices in Scotland have also actively adapted their services by taking advantage of digital technologies, specifically providing virtual support. A study investigating palliative rehabilitation found that transitioning to digital media required providers to be creative in the delivery of care. Care providers reported that this involved anticipating symptoms and issues that would hinder involvement with digital rehabilitation, such as breathlessness, anxiety and fatigue. Providers also tried to ensure family members had active involvement in the rehabilitation process. It was noted, however, that some rehabilitative interventions were not viable using digital methods, as these required clinicians to be physically present, and therefore offering the same full range of care was not always possible.[[834]](#footnote-835)

The feedback around digital support has been mixed. Offering virtual supports has been received positively. It has allowed hospices to reach more people and can be less time-consuming for staff. However, difficulties have arisen in relation to digital exclusion and access to virtual support.[[835]](#footnote-836)

*“It’s a way into the hospice world for some people that wouldn’t have accessed those services before. The virtual platform is definitely a way forward for different client groups who physically cannot get into the hospice, or potentially don’t want to meet face to face”. (Hospice Senior Manager)*

Some had doubts on the efficacy of virtual support: *“Of no use whatsoever! Because they’d speak to my dad and he goes, ‘Yeah I’m okay today’. Well, no, you’re not okay, you haven’t eaten, you can’t lift your head . . . and so they needed to see him. Anybody can say anything on the phone.” (Carer)*

On digital exclusion: *“We try to introduce virtual consultations, but the difficulty we found, or the challenge that we found was a lot of our patients hadn’t got the IT set up at home, to be able to instigate that. So, the even though we’ve tried it, it hasn’t always worked.” (Senior Manager).”* [[836]](#footnote-837)

A recent scoping review by Dobrikova et al. (2023) reviewed the challenges that staff and carers faced during the pandemic, which highlighted transition to telemedicine and reliance on technology as key challenges reported by staff.[[837]](#footnote-838) It was reported that the “absence of human connectedness” made it difficult to provide emotional support virtually.[[838]](#footnote-839)

Many workers reported that they increased their contact time with care recipients to counteract the fact they were unable to see family and friends and attempt to ‘mend this gap’. For many staff members, this would involve calling more, comforting care recipients and video-calling more often. Some staff members admitted to ‘bending the rules’, as they felt morally obliged as the restrictions felt too “*unfair*” in some situations. [[839]](#footnote-840)

## 13.5 Shortages of PPE, Medicine and Equipment

Many hospices experienced difficulties accessing PPE, medicine and equipment in the early stages of the pandemic. The CovPall Project reported that Scotland faced shortages accessing medicine and equipment. In the survey, 15% of respondents experienced shortages in medicine and 12% in equipment.[[840]](#footnote-841) It was found that charity managed services were more likely to experience PPE shortages compared to publicly managed services and staff shortages were felt significantly more by services in the UK, compared to the rest of Europe.[[841]](#footnote-842)

A study investigating the impact on hospice services using a sample from the United States found that medication shortages negatively affected patient outcomes.[[842]](#footnote-843) In Scotland, however, the relationship between resource shortages and patient outcomes during this time remains unclear.

A contributing factor is the fact that hospice care was not viewed as ‘frontline NHS’. The WHO did not list palliative care as ‘essential health services’ in their guidance issued at the start of the pandemic (March 2020). [[843]](#footnote-844) It has been reported that 40% of hospices in Scotland faced shortages of PPE during the initial stages of the pandemic and palliative care was compromised as a result.[[844]](#footnote-845)

*“As we are not classed as ‘frontline NHS’ we were unable to access [masks and gowns] from our local NHS board…this was less than satisfactory for seven weeks, however this has now been resolved.” (experience from Scottish hospice provider)*.[[845]](#footnote-846)

Lack of PPE caused increased fear in care providers:

*“But again there was that fear, I think, I’m going into houses with, you know, very little PPE. You know, we just really had, these masks and the visors and an apron. And yeah, you were going into a house.” (Nurse)*.[[846]](#footnote-847)

A hospice in Paisley described the desperation that many hospices felt, whereby they were left with no option but to use social media to ask the public for advice on sourcing much needed equipment.[[847]](#footnote-848)

Although it was agreed that the use of PPE, when accessed, was important in tackling the pandemic, it was reported that the use of face masks and PPE equipment interfered with the staff’s ability to provide compassion, as facial expressions and physical contact can be important therapeutically. *[[848]](#footnote-849)*

*“Not touching a family member when all they want is human comfort in one of the times when they are most vulnerable and need comfort after someone has died has been the hardest thing. Watching someone in distress causes distress to the nurse/Healthcare Assistant too”*

*“Wearing/ use of PPE can cause difficulties for the team supporting loved ones especially if they are of an older generation. It poses barrier to communication and completely takes away the use of therapeutic touch often used to reassure people”*

*“I still think a lot of people missed the human connection and you know being able to sit here and, you know, we felt it too, being able to hug people and hold their hand . . .” (Staff) [[849]](#footnote-850)*

*“She was so confused because everybody around her had masks then she wouldn’t be able to tell us apart from other people . . . that was quite distressing . . . I think she wanted to say something and then she died, but . . . we had the masks [on] and I hope, I hope that she realised it was us.” (Carer)*

In their study, Bradshaw and colleagues (2022) shared experiences from staff and carers in palliative care that revealed they felt PPE impacted their ability to communicate with care recipients and thus ‘*created a barrier’*.[[850]](#footnote-851) Similar findings were reported in other studies, where the lack of human contact made staff feel uncomfortable and the new adapted care was seen as “*less humane*” compared to the level of support offered pre-pandemic.[[851]](#footnote-852)

## 13.6 Shortages of Staff

Staffing issues existed before the pandemic and were arguably made worse by transmission of COVID and restrictions. It was reported that many hospices lacked the staffing capacity to meet the level of need. Staffing shortages were highlighted in the CovPall Project survey, where 22% of respondents experienced difficulties with staffing capacity.[[852]](#footnote-853)

In terms of reasons behind these shortages, a study investigating the impact on care providers found that more than a quarter of the respondents were subject to involuntary redeployment, furlough or redundancy during the pandemic.[[853]](#footnote-854) Enforced measures such as ‘track and trace’ further exacerbated issues with staffing, which stretched an already strained workforce: *“Maintaining adequate staffing levels, particularly with track and trace affecting attendance”* on an already *“reduced number of staff available” (Hospice provider, survey response).* [[854]](#footnote-855)

The implementation of measures meant that not only did staff have to avoid work to self-isolate or recover, but also volunteers who would often supplement the workforce prior to the pandemic, could no longer provide help. Losing volunteer support greatly impacted the delivery of the service, leading many hospice providers to recruit to cover these roles: *“I mean it was a double whammy, I think. We really missed their [volunteers] support, because they used to do beyond reception, so you know actually a lot of the roles that they were doing, suddenly the staff were having to do all of that, so workload of paid staff increased, so that was hard. And then at the same time, the volunteers losing their role” (Senior Manager)* [[855]](#footnote-856)

Many volunteers were redeployed to assist psychological support and bereavement care for patients and carers, often via digital technologies or telephones.[[856]](#footnote-857) A multi-nation study by Walshe et al. (2023) found that 47.7% of responding organisations had changed how they deployed volunteers during the pandemic, with volunteers being removed from patient-facing work and directed towards home-based administration and support or carrying out deliveries for care recipients.[[857]](#footnote-858) The study found that volunteer deployment was most prevalent in organisations in Europe. Many organisations also experienced volunteers stepping down by choice as the pandemic emerged, in order to reduce infection transmission or shield.

Interestingly, the loss of volunteers was felt more strongly by staff than care recipients. In the same study, just above half of respondents reported they felt impacted by the reduced presence of volunteers.[[858]](#footnote-859) Staff appeared to be more impacted by the lack of volunteer support, as they reported it added workload and staffing pressures:

*“Has put additional pressure on paid staff who have to cover roles previously filled by volunteers.”*(Respondent 115, Western Europe, Adult/Child, mixed settings). [[859]](#footnote-860)

*“Volunteers made our space more lively and caring for patients and their families. The patients don’t notice the impact but we do. We know that volunteers can help stave off loneliness in patients who have no care circle, and can fill in the voids when family/friends aren’t able to visit.”*

The lack of volunteer presence was reported to impact the atmosphere of hospice settings with one respondent sharing *“The role volunteers play in enabling conversation and joy has been deeply missed.”*

## 13.7 Impact on Health and Wellbeing of Staff

The surge in demand for palliative and end-of-life care put immense pressure on the workforce with many providers feeling overwhelmed by the increased workload and having to balance new patients with existing patients.[[860]](#footnote-861) Although initiatives were devised to protect the mental wellbeing of staff and carers of palliative care, the increased workload has proven to be emotionally exhausting for the workforce, causing some to experience burnout and, or leave the profession:[[861]](#footnote-862) *“There’s just the sense of absolute fatigue within the team of, like their resilience to just keep going during the, you know stresses of it.” (Senior Nurse)*

Solidarity amongst the workforce was found to be comforting for many workers.[[862]](#footnote-863) Some staff members reported feeling emotional and physical distress arising from the changes in care delivery and the pressure to adapt. Another source of anxiety and distress was job security, whereby there was consensus that the messaging was inconsistent and this affected staff morale, resulting in some workers leaving their roles.[[863]](#footnote-864) Another study found that half the respondents also were not able to provide the full range of social work care as a result of government restrictions, which many providers found very challenging and suffered increased stress. In contrast, others reported that adapting to new ways of working, enabled providers to reach more people in less time, which improved time management and assessment times.[[864]](#footnote-865)

The social distancing measures meant that relatives could not interact with the care recipients, which placed additional emotional stress on all parties, including staff. A survey reported that staff felt pressure to *“fill the void this creates”: “Family members are much less socially supported, and this increases burden on healthcare staff to fill the void this creates.”*[[865]](#footnote-866)Staff also reported significant pressure on morale, anxiety and illness rates. One participating hospice in the survey shared that they felt it was unfair that staff did not have access to routine testing like other frontline workers and argued this was potentially a contributing factor to the anxiety experienced by staff.[[866]](#footnote-867)

## 13.8 Calls for More Sustainable Funding

Hospices have been greatly impacted by the COVID-19 pandemic, as many relied on fundraising as a primary source of income. Hospice UK has argued that the sector was overlooked during the pandemic and has argued for more consistent and stable funding to continue the end of life support they provide.[[867]](#footnote-868) Hospices currently receive approximately a third of their funding from public bodies and are required to fundraise extra funds themselves. However, the aftermath of the pandemic and cost of living crisis has impacted the yield of many fundraising efforts, putting increasing pressure on hospices.[[868]](#footnote-869)

The lack of consistent support for community end-of-life services has been exacerbated by the pandemic, creating an urgent need for reform to ensure these services are sustainable. The Independent Review of Adult Social Care highlighted support for reform in this area.[[869]](#footnote-870) In light of the Scottish Government’s Strategic Framework for Action on Palliative Care 2016-2021 which aimed to ensure that “everyone who needs palliative care will have access to it”, it is clear hospice services need more funding support to full recover financially from the pandemic.[[870]](#footnote-871) Scottish Hospices were allocated an emergency funding package of approximately £27m to support their work during the pandemic in the year 2020-21, however it was reported that they received only 10m of this amount.[[871]](#footnote-872)

Calls have been issued for more sustainable funding, as it is anticipated that as many as 10,000 will be in need of end of life care by 2040, with increasingly complex care.[[872]](#footnote-873) Conditions such as cancer and dementia are expected to be the leading causes for deaths and therefore it has been argued that resources should be directed and prepare for these populations.[[873]](#footnote-874)

Funding pressures remain an issue for hospices in 2023, as a representative for Hospice UK reported that hospices in Scotland are *“feeling the cost of living crisis, with rising energy bills and staff costs stretching finances to the extreme.*” It was also felt that hospices experience a lack of public financial support and funding is “*now too skewed towards charitable fundraising.”[[874]](#footnote-875)* The current funding framework has been criticised as not recognising hospices as equal partners in health and social care in Scotland. Stakeholders have pushed for their own funding agreement nationally, *“so that [they] do not have to go with a begging bowl to our localities.”* The allocation of funding has also been described as a “*patchy picture”* resembling *“postcode palliative care.”* This inequity of funding for palliative and end-of-life care in Scotland has been highlighted as an issue that needs to be addressed as part of a new revised funding framework.

# 14. COVID-19 Recovery and Aftermath

## 14.1 Key Messages

* Government guidance states that building based social care day services should return to pre-pandemic capacity wherever possible.
* The Government reported on a repeated 2022 survey of adult day services and respite services in June 23, showing that these were still significantly below previous capacity, with causes including recruitment problems, building closures, Covid outbreaks and service redesign.

The May 2023 update report for the Inquiry by McKay et al contained a chapter on COVID Recovery and Aftermath, which included discussion of recovery in the social care sector. This section provides a brief update of new material.[[875]](#footnote-876)

## 14.2 Recovery of adult social care services

As mentioned in the earlier report, the Scottish Government commissioned an audit of adult day and respite services across all Scotland’s local authorities in May 2022. The findings of the audit were set out in a letter from the Cabinet Secretary for Health and Social Care on 19 October 2022.[[876]](#footnote-877)

The letter urged local authorities to ‘to ensure that the updated guidance is fully implemented to enable services to return to pre-pandemic capacity wherever possible. The audit found that at the time of the survey, only 48.7% of day services were fully open, with 38.4% partially open or at reduced capacity and 11.8% closed. For respite services, 68.3% were open, 16.9% were partially open or at reduced capacity, and 14.1% were closed. Reasons given for reduced capacity included:

* COVID restrictions
* Risk assessments being undertaken with a view to increasing capacity
* Current COVID outbreaks
* Service redesign
* Recruitment and retention issues.

The survey was repeated in November 2022, and the findings were communicated to authorities in June 2023.[[877]](#footnote-878) The letter said that: *“changes to the Coronavirus (COVID-19): adult social care building-based day services guidance in May 2022 to remove physical distancing measures has resulted in more services being accessible to those who need them. However, pressure regarding recruitment and staffing continue to delay services meeting pre-pandemic levels.”*

The survey returns indicated that 79% of day services were now open, with 13% partially open or at reduced capacity, and 8% still closed. For respite services, 88% were open, 4% partially open or at reduced capacity, and 9% closed. Overall, day services were at 75% of capacity and respite services at 68% of capacity.

In the November 2022 survey, the factors affecting capacity were summarised as

* Staff recruitment and retention
* COVID outbreaks
* Service redesign
* Building closures, with some buildings no longer fit for purpose.

The Minister indicated an intention to repeat the survey on an annual basis, and that the Government would commence a review with a view to removing the *Coronavirus (COVID-19): adult social care building-based day services guidance*. As at 31 October 2023, the guidance does not appear in the page listing COVID-19 guidance for adult social care.[[878]](#footnote-879) Guidance from Public Health Scotland, updated on 31 August 2023, still appears.[[879]](#footnote-880)

# 15. Key Questions for Investigation

Drawing on the core questions identified in our earlier reports, we suggest the following matters would be relevant for the Inquiry to interrogate further. Further suggestions can be found in the Key Messages throughout the report.

* Were human rights considerations understood and applied?
  + Given the devolved nature of the decision-making process, how far did local authorities and integration authorities factor human rights into their decision making?
  + In our earlier reports, some guidance to health professionals explicitly referenced human rights. So far as we can identify, this did not happen to the same extent in relation to guidance on non-residential social care.
* Were the measures lawful?
  + In particular, when services were withdrawn, was there proper consideration of the statutory duties of local authorities?
  + Was there a proper, rational and rights-compliant process of prioritisation to address limitations on services caused by the pandemic?
  + What differences can be seen between those who took advantage of emergency legislation to waive some legal duties, and those who did not?
* What were the expectations on local authorities?
  + Although Scottish Government initially stated that the level of services should be retained, this clearly did not happen. Most of the guidance related to measures such as infection control. We found little evidence of clear guidance in relation to how far services should be retained, modified or prioritised until later in the pandemic, when Government encouraged services to reopen.
  + Could Scottish Government have used its powers of guidance and direction more proactively to mitigate harms to service users, or would this have made things worse because of a lack of local knowledge?
* How can we better ensure that policy intent is translated into achieving the desired outcomes on the ground?
* What harms were caused, and how could they have been mitigated?
  + As we set out, there is significant evidence of a range of harms caused to users of social care and their carers.
  + How far were difficulties attributable to a lack of resilience in the system prior to the pandemic?
  + Did social care suffer by comparison with the NHS?
  + How can public bodies ensure the people affected by decisions about services, both at a collective and individual level, are able to influence these decisions?
* Were actions justified and proportionate?
  + Was there a balance of risk against other harms, *and* against human rights?
  + What mitigations were considered, and were these practical?
* Was there discrimination?
  + Most if not all recipients of social care are in at least one protected category under the Equality Act. Were they subject to direct or indirect discrimination?
* What were the impacts on social workers and social care staff
  + How easily were social workers and care support staff able to locate and access support for themselves?
* Did any local areas do particularly well or badly, and what factors influenced this?
* What lessons have been learned, and how will they feed into the development of social care for the future?

**ANNEXES**

# Annex A: Search Strategy

The following databases and platforms were searched in July 2023, CINAHL with Full text (EBSCO), Medline (EBSCO), APA PsycInfo (EBSCO) PubMed Central, Web of Science Core Collection, Ovid Emcare and Proquest Social Science Premium Collection. Numbers of articles retrieved from the academic databases following the searches, and prior to screening for relevance were as follows: CINAHL (N=181); Medline (N=33); PubMed Central (N=121); Web of Science Core Collection (N=602), Ovid Emcare (N=54); and Proquest Social Science Premium Collection (N=496).

Rather than present the specific search terms and dates used for each of the databases and platforms, we present an example of the search strategy used on one of the searched databases below (i.e., CINAHL). Search terms and dates for each of the other databases can be provided upon request.

In addition, handsearching in the Edinburgh Napier University LibrarySearch facility, Google Scholar <https://scholar.google.com/>, and Social Care Online <https://www.scie-socialcareonline.org.uk/> was undertaken using adapted free-text search terms to account for the difference in allowed characters and search terms in these platforms. A simpler search of (covid OR coronavirus) AND (Scotland OR Scottish) was used, with search results screened for relevance to social care and the eligibility criteria. Citation tracking using both forwards and backwards citation searching was done after the first stage of title and abstract eligibility screening.

Hand searches were also carried out in the following websites:

* Audit Scotland <https://www.audit-scotland.gov.uk/>
* Age Scotland <https://www.ageuk.org/uk/scotland/>
* BBC News Scotland <https://www.bbc.co.uk/news>
* Care Inspectorate <https://www.careinspectorate.com/>
* Court of Protection Hub <https://www.courtofprotectionhub.uk/>
* Freedom of Information requests <https://www.gov.scot/publications/>
* Health and Social Care Alliance Scotland <https://www.alliance-scotland.org.uk>
* HealthandCare.Scot - <https://healthandcare.scot/>
* Healthcare Improvement Scotland COVID pages <https://www.healthcareimprovementscotland.org/our_work/coronavirus_covid-19.aspx>
* Public Health Scotland - <https://publichealthscotland.scot/>
* Scottish Government - A National Care Service for Scotland  published responses to the consultation (<https://consult.gov.scot/health-and-social-care/a-national-care-service-for-scotland/consultation/published_select_respondent>), where we have permission to do so and an independent analysis of the consultation (<https://www.gov.scot/publications/national-care-service-consultation-analysis-responses/>)
* Scottish Parliament - <https://www.parliament.scot/chamber-and-committees/questions-and-answers>

**Example of Search Terms and Dates:**

***CINAHL 26 July 2023***

|  |  |  |  |
| --- | --- | --- | --- |
| Main Concept | Search No. | Search Line | No. of Results |
| Covid | 1 | TI ( covid or covid-19 or coronavirus or 2019-ncov or sars-cov-2 or cov-19 ) OR AB ( covid or covid-19 or coronavirus or 2019-ncov or sars-cov-2 or cov-19 ) | 127,335 |
| 2 | (MH “COVID-19”) OR (MH “COVID-19 Pandemic”) OR (MH “SARS-CoV-2”) OR (MH “Coronavirus”) OR (MH “Coronavirus Infections”) | 82,175 |
| 3 | S1 OR S2 | 143,390 |
| Scotland | 4 | TX ncapaci or ncapaci or scots | 57,915 |
| 5 | (MH “Scotland”) | 17,165 |
| 6 | S4 OR S5 | 57,915 |
| Social Care | 7 | TI ( vulnerable N2 adults or community N2 care or disab\* N2 adults or ncapacity\* N2 adults or domiciliary N2 care or domiciliary N2 services or social N2 care or social N2 services or social N2 work or carers or caregivers or care N2 workers or adult N2 protection or adult N2 social or adult N2 support or day N2 services or supported N2 living or supported N2 housing or assisted N2 living or respite N2 care or respite N2 services or home N2 settings or DNACPR or Cardiovascular or Cardiac or life N2 support or ventilat\* or resuscitat\* ) OR AB ( vulnerable N2 adults or community N2 care or disab\* N2 adults or ncapacity\* N2 adults or domiciliary N2 care or domiciliary N2 services or social N2 care or social N2 services or social N2 work or carers or caregivers or care N2 workers or adult N2 protection or adult N2 social or adult N2 support or day N2 services or supported N2 living or supported N2 housing or assisted N2 living or respite N2 care or respite N2 services or home N2 settings or DNACPR or Cardiovascular or Cardiac or life N2 support or ventilat\* or resuscitat\* ) | 525,475 |
| 8 | (MH “Resuscitation Orders”) OR (MH “Ventilation, Manual”) OR (MH “Life Support Care”) OR (MH “Health Services for Persons with Disabilities”) OR MH “Social Work”) OR (MH “Acute Care”) OR (MH “Cardiovascular Care”) OR (MH “Critical Care”) OR (MH “Emergency Care”) OR (MH “Gerontologic Care”) OR (MH “Palliative Care”) OR (MH “Hospitalization of Older Persons”) OR (MH “Cardiac Patients”) OR (MH “Critically Ill Patients”) OR (MH “Emergency Patients”) OR (MH “Ventilator Patients”) OR (MH “Resuscitation, Cardiopulmonary”) OR (MH “Resuscitation”) OR (MH “Persons with Disabilities”) OR (MH “Persons with Intellectual Disabilities”) OR (MH “Social Workers”) OR (MH “Social Work, Psychiatric”) OR (MH “Social Work Service”) OR (MH “Caregivers”) OR (MH “Caregiver Burden”) OR (MH “Community Living”) OR (MH “Assisted Living”) OR (MH “Respite Care”) | 323,387 |
| 9 | S7 OR S8 | 746,350 |
| Combined | 10 | S3 AND S6 AND S9 | 181 |
| Final | 11 | Date limiter from 2020 | 181 |

# ANNEX B: References

**Legislation and international treaties**

*Coronavirus legislation*

Coronavirus Act 2020

Coronavirus (Scotland) Act 2020

Coronavirus (No. 2) (Scotland) Act 2020

Coronavirus (Extension and Expiry) (Scotland) Act 2021

Coronavirus (Discretionary Compensation for Self-isolation) (Scotland) Act 2022

Coronavirus (Recovery and Reform) (Scotland) Act 2022

The Coronavirus Act 2020 (Commencement No. 1) (Scotland) Regulations 2020 SSI 121

Coronavirus Act 2020 (Suspension: Adult Social Care) (Scotland) Regulations 2020 SSI 337

*Other key legislation*

Social Work (Scotland) Act 1968

Chronically Sick and Disabled Persons Acts 1970 and 1972

Housing (Scotland) Act 1987

National Health Service and Community Care Act 1990

Human Rights Act 1998

Scotland Act 1998

Adults with Incapacity (Scotland) Act 2000

Mental Health (Care and Treatment) (Scotland) Act 2003

Adult Support and Protection (Scotland) Act 2007

Equality Act 2010

Public Services (Reform) (Scotland) Act 2010

Social Care (Self-directed Support) (Scotland) Act 2013

Public Bodies (Joint Working) (Scotland) Act 2014

Carers (Scotland) Act 2016

Health and Care (Staffing) (Scotland) Act 2019

*Key international treaties*

European Convention on Human Rights

International Covenant on Economic Social and Cultural Rights

United Nations Convention on the Rights of Persons with Disabilities

*Caselaw*

R v Gloucestershire County Council, ex parte Barry 1997 A.C.584

MacGregor v South Lanarkshire Council 2001 S.L.T. 233

R (on the application of McDonald) v Kensington and Chelsea RLBC [2011] UKSC 33

R (on the application of KM) v Cambridgeshire County Council [2012] UKSC 23

McDonald v UK (European Court of Human Rights 4241/12) Judgment 20 May 2014

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# ANNEX C: Table 1 Care at Home for 2019/20 Q4 – 2020/21 Q4

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **2019/20 Q4** | **2020/21 Q4** |  |  |
| **Local Authority** | **Number of People** | **Number of People** | **Difference** | **% Difference** |
| Scotland (All Areas Submitted) | 120,315 | 91,075 | -29,240 | -24% |
| **Grand Total** | **120,315** | **91,075** | **-29,240** | **-24%** |

# ANNEX D: Table 2. Care at Home by Client Group

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **2019/20 Q4** | **2020/21 Q4** |  |  |
| **Client Group** | **Number of People** | **Number of People** | **Difference** | **% Difference** |
| Dementia | 5885 | 4520 | -1,365 | -23% |
| Elderly / Frail | 48330 | 33845 | -14,485 | -30% |
| Learning Disability | 8220 | 4675 | -3,545 | -43% |
| Mental Health | 6530 | 4980 | -1,550 | -24% |
| Not Recorded | 3130 | 5040 | 1,910 | 61% |
| Other | 14660 | 12395 | -2,265 | -15% |
| Physical / Sensory Disability | 33560 | 25620 | -7,940 | -24% |
| **Grand Total** | **120315** | **91075** | **-29,240** | **-24%** |

# ANNEX E: Table 3. Hours of Care at Home Received

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **2019/20 Q4** | **2020/21 Q4** |  |  |
| **Hours of Care at Home Received** | **Number of People** | **Number of People** | **Difference** | **% Difference** |
| 0 - <2 hours | 6,985 | 7,340 | 355 | 5% |
| 10+ hours | 24,620 | 25,245 | 625 | 3% |
| 2 - <4 hours | 10,875 | 9,835 | -1,040 | -10% |
| 4 - <10 hours | 22,655 | 23,190 | 535 | 2% |
| **Grand Total** | **65,135** | **65,610** | **475** | **0.73%** |

# ANNEX F: Table 4. Care at Home by Age Group

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **2019/20 Q4** | **2020/21 Q4** |  |  |
| **Age Group** | **Number of People** | **Number of People** | **Difference** | **% Difference** |
| 0-17 years | 280 | 420 | 140 | 50.00% |
| 18-64 years | 25,265 | 17,630 | -7,635 | -30.22% |
| 65-74 years | 19,340 | 14,810 | -4,530 | -23.42% |
| 75-84 years | 36,985 | 28,120 | -8,865 | -23.97% |
| 85+ years | 38,445 | 30,090 | -8,355 | -21.73% |
| **Grand Total** | **120,315** | **91,070** | **-29,245** | **-24.31%** |

# ANNEX G: Table 5. Service Types

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **2019/20** | **2020/21** |  |  |
| **Service Type** | **Number of People** | **Number of People** | **Difference** | **% Difference** |
| Care at Home | 89,110 | 92,910 | 3,800 | 4% |
| Care Home | 50,595 | 48,210 | -2,385 | -5% |
| Community Alarms / Telecare | 117,345 | 112,980 | -4,365 | -4% |
| Day Care | 9,775 | 6,260 | -3,515 | -36% |
| Meals | 6,430 | 5,650 | -780 | -12% |
| Social Worker | 122,050 | 128,685 | 6,635 | 5% |
| **Grand Total** | **395,305** | **394,695** | **-610** | **-0.15%** |

# ANNEX H:Table 6. Service Type by Locality (2019/20 – 2020/21)

|  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | **Care at Home** | |  |  | **Day Care** | | |  | **Community Alarms/Telecare** | | | |
|  | **2019/20** | **2020/21** |  |  | **2019/20** | **2020/21** |  |  | **2019/20** | **2020/21** |  |  |
| **Local Authority** | **Number of People** | **Number of People** | **Difference** | **% Difference** | **Number**  **of People** | **Number of People** | **Difference** | **% Difference** | **Number of People** | **Number of People** | **Difference** | **% Difference** |
| Aberdeenshire | 3,500 | 3,625 | 125 | 4% | 645 | 575 | -70 | -11% | 5,335 | 5,195 | -140 | -3% |
| Angus | 2,185 | 2,225 | 40 | 2% | 415 | 300 | -115 | -28% | 4,000 | 3,970 | -30 | -1% |
| Argyll and Bute | 2,105 | 2,190 | 85 | 4% | - | - | - | - | 2,735 | 2,815 | 80 | 3% |
| City of Edinburgh | 6,505 | 7,195 | 690 | 11% | 370 | 360 | -10 | -3% | 9,915 | 9,655 | -260 | -3% |
| Clackmannanshire | 1,150 | 1,225 | 75 | 7% | 60 | 50 | -10 | -17% | 1,895 | 1,875 | -20 | -1% |
| Comhairle nan Eilean Siar | 545 | 485 | -60 | **-11%** | 75 | 40 | -35 | -47% | 1,210 | 1,370 | 160 | 13% |
| Dumfries and Galloway | 3,070 | 3,270 | 200 | 7% | 145 | 120 | -25 | -17% | 4,270 | 4,185 | -85 | -2% |
| Dundee City | 2,580 | 2,570 | -10 | 0% | 285 | 225 | -60 | -21% | 5,880 | 4,995 | **-885** | -15% |
| East Ayrshire | 2,825 | 2,555 | -270 | -10% | 235 | 250 | 15 | 6% | 4,315 | 3,505 | -810 | **-19%** |
| East Dunbartonshire | 2,225 | 2,155 | -70 | -3% | 515 | 515 | 0 | 0% | 1,705 | 1,835 | 130 | 8% |
| East Lothian | 1,920 | 1,815 | -105 | -5% | 355 | - | - | - | 1,000 | - | - | - |
| East Renfrewshire | 1,665 | 1,855 | 190 | 11% | 140 | 160 | 20 | 1% | 3,195 | 3,195 | 0 | 0% |
| Falkirk | 2,970 | 2,890 | -80 | -3% | 590 | 455 | -135 | -23% | 5,065 | 4,950 | -115 | -2% |
| Fife | 4,710 | 4,985 | 275 | 6% | 770 | - | - | - | 9,915 | 10,610 | **695** | 7% |
| Glasgow City | 9,840 | 9,470 | -370 | -4% | 725 | 220 | **-505** | **-70%** | 10,045 | 9,675 | -370 | -4% |
| Highland | 2,865 | 3,040 | 175 | 6% | 335 | 360 | 25 | 7% | 3,680 | 3,245 | -435 | -12% |
| Inverclyde | 2,030 | 1,875 | -155 | -8% | 195 | 230 | 35 | 18% | 2,645 | 2,565 | -80 | -3% |
| Midlothian | 1,310 | 1,370 | 60 | 5% | 175 | 420 | **245** | **140%** | 2,125 | 2,060 | -65 | -3% |
| Moray | 1,465 | 1,415 | -50 | -3% | 565 | 295 | -270 | -48% | 1,825 | 1,925 | 100 | 5% |
| North Ayrshire | 3,635 | 4,445 | **810** | **22%** | 320 | - | - | - | 5,120 | 5,255 | 135 | 3% |
| North Lanarkshire | 6,000 | 5,540 | **-460** | -8% | - | - | - | - | 11,125 | 10,995 | -130 | -1% |
| Orkney Islands | 275 | 275 | 0 | 0% | - | - | - | - | 895 | - | - | - |
| Perth and Kinross | 2,875 | 2,885 | 10 | 0% | 300 | 240 | -60 | -20% | 3,825 | 3,910 | 85 | 2% |
| Renfrewshire | 3,445 | 3,430 | -15 | 0% | 895 | 795 | -100 | -11% | 4,745 | 4,430 | -315 | -7% |
| Scottish Borders | 2,045 | 2,030 | -15 | -1% | 120 | 95 | -25 | -21% | 310 | 665 | 355 | **115%** |
| Shetland Islands | 515 | 495 | -20 | -4% | 130 | 105 | -25 | -19% | 675 | 675 | 0 | 0% |
| South Ayrshire | 2,310 | 2,560 | 250 | 11% | - | - | - | - | - | - | - | - |
| South Lanarkshire | 5,840 | 6,010 | 170 | 3% | 650 | - | - | - | - | - | - | - |
| Stirling | 1,750 | 1,755 | 5 | 0% | 115 | 105 | -10 | -9% | 2,615 | 2,515 | -100 | -4% |
| West Dunbartonshire | 2,340 | 2,215 | -125 | -5% | 225 | - | - | - | 2,805 | 2,610 | -195 | -7% |
| West Lothian | 2,600 | 2,645 | 45 | 2% | 415 | 285 | -130 | -31% | 4,475 | 4,310 | -165 | -4% |
| **Grand Total** | **89,095** | **92,905** | **3,810** | **4%** | **9,765** | **6,200** | **-3,565** | **-36.51%** | **117,345** | **112,990** | **-4,355** | **-4%** |

# ANNEX I: Table 7. Comparing Service Type by Age Group

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **2019/20** | **2020/21** |  |  |
| **Age Group & Service Group** | **Number of People** | **Number of People** | **Difference** | **% Difference** |
| **18-64 years** | **69800** | **70985** | **1,185** | **2%** |
| Care at Home | 14795 | 16290 | 1,495 | 10% |
| Care Home | 5235 | 4710 | -525 | -10% |
| Community Alarms / Telecare | 15640 | 15180 | -460 | -3% |
| Day Care | 3965 | 3135 | **-830** | **-21%** |
| Meals | 535 | 550 | 15 | 3% |
| Social Worker | 29630 | 31120 | 1,490 | 5% |
| **65-74 years** | **56510** | **56245** | **-265** | **0%** |
| Care at Home | 13720 | 14425 | 705 | 5% |
| Care Home | 5360 | 5135 | -225 | -4% |
| Community Alarms / Telecare | 18360 | 17740 | **-620** | -3% |
| Day Care | 975 | 580 | -395 | **-41%** |
| Meals | 930 | 810 | -120 | -13% |
| Social Worker | 17165 | 17555 | 390 | 2% |
| **75-84 years** | **124745** | **121605** | **-3,140** | **-3%** |
| Care at Home | 28945 | 29375 | 430 | 1% |
| Care Home | 15165 | 14495 | -670 | -4% |
| Community Alarms / Telecare | 41045 | 38585 | **-2,460** | -6% |
| Day Care | 2310 | 1175 | -1,135 | **-49%** |
| Meals | 2200 | 1870 | -330 | -15% |
| Social Worker | 35080 | 36105 | 1,025 | 3% |
| **85+ years** | **141280** | **142540** | **1,260** | **1%** |
| Care at Home | 31380 | 32435 | 1,055 | 3% |
| Care Home | 24695 | 23780 | -915 | -4% |
| Community Alarms / Telecare | 41615 | 40790 | -825 | -2% |
| Day Care | 2465 | 1325 | **-1,140** | **-46%** |
| Meals | 2760 | 2420 | -340 | -12% |
| Social Worker | 38365 | 41790 | 3,425 | 9% |
| **All Ages** | **395305** | **394695** | **-610** | **0%** |
| Care at Home | 89110 | 92910 | 3,800 | 4% |
| Care Home | 50595 | 48210 | -2,385 | -5% |
| Community Alarms / Telecare | 117345 | 112980 | -4,365 | -4% |
| Day Care | 9775 | 6260 | -3,515 | -36% |
| Meals | 6430 | 5650 | -780 | -12% |
| Social Worker | 122050 | 128685 | 6,635 | 5% |
| **Grand Total** | **787640** | **786070** | **-1,570** | **0%** |

\* There was incomplete data for housing support for each age group, therefore this was removed from the table.

# ANNEX J: Glossary of Acronyms

This annex presents a glossary of acronyms used throughout this report.

AAAQ Accessible, Available, Appropriate, and high Quality

ALLIANCE The Health and Social Care Alliance

APA American Psychological Association

ARC Association for Real Change

BASW British Association of Social Work

BBC British Broadcasting Corporation

CEO Chief Executive Officer

CI Care Inspectorate

CINAHL Cumulative Index to Nursing and Allied Health Literature

COSLA Convention of Scottish Local Authorities

COVID-19 Coronavirus Disease

CRPD Convention on the Rights of Persons with Disabilities

ECHR European Convention on Human Rights

EEA European Economic Area

EU European Union

GB Great Britain

GDA Glasgow Disability Alliance

HSC Health and Social Care

HSCP Health and Social Care Partnership

HSCS Health and Social Care Scotland

ICESCR International Covenant on Economic Social and Cultural Rights

ICT Information and Communication Technologies

ICU Intensive Care Unit

IEP Injection Equipment Provision

ILF Independent Living Fund

IoRN Indicator of Relative Need

IRASC Independent Review of Adult Social Care

Iriss The Institute for Research and Innovation in Social Services

IT Information Technology

JCVI Joint Committee on Vaccination and Immunisation

LFD Lateral Flow Device

MBSWSC Mindfulness-Based Social Work and Self-Care

MND Motor Neurone Disease

MSP Member of the Scottish Parliament

NDPB Non-Departmental Public Body

NHS National Health Service

NSS National Services Scotland

ONS Office for National Statistics

OST Opioid Substitution Therapy

PA Personal Assistants

PCR Polymerase Chain Reaction

PEH People Experiencing Homelessness

PHS Public Health Scotland

PPE Personal Protective Equipment

PTSD Post Traumatic Stress Disorder

PVG Protection of Vulnerable Groups

PWUD People Who Use Drugs

SASW Scottish Association of Social Work

SCIE Social Care Institute for Excellence

SDS Self-Directed Support

SHAAP Scottish Health Action on Alcohol Problems

SHRC Scottish Human Rights Commission

SIMD Scottish Index of Multiple Deprivation

SSSC Scottish Social Services Council

TEC Technology Enabled Centre

UK United Kingdom

UN United Nations

WHO World Health Organisation

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