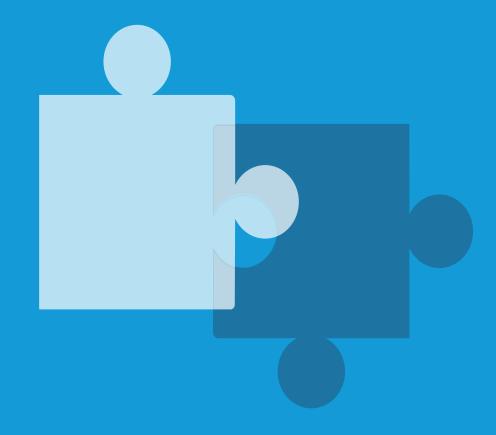


# A TELLING EXPERIENCE:

Understanding the impact of Covid-19 on people who access care and support – a rapid evidence review with recommendations



## **FOREWORD**

Few of us could have predicted that we would be hit so hard by the Covid-19 pandemic this year. TLAP's mission is personalisation and ensuring that the voice of people with lived experience is heard in all aspects of care and support. It therefore made absolute sense for us to try and understand the impact of Covid-19 on people. This was a big task, only made possible through the combined efforts of our TLAP partners and allies who agreed to share their knowledge and experience as the pandemic unfolded as part of the TLAP Insight Group. A big thanks to all those that contributed.

This report documents the results of this collaborative effort in the form of a rapid evidence review. It brings together and makes sense of a diverse range of research, intelligence and insight. There are inevitably limitations. It has not been possible to capture the experience of all groups in every place or setting, in a situation which remains fast moving and fluid. For all that, what the report succeeds in doing in my view is to paint a picture of the experiences and concerns that have commonly affected people accessing care and support and unpaid family carers. Whilst each of us has our own unique story of this time, important issues and themes stand out.

Some of the findings make uncomfortable reading. Whilst there are examples where people have received good support, others have fared less well. Throughout this immensely difficult time, I have been clear that people working in social care (and I include unpaid carers within this definition) have done their level best to respond to the challenges - many going over and beyond. Shortcomings were perhaps inevitable, because at one important level what Covid-19 has done is expose the existing fault lines with social care, with too many people experiencing too little personalisation.

We have not produced the report as a historical record, but to help things move forward. It is important that the opportunity is taken to apply the lessons from the Covid experience and avoid repeating past mistakes. That is why we have included recommendations to help the care and support sector adapt to the new realities brought about by the pandemic and to capture what can be learnt and applied for the future.

Clenton Farquharson, MBE
Chair of Think Local Act Personal
October 2020

## **EXECUTIVE SUMMARY**

Think Local Act Personal (TLAP) is a partnership working to promote personalisation and community-based approaches to social care. As part of its response to Covid-19, it established the TLAP Insight Group, known as TIG, with key partners from organisations across social care (listed at the end of this report). TIG's role is to explore the experience and impact on people accessing care and support and unpaid carers during the first phase of the pandemic. Its purpose is to collect information, collate findings and summarise issues to share publicly and with policy makers and influencers.

As the pandemic took hold, the Coronavirus Act 2020 – including the Care Act Easements (CAE) came into effect. CAE gave councils the flexibility to redeploy or re-target capacity in order to help them respond to the crisis if they judged this essential to meet the most urgent and acute needs. In this context TIG was established with the aim of investigating the impact on people in CAE areas. However, as a result of early discussion with TIG members, the scope was extended to encompass the wider impact of Covid-19 on people accessing care and support and unpaid carers across all council areas.

Members of the TIG submitted details of research and/or data collection that explored the impact of CAE and/or Covid-19 on the lives of people who accessed care and support, and unpaid carers. This process was primarily intended to highlight the experiences and views of people receiving social care and support. However, as peoples' experiences do not neatly fit into organisational boxes, insight was also captured into the wider impact of the pandemic on aspects of health care and provision (both physical and mental).

The data was analysed as part of a rapid evidence review to pull out learning to inform future practice. Key findings are detailed below and a series of recommendations for TIG partners and the sector are contained in section 5.

#### **Impact of Care Act Easements**

It was not possible build up a comprehensive picture of Care Act Easement activity and its impact on people that accessed care and support through this review. Eight local authorities introduced CAE but in different ways over different timeframes, and not all across the whole of adult social care. Impact data highlighted the difficulties of attributing change to CAE directly, as opposed to the wider impact of Covid-19. This meant that the majority of the research talked more generally to the broader effect of Covid-19. The Department of Health and Social Care recognise the importance of the need for research on the impact of Care Act Easements.

#### **General impact of Covid-19**

- 1. The research pointed to the general confusion and anxiety of the early pandemic upon the general public and specifically upon those who accessed care and support including:
  - loneliness and isolation of social distancing and the impact on mental health, including an
    increase in general anxiety and reduction or removal of support mechanisms for people with
    existing mental health conditions
  - financial pressures as a result of extra cost to households, particularly in food and bills
  - practical issues around food shopping including reliance on friends and family, issues
    with getting onto the vulnerable list for online shopping, issues with 'protected shopping
    times' and large queues
  - increase in health anxiety (fear of catching Covid-19) leading to some reluctance to check out other health concerns (potentially escalating problems) and barriers to accessing medicine or prescriptions
  - changes to the streetscape to accommodate social distancing impacting on visually impaired people and their ability to get around safely.

#### Impact of Covid-19 on those who accessed care and support

- 2. As well as the general pressures reported around Covid-19, many of which affected the general population, the research also revealed more specific findings related to those who accessed care and support and their unpaid or family carers, including:
  - overarching challenge around communications, both locally and nationally, between councils and people who access care and support and perceived delays to government guidance
  - concerns around Personal Protective Equipment (PPE) and testing at all levels of care
    and support, including PPE for direct payment holders (DP) with personal assistants (PAs) and
    the wider workforce and testing in care homes
  - cancellations of respite and day services adding to increased pressures, particularly on carers, and Shared Lives members
  - some examples of changes to care packages including reduced care packages and cancelled support, although the picture is mixed at local level.

#### **Impact of Covid-19 on specific groups**

- 3. Concerns were raised around specific groups, specifically impacting upon:
  - care home residents, visitors and staff, particularly in terms of stress and mental health;
     issues of residents accessing GPs; and communication with relatives and friends when care visits were paused
  - some of the most at risk and disadvantaged groups in society impacted by the
    reduction or withdrawal of mental health staff from face-to-face support in many voluntary,
    community and social enterprise sector (VCSE) organisations and/or those who accessed
    black and minority ethnic (BAME), VCSE organisations at the threat of closure

- BAME groups, specifically individuals who felt isolated or frightened about how they might be disproportionately impacted by Covid-19
- individuals experiencing digital exclusion through people's inability to use technology;
   access to equipment; and concerns over online safety
- unpaid/family carers who picked up extra care responsibilities when day care centres closed, adopted shopping duties, absorbed financial pressures and themselves lost trusted and valued support
- direct payment (DP) holders, who reported a very mixed picture ranging from poor to good practice in communications guidance around employing PAs as well as changes in support arrangements as a result of shielding or services being stopped or having their direct payment reduced or restricted
- people who were shielding receiving advice from clinicians/GPs that conflicted with government guidance and messages. Also having to make decisions around managing the risks of shielding at the expense of their quality of life.

#### **Areas of good practice or learning**

More positively, the review identified areas of good practice or learning which might be drawn upon to help build a legacy for future care and support, including:

- support to shape future communications and advice around a potential second
   Covid-19 wave and the application of easements
- building on aspects of **flexible and agile working**, particularly in terms of digital models of provision
- supported living and extra care providers such as Shared Lives that adapted to the crisis, particularly in terms of finding meaningful activities and connectedness
- potential of personalisation reaffirmed as the cornerstone of future delivery, including future partnership working for mental health providers
- pockets of good practice around co-production to build upon for future learning
- innovation and good practice in commissioning to build a new a vision for mental health support and more widely across health and social care
- potential of the informal networks of Mutual Aid groups and neighbourhood support
  which emerged during Covid-19 and of national networks to share information, good
  practice and learning at a sector leadership level.

#### Conclusion

In conclusion, the research painted a vivid but partial picture of the impact of Covid-19. More research is required a) to fill the gaps, particularly around CAE and community support/mobilisation and b) keep a live picture of needs as lockdown changes. Despite these limitations, the findings from this review have informed a series of recommendations to learn from the lessons of the early stage of the pandemic and highlight some key themes and opportunities that can help shape a better, more positive and personalised future for social care. Full recommendations are presented in section 5.

## 1. INTRODUCTION

Think Local Act Personal (TLAP) is a partnership working to promote personalisation and community-based approaches to social care. As part of its response to Covid-19, it established the <u>TLAP Insight Group</u>, known as TIG, with key partners from across social care<sup>1</sup>. TIG's role is to explore the experience and impact on people accessing care and support and unpaid carers during the first phase of the pandemic. Its purpose is to collect information, collate findings and summarise issues to share publicly and with policy makers and influencers. The first phase also included gathering examples of both good practice and poor practice that came to light through members of the group.

As the pandemic took hold, the Coronavirus Act 2020 – including the Care Act Easements (CAE) came into effect. CAE gave councils the flexibility to redeploy or re-target capacity in order to help them respond to the crisis if they judged this essential to meet the most urgent and acute needs. Once 'switched on' the easements allowed councils to temporarily streamline assessments, reviews and care planning, and to prioritise the provision of care and support.

In this context TIG was established with the aim of investigating the impact on people in CAE areas. However, as a result of early discussion with TIG members, the scope was extended to encompass the wider impact of Covid-19 upon people accessing care and support and unpaid carers across all council areas. This was an ambitious aim, made possible only through the 'heavy lifting' of TIG members and supporting organisations.

Members of the TIG submitted details of research and/or data collection that explored the impact of CAE and/or Covid-19 on the lives of people who accessed care and support, and unpaid carers. This process was primarily intended to highlight the experiences and views of people receiving social care and support. However, as peoples' experiences do not neatly fit into organisational boxes, insight was also captured into the wider impact of the pandemic upon aspects of health care and provision (both physical and mental).

<sup>&</sup>lt;sup>1</sup> Participating organisations are listed on the back page of this report.

The research data was mapped in an analysis framework, to plot the findings against the following TIG priorities:

- 1. Care Act Easements: The group will seek to work with a number of councils using the CAE in order to develop an understanding of the impact on people accessing care and support and unpaid carers. Areas of good practice will be identified so that they can be shared more widely.
- 2. Impact of Covid-19: The group will work together to build a picture of the impacts on people (including unpaid carers) of Covid-19 by drawing on the insights and expertise of members, together with the voice and views of people with lived experience. Priority areas to focus on will be identified and agreed.
- **3. Creating a legacy:** The group will identify key issues and areas that contribute to creating a positive legacy to inspire and influence social care reform in the direction of personalised care and support and community-based support.

The data was thematically analysed as part of a *rapid evidence review* to pull out the key headlines against these three priority areas. The initial analysis was presented to a TIG meeting in June 2020, with a discussion and further data incorporated into this final version, written in August 2020.

A number of recommendations were developed, based on the analysis, and agreed by TIG members. This report presents the key findings from the analysis in section 3 and concludes with the recommendations set out in section 5.

## 2. APPROACH AND METHODOLOGY

Over May and June 2020, TIG members were invited to submit details of research and/or data gathering that explored the impact of Covid-19 and CAE upon people who accessed care and support. Some of this data came from other organisations that were identified by TIG members. 42 different strands of research and data were identified (including briefing notes, strategies and other resources) with 28 of these included in this analysis. Data not included in this review contained research that was still in progress at the time of writing. The data varied tremendously in scope and depth, and it is important to note this variation and the impact this had on the subsequent analysis.

For example, there were examples of research which looked at the experiences of all people who accessed care and support in a specific local authority area, and others which sought to elicit a national view of a particular cohort's experience. Some of the research asked the views of people who directly accessed care and support, whereas other pieces asked for feedback from other groups such as providers or the workforce. As mentioned above, some of the research and data strayed beyond the confines of social care, particularly around mental health and shielding. This has been included in this report to give a more holistic view of the pandemic's impact.

Similarly, the research methodologies varied widely. Much of the research used surveys as a means to gather a body of responses as quickly as possible. Where survey analysis had taken place, TIG received full reports and/or analysis. Other members submitted more anecdotal feedback, vignettes or individual stories from across the sector. Consequently, the research drew on different sample sizes, with larger surveys alongside small sample surveys, which raised questions of representation. It also suggested a gap in qualitative research approaches.

Finally, much of the submitted research focussed on the early experiences of the pandemic. TIG members have described pieces of research which are currently ongoing and are designed to explore the longer-term experiences and needs of those who access care and support. The timings of these fall outside the remit of this report.

The variation in focus, perspective and approach meant that data – and analysis - must be treated with some degree of caution when seeking a 'universal' picture of experience. There are inevitable gaps in the data and the potential to over-represent the views of certain cohorts at the expense of under-represented groups. Additionally, given the fast pace of the pandemic, the highlights presented here offer a snapshot in time, meaning that things might have changed since the data was collected.

With these caveats in mind, the *rapid evidence review* identified some significant trends and key themes which can be used to help shape a future vision of social care.

## 3. RESEARCH FINDINGS

#### **Introduction**

Much of the research pointed to the general climate of uncertainty around Covid-19, and how the virus had a significant and unprecedented impact upon society and the wider population. This section contains the findings from the cross-research analysis and the key themes are presented under the following four headings:

- 3.1 Impact of Care Act Easements
- 3.2 General pressures during the Covid-19 pandemic
- 3.3 Specific pressures during the Covid-19 pandemic
- 3.4 Building a legacy

#### 3.1 THE IMPACT OF CARE ACT EASEMENTS

In response to the unprecedented demands of the Covid-19 crisis, the Coronavirus Act 2020 offered councils the opportunity to introduce Care Act Easements (CAE) as a means to redeploy or re-target capacity as and when it was needed the most. Eight local authorities introduced CAE over this period. However, building a comprehensive picture of the impact on people accessing care and support practice proved not to be possible due to the different approaches taken by those councils that used the easements. For example, the freedom of information (FOI) requests collated by Voluntary Organisations Disabled Group (VODG), and feedback from TIG members, revealed how those with councils that introduced easements did so in very different ways. Some introduced focussed, streamlined assessments and support planning or suspended reviews. Others adapted particular areas of service, for example deploying staff to different workstreams, depending on specific capacity gaps or pressures.

Furthermore, feedback from work with Directors of Adult Social Services undertaken through the auspices of the TIG² suggested that certain changes introduced by CAE councils were not noticeably different to the changes introduced by councils that did not introduce easements. This created a very grey line between CAE implementation and other local authority responses to Covid-19. There was some sense that CAE councils were unduly susceptible to criticism for triggering CAE when their actual practice was not substantially different to non-CAE councils. Indeed, Healthwatch also noted that some of the councils that enacted easements seemed to do so in preparation of potential capacity issues, which then didn't always materialise.

<sup>&</sup>lt;sup>2</sup> This work on the insights from Directors of Adult Social Care, undertaken by ADASS with support with TLAP, is due to be published in a separate report.

There was little data which sought to explore the specific impacts of CAE on people who accessed care and support, but the pieces that did highlighted the difficulties of attributing change to CAE directly, as opposed to the wider impact of Covid-19. For example, In Control's Be Human register (interim report) found that 29 respondents cited CAE as reasons for changes to their care and support, whilst only three of those respondents actually lived in CAE areas.

In conclusion, the methodological issues around gathering data to produce a clear picture of CAE in practice across the eight local authority areas, combined with the problems of attributing change to CAE compared to the pandemic, meant that the majority of the research talked more generally to the wider impact of Covid-19.

DHSC, through the National Institute for Health Research (NIHR), has encouraged research projects exploring the effects and impacts of care act easements through the NIHR Policy Research Programme COVID-19 Renewal, Recover and Reset call. The NIHR School for Social Care Research (SSCR) has funded a research project exploring the impact of Care Act Easements.

#### **3.2 GENERAL PRESSURES DURING COVID-19 PANDEMIC**

The pockets of research and data submitted to TIG set the scene of the pandemic. They described both the general pressures experienced by the wider population and the specific ways these pressures impacted on people who accessed care and support. This is explored in more detail below.

#### **Lockdown and social distancing**

With the lockdown and guidelines around social distancing, the research highlighted the risk of loneliness and isolation associated with the lack of social contact. For isolated respondents to In Control's survey, this left them with a sense of feeling 'imprisoned'. As the Wiltshire CIL reported, 61% of people who responded to their survey were feeling isolated and lonely. This had a significant impact on the respondents' wellbeing.

On the flip side, those who spent lockdown with their family members reported the impact of having to live in close proximity in the family home. This could lead to a strain on relationships, and a lack of personal space, particularly felt by carers.

Social distancing also brought specific access issues. For example, the Research Institute for Disabled Consumers (RiDC) research and National Co-production Advisory Group (NCAG) feedback highlighted how the 2-metre distance rule was challenging for visually impaired people, particularly given social distancing adaptations to local streets. This was echoed by Social Care Institute for Excellence (SCIE) research, which noted the clear impact on the visually impaired and deaf community in relation to higher isolation, and in terms of lack of accessible information and guidance (explored in more detail in the communications section).

#### **Financial concerns**

Shared Lives' members noted the extra financial costs to households as a result of the pandemic and Carers UK research revealed that 81% of carers were spending more money since the start of the pandemic. Indeed, 72% of carers were spending more on food and 50% were spending more on household bills. In Control noted issues around rising food costs and Inclusion London noted that some people were forced to spend more money on shopping by having to source food from more expensive places than they would previously.

#### **Food shopping**

Many reports noted practical concerns that respondents raised around food shopping, many of which were triggered by panic-buying in the week leading up to the start of lockdown. Wiltshire Centre for Independent Living (CIL) reported the reliance on friends and family to pick up shopping. For those who preferred to do their own shopping, problems were reported when attempting to shop during protected times; both Wiltshire CIL and RiDC reported that respondents were turned away for 'not looking disabled'. Alternatively, the large queues to get into shops meant that those with time pressures (e.g. those with caring duties) were unable to complete the shop in the time they had available.

Online shopping brought a range of issues. For those who were on the vulnerable list and able to complete an online shop, there were reported problems in food supply of the goods they wanted to buy. Many more struggled to get on the vulnerable list and so online access to shopping remained unavailable to them:

'Sainsbury's has still not got my son and myself on vulnerable list and I applied to do this at least four weeks ago and it's a challenge to get online delivery slots even though I am in the extremely vulnerable category'. Respondent to Wiltshire CIL survey

The impact of a 'vulnerable list' was explored by Inclusion London who pointed out that this left many disabled people who were deemed not to fall within the category of 'clinically vulnerable' unable to get online deliveries for weeks. This included people who were not able to shop in supermarkets and used online shopping as the only accessible option, as well as people who were shielding. Whilst local authorities supported people who were shielding with food parcels and medication, In Control's research noted examples whereby respondents attempted to contact the council, but with no response, felt that they were and left alone to cope with no back up plan. In addition, the delivery of food boxes did not always cater for people's access or dietary needs.

#### **Health concerns**

The research recorded how respondents were anxious about catching Covid-19. Fear of becoming infected led to a knock-on effect for some of discouraging attempts to investigate other health problems. Some people experienced delays or cancellations in accessing health services. RiDC highlighted two examples:

'[I'm] struggling as recently diagnosed with cancer, operation cancelled, so very worried about own health & whether will get treated, worry that my age and disability are against me currently getting cancer treatment'. RiDC survey respondent

'At the moment I have terrible bowel problems and am very uncomfortable but can't see a doctor to examine me but I don't feel safe going to the practice or even receiving a home visit as I am at risk.'

RiDC survey respondent

Fear of accessing treatment was noted by the In Control report, with concerns around delaying treatment that would exacerbate future problems. RiDC reported that 39% of respondents who needed to see or get in touch with a healthcare professional for a medical consultation or treatment experienced difficulty in obtaining an appointment. The research also pointed to lack of access to medicine or prescriptions over this time. The RiDC reported that 10% of respondents were having to do without their usual prescriptions or medication because of the restrictions. Additionally, they reported various barriers to using health services by phone or online.

#### Not being able to access other services

As well as health services, Wiltshire CIL research described how the lockdown period meant that people were unable to access other services, for example difficulties with domestic repairs.

#### **Increase in anxiety**

Unsurprisingly given the complex and far-reaching change to people's lives, the research noted a general increase in people's anxiety. As well as what has already been described, having to change routines, a lack of being in control, boredom, lack of physical activity, few breaks from the routine and the pressures of looking after young children or other dependents took a heavy toll on mental health.

As the Association of Mental Health Providers (AMHP) reported, in the first few weeks of the pandemic, some AMHP members experienced an unprecedented rise in demand for their services especially those providing diagnoses-specific helplines. In particular, Anxiety UK saw a 220% increase in visits to their website. These themes were echoed by RiDC, with one respondent noting that they were finding it harder during the lockdown to cope with general feelings of depression. The AMHP described how the wider context might quickly accelerate to crisis point.

'We believe there need to be arrangements in place for people with anxiety disorders who might not be able to manage isolation, feelings of being psychologically trapped, and having their usual social coping methods limited, as this is having a highly detrimental effect on their ability to sustain their mental health and wellbeing and accelerating the need for crisis mental health services and support'.

AMHP report

Furthermore, the AMHP research raised concern that things might only escalate with further economic recession.

#### 3.3 SPECIFIC PRESSURES DURING COVID-19 PANDEMIC

As well as the general pressures reported around Covid-19, many of which affected the wider population, the research also revealed more specific findings related to those who accessed care and support and their unpaid or family carers.

#### **Communications and guidance**

There was an overarching challenge around communications and guidance in the response to Covid-19, from both local and national government. Regarding the latter, RiDC reported inadequate government communications with the deaf community and lack of interpreters during government briefings compared to Scotland and Wales. Inclusion London noted that there was very little information in accessible formats such as Easy Read and British Sign Language which added to a general sense of anxiety from those groups.

Guidance issues which specifically faced DP holders are recorded later in this report, but Skills for Care highlighted issues and delays around this guidance, whilst Shared Lives noted that government guidance in general was felt to be a poor fit for community-based services and for people living at home. TLAP noted concerns around shielding guidance which NCAG colleagues felt conflicted with clinical guidance, with some NCAG colleagues going into lockdown ahead of government advice following advice from their clinicians or GPs and staying in shielding despite a relaxation of government guidance. Indeed, one NCAG member wrote her own guidance for PAs coming back into the house following the relaxation of shielding advice.

Communication challenges were not just top down. Skills for Care research noted a general lack of contact between local authorities and people who accessed care and support. From their survey, SCIE highlighted communication barriers between providers, social workers, and people receiving support, which had negative consequences for practice, relationships and trust.

#### **Concerns around PPE and testing**

The research noted a general struggle to obtain PPE, as well as the specific issues for the workforce. This was noted by Skills for Care, Healthwatch, In Control, Inclusion London and AMHP. Unison noted how the lack of PPE provision for the workforce had a disproportionate impact on women and BAME communities given their contribution to their sector, stating:

'The lack of PPE has been a bigger issue for black workers as they face a greater risk of death than their white colleagues'. Unison, A Vision for Social Care

The stock issues or prioritisation of PPE for NHS staff was noted to have had an impact on both regulated and unregulated social care services. Linked to PPE was the lack of testing available in care homes, particularly noted by Healthwatch.

The issues around accessing PPE for DP holders with PAs is captured elsewhere in this report, but those who had carers visiting their homes also expressed concerns about the lack of PPE for their carers. This led some respondents to cancel care visits, or increased their anxiety around them. As In Control reported, a small number of respondents stated they had actively refused services due to lack of confidence in the provider system for PPE and practice.

#### **Cancellations of respite and day care services**

As Healthwatch and Shared Lives noted, the lockdown led to suspension of most breaks, respite and day services. This, along with the general disruption this caused, increased pressures on unpaid family carers. Carers UK noted that the closure of key day services and specialist provision was particularly hard for certain groups, such as those caring for some with a learning disability, autism, or dementia. At the same time, carers respite services also closed, and alternative therapeutic options (such as phone support) were not always possible with the person they cared for also being at home:

'I have a support network, but the main support I need is respite (which I usually get when he attends specialist provision) and no one can offer this at the moment.

Even therapeutic support is tricky at the moment as son can't cope with me being on the phone'.

Carers UK, Behind Closed Doors

#### **Changes to care packages**

Changes to care and support experienced by DP holders are explored in more detail below, but Healthwatch reported various changes to care packages including:

- those with family/unpaid carers seeing care packages decreased;
- retrospective charging; and
- reduction in care packages in areas where easements hadn't been applied at stages 3/4.

In Control also reported on cancelled support. Respondents to their survey reported instances where their regular support had been cancelled by their local authority and they were instructed to access family or local volunteers to help instead. CQC research with experts by experience from CAE areas also described changes to care packages. One respondent had deep concerns about the suitability of providers being suggested for her daughter who had autism and who was transitioning from residential care to more independent living. She worried that transition was being driven by staffing and increased case-loads rather than her daughter's care and support.

In the interest of balance, the data suggested that changes to care varied across the country. For example, Wiltshire ILC reported that out of 77 disabled people and their carers, only one respondent reported a change to their care package as a consequence of the council. This again suggested variability in response and practice at local authority level.

#### **Care home specific concerns**

A number of concerns were raised specifically for care home residents and the people who visited them. As already mentioned, much of the earlier research picked up on the general lack of testing in care homes (although this had been partially addressed at the time of writing). Alongside this, In Control described the impact of living in a care home when someone had been suspected of having Covid-19 and the stresses involved for residents and staff. Healthwatch noted the number of deaths in some care homes, and described how these high rates of mortality made it difficult for residents and staff to process what was happening. With residents reporting a sense of being 'imprisoned in their own bedrooms with no access to visitors or fresh air' (In Control) these factors all took a significant toll on resident and staff mental health.

These themes were explored in great detail in a report produced by Leeds Healthwatch which presented key findings from a survey of 40 relatives of Leeds Care Home residents<sup>3</sup>. Of these respondents, 51% felt that their relatives' emotional wellbeing was a bit or a lot worst than before lockdown. More significantly perhaps was the 28% who could not comment on their relatives' wellbeing, explained largely due to having a relative with dementia and who were unable to use existing communication channels effectively to stay in contact. This highlights dependency on care staff communication, the consistency of which was variable and caused significant distress to relatives as well as residents.

Additionally, Healthwatch noted issues of residents accessing general practice and raised the importance of timely and regular communication between carers family and friends when care visits were not allowed.

#### **Mental health and providers**

The research revealed layers of concern around mental health and the ability of the wider sector beyond the Care Act - to respond to these. As already described, the first weeks of the pandemic saw an exponential increase in the numbers who reached out to Anxiety UK but the research reveals that mental health concerns and provision was affected across the scale. Whilst it is important to note that Mental Health Act (MHA) easements provisions in the Coronavirus Act (separate to the Care Act Easements) were not implemented in any area, Inclusion London reported long waiting lists, delays in responses and a general sense of not knowing where to go for help. In Control noted that many respondents with mental health conditions reported that they no longer had access to their psychiatrist, mental health support worker, community psychiatric nurse or drug workers. This led to a situation of escalating crisis, with some respondents concerned they were heading for immediate crisis and would be sectioned, or that they felt suicidal.

<sup>&</sup>lt;sup>3</sup> The report contained a series of recommendations which were being shared with Healthwatch England to be fed into a Task Force for the Department of Health and Social Care looking at the impact of Covid on health and social care.

Alongside this increased need was a decline in provision. AMHP described the impact on mental health providers of the reduction in their workforce, for example through staff needing to self isolate or being seconded to statutory services. Other staff were denied key worker status or reported slow progress with the paperwork to evidence their status. As in care homes, mental health practitioners also experienced difficulties in accessing Covid-19 testing. As the local community closed down, so did many opportunities to fundraise for mental health providers which particularly impacted smaller organisations.

AMHP noted the impact upon lack of mental health provision upon some of the most disadvantaged groups in society. Issues highlighted included:

- concern that some people were being sectioned with no contact with family, friends or independent advocates.
- difficulties experienced by people in the criminal justice system such as access to advocacy services and effective care management, in addition to ongoing health and safety concerns as a result of a lack of PPE
- the reported imminent closure of the majority of BAME VCSE organisations and the implications of this for BAME communities,
- fear that some members of BAME communities who had mental health conditions were more likely to be targeted with extra police powers in this context.

#### **BAME** communities

As above, AMHP noted the wider and deepening context of inequalities, particularly facing those from BAME groups. In Control echoed these concerns, with people from BAME communities reporting that they felt further isolated and frightened as they had not received additional information about their risk to Covid-19, other than that reported in the news. A CQC survey of 200 respondents from BAME communities and 50 respondents from non BAME communities<sup>4</sup> revealed that BAME respondents tended to receive their information about coronavirus from the television, but compared to their white counterparts a higher proportion used online sources, mainly social media based, and some relied on information from providers.

Nearly an equal proportion of BAME and non-BAME respondents to the CQC survey found it somewhat or very difficult to follow government guidance around Covid-19. There was more variety in the specific reasons selected by BAME respondents. These included:

- "I experience ill mental health;
- I am expected to take on the majority of any childcare arrangements;
- I live in a multigenerational household;
- I live in a household with more than 5 people; and

<sup>&</sup>lt;sup>4</sup> These respondents were drawn from a population-wide CQC survey database and were not necessarily in receipt of care and support themselves. However, the results are included here as they help illustrate some of the themes indicated in other sources of data.

 I have to work outside my home and I do not feel that I have adequate protection from infection".

A higher proportion of BAME respondents also said their care was affected by coronavirus (59.5% vs 44% of non-BAME respondents) with concerns about using and accessing health and social care services, as well as some worries about entitlement to free NHS treatment, or having fewer staff available to assist with things like translation.

#### **Impact on unpaid/family carers**

Across the research, the data showed the significant impact of Covid-19 on unpaid and/or family carers. Carers faced extra responsibilities, losing trusted and valued support particularly when day centres closed. Carers stepped in to provide essential support including shopping responsibilities and absorbing financial pressures. Wiltshire CIL reported that more people were relying on their families for support and connection rather than accessing the Covid-19 community groups, voluntary organisations or Wiltshire Council. As summarised by Inclusion London:

"Because of fear of contracting the virus and the need to shield, many people have reduced the support they get and heavily rely on family, this is causing emotional and psychological stress, and as a result many people feel they are at breaking point".

Inclusion London briefing

Carers experienced little respite from their caring duties and the research described the exhaustion and strain upon them in doing so. The Carers UK report, <u>Behind Closed Doors</u>, quantified much of this through their national survey. Key findings were:

- 70% of carers were providing more care due to the coronavirus outbreak
- over a third (35%) of carers are providing more care as a result of local services reducing or closing
- carers were, on average, providing 10 additional hours of care a week
- 69% of all carers were providing more help with emotional support, motivation, or keeping an
  eye/checking in on the person they care for
- 81% of carers were spending more money with 72% spending more on food and 50% spending more on household bills.

These findings have helped inform Carers UK <u>Recovery Plan for Carers</u>, which describes the challenges faced by carers and proposes action from central and local government, health services, businesses, local communities and the general public. This is to ensure the needs of carers and the people they care for are fully considered in the recovery plans.

#### Impact on direct payment (DP) holders

One consistent theme across the research described the impact of Covid-19 upon direct payment holders. These issues are reviewed below.

#### Communication around direct payments

The research suggests a mixed picture around the communications between local authorities and DP holders. There were examples of people reporting that they had to continually contact their local authority for information and advice with regard to their care and support. For these people, In Control described a sense of 'complete radio silence', with many people feeling abandoned by their usual statutory support mechanisms.

By contrast, In Control noted that there was another cohort who reported excellent support around DP from their local authority. These respondents reported good and supportive advice and action taken by their local authority, who immediately contacted people to check if anything was needed and others had good conversations on enabling flexibility of budget to revise what was needed in light of the pandemic. This suggested that there was a potential polarisation of experience, between those councils which delivered very good and very poor practice.

#### Guidance around direct payments

For DP recipients or self-funders employing PAs in health or social care, Covid-19 led to significant confusion around employment issues, given the time taken to produce the guidance (which has now been produced and published<sup>5</sup>). As Inclusion London explained:

'About 70,000 people employ their own support staff, but they were largely left on their own, expected to deal with HR issues, source PPE and put in place contingency plans themselves'.

Inclusion London briefing

Looking for guidance on PAs, particularly in terms of whether to furlough or retain, In Control's research suggested a mixed response from local authorities. In some instances, respondents got no reply from their local authority in response to their request for advice, and in other examples, they were signposted elsewhere for advice e.g. to their employer insurance.

<sup>&</sup>lt;sup>5</sup> Guidance for people receiving DP and care providers through personal budgets (PB) and personal health budgets (PHB) was published taking account of Public Health England (PHE) guidance on PPE and safe ways of working.

#### Direct payment removed, reduced or restricted

In Control revealed that several respondents reported they had been refused flexibility in the use of their DPs. Two people reported they were stopped completely from using their DPs whilst another was informed their DP would be removed and agency support was imposed as a replacement with no route for complaint or appeal. Skills for Care reported issues with councils reducing individual DP budgets because individual employers asked their PAs not to attend work and issues with services being purchased through DPs still requiring payment even though the service couldn't operate<sup>6</sup>.

#### **Digital inequality**

The research noted the speed at which providers and staff adapted to delivery during a time of social distancing. AMHP described how members shared examples of therapeutic interventions including their peer support, recovery colleges, counselling sessions, and crisis support services being delivered online or via telephone. However, they also described how it was not always possible to support all people digitally and that some might struggle with access i.e. inability to use technology or ownership of equipment.

AMHP's report noted that digital exclusion remains a barrier for a considerable number of people and communities. This was echoed by a CQC survey with people on low incomes, who reported a higher preference for face-to-face contact and concerns over digital access. Inclusion London highlighted the barriers faced by disabled people in accessing online solutions, arguing that disabled people therefore faced greater exclusion from services.

AMHP also reported instances whereby people with lived experience questioned the safety and confidentiality of video calls and digital services as safe environments. Similarly, RiDC noted some difficulties in accessing and using online platforms, with similar concerns that they were not secure, had poor audio quality, and missed information for visually impaired people. SCIE reported the frustration of those relying on technology for communications and interactions between care homes, organisations and households, specifically around gaps in provision and unreliability in usage. None of the research described any impact of Covid-19 upon the use of assistive technology during the pandemic.

#### People who were shielding<sup>7</sup>

NHS England conducted a series of workshops to explore the experiences of a range of people who were directly affected by shielding restrictions during the lockdown and to understand what this cohort found to be difficult, what helped them and what they would like to happen next. There were some clear themes over the three workshops, including:

a) that the mental health/maintaining mental wellbeing challenges were complex in what was a heterogeneous group of people advised to shield

<sup>&</sup>lt;sup>6</sup> These findings were not disaggregated according to whether they took place or not in a CAE area.

<sup>&</sup>lt;sup>7</sup> One gap in the data is around the local authority role in response to shielding

- b) mental health was becoming more of an issue for some people with existing mental health conditions, and respondents saw a reduction in mental wellbeing in others
- c) participants were clear that timely, sensitive and clear communication with people shielding and with the organisations supporting them was essential
- d) local authorities had established services to support people shielding, but there were concerns about capacity to continue as business as usual ramped up
- e) there was a need for good joined up support across services (health services, local authorities and the VCSE), and there were some good examples of this.

Several of these themes are presented elsewhere throughout this report in common with other groups that access care and support. These echo the feedback from NCAG colleagues who found government guidance unhelpful and (for some) conflicting with their own GP advice.

Respondents who were shielding also described having to weigh up very significant decisions round risk and quality of life:

'My son's time is very limited on this planet. We have to weigh risk versus quality of life. He doesn't have 30/40 years ahead of him. He has maybe one or three years of life and if he doesn't enjoy his time it is heart breaking.'

NHS England

> 'As a family we need help with risk assessment, more scientific evidence, how do we assess risk?' NHS England

This work informed NHS England's approach to mental health support during and as a result of the Covid-19 pandemic, with specific offers for people who had been shielding to ensure they knew where to access support and guidance<sup>8</sup>.

#### **Disabled people in employment**

Inclusion London described how disabled people who received support from government's Access to Work scheme 'felt abandoned', as there was no communication, advice or guidance or confirmation of variation in support packages from Access to Work. Furthermore, disabled people in work, including those who needed to continue to shield, were at risk of losing their highly skilled support staff. As such, Inclusion London noted the additional support required by disabled people who worked, to ensure their working environment was safe and accessible.

<sup>&</sup>lt;sup>8</sup> This included the <u>Every Mind Matters website</u> and an enhanced wellbeing support offer from the NHS Volunteer Responders.

#### 3.4 BUILDING A LEGACY

This final section reviews aspects of good practice or learning which might be drawn upon to help build a legacy for future care and support, as identified through the *rapid evidence review*.

#### **Shape future communications and advice**

Healthwatch reported that some local Healthwatch organisations had been approached by their councils to prepare to help with information, advice, communications and services should there be a second Covid-19 wave leading to the application of easements. Similarly, TLAP contributed to direct payment guidance detailed in the A Better Deal for DP holders recommendations (see section 5) and has been heavily involved in co-producing revised guidance since then. TLAP has also contributed to a range of national guidance (e.g. care homes, home care, supported living, shielding guidance, and discharge to assess). This was often at short notice and in future the expectation should be that input is sought at the earliest stage, as this is most likely to result in better and more accessible guidance.

#### Flexible and agile working: adapting to digital models of provision

AMHP members shared examples of their peer support, recovery colleges, counselling sessions, and crisis support services being delivered online or via telephone. One member re-configured their service in collaboration with local hospital colleagues and set up a dedicated resource which meant that the hospital was able to free up capacity to create an intensive care unit for people with Covid-19.

The report, <u>The Doctor Will Zoom You Now</u>, produced by Healthwatch, National Voices and Traverse, portrays the opportunities of remote consultations and use of technology for general practice, hospital outpatient and mental health appointments, but described how this would be best part of a 'blended offer' alongside face to face visits, to meet the needs of the individual.

#### **Supported Living models**

Shared Lives have captured positive stories of Shared Lives and Homeshare households adapting to the crisis, finding meaningful activities, supporting each other, and staying connected. Most local Shared Lives and Homeshare organisations adapted their support to households to keep people well during the crisis. Examples of how other person-centred organisations also responded proactively and positively have been captured by TLAP (see section below on Mobilising Networks).

#### Impact and importance of personalisation

Healthwatch noted some concerns over personalised care during the Covid-19 pandemic. In particular they raised the fact that voluntary sector providers were not being involved in assessments and a more general lack of choice around care provision.

The AMHP argued that Covid-19 had brought the importance of personalisation into sharp relief, and stated commitment around personalisation – and partnership working - as the future for mental health care and support.

'We think Covid-19 is reinforcing the importance of personalisation, of the imperatives for services being shaped (and judged) by the people who need them. That has to be the starting point for how we look at the future funding and commissioning (in all senses) of health and social care services (and indeed relevant others, such as homelessness and housing support) for people with mental health issues-and what's required to sustain and develop a robust and diverse VCSE sector to that end'.

**AMHP** 

#### **Good practice around co-production**

In Control suggested that there were various pockets of good practice around co-production taking place in some local authorities across the country. Shared Lives described how a number of areas had started up virtual local groups for participants for mutual support and to inform service developments during this period. Inclusion London noted that:

'We know at regional level local authorities that co-produced their response with disabled people did much better compared to others. Disabled people must be included in policy development at national and local level'.

Inclusion London

This view is supported by NCAG who, through their participation in the production of national guidance, were able to reflect their own experience. This was mixed: some had experience of councils who had reached out to work co-productively with people accessing care and support in contrast with others that were not felt to have been pro-active at all. There was felt to be a disparity in the quality of communications between those local authorities who adopted a more co-productive approach to their response to Covid-19 compared to those that didn't.

#### Innovation and good practice in commissioning

Given the importance of partnership working, AMHP reviewed key elements of effective working practice between statutory service commissioners and providers working with their voluntary and community sector partners to respond to the crisis and build up a positive future for mental health support. This, and practical advice on how to build effective partnerships locally, is presented in an AMHP briefing note.

Innovation and good practice in commissioning was noted more widely than just across mental health provision. As part of <u>Covid-19</u>: <u>our action plan for adult social care</u>, the Department for Health and Social Care (DHSC) commissioned SCIE to develop guidance to support good commissioning practice during the pandemic<sup>9</sup>. These materials are captured on <u>Commissioning</u> and Covid-19: advice for social care.

#### Mobilising networks: the community and national response

Given the importance of community in the response to Covid-19, there was an opportunity for more research to explore the impact of neighbourhood responses on those that accessed care and support to help mobilise this energy in future. As reported by Carers UK, some carers shared positive stories of local businesses and community groups helping them to access necessary supplies.

'The town I live in is very community minded, so within days of the outbreak the local community association, town council and food bank got together and created a central volunteer group...This group can arrange anything you need outside the house within literally hours'.

Carers UK, Behind Closed Doors

However, there was a mixed picture around the community response, Wiltshire CIL reported that despite a large number of local Covid-19 support groups that had been set up to support those who were isolated and lonely, there was only one person who specified that they were in regular contact with a Covid group. Similarly, the research suggested that very few of the Wiltshire CIL respondents kept in contact with their neighbours over this period.

In Control noted areas of improvements in the community and wider services and these included neighbourhood support, mutual aid groups, GP telephone service and support, and access to others via webinars/zoom etc. Other opportunities were very specific to local services such as particular pharmacists, supermarkets, and shops. However, it was still noted that the majority of respondents felt that nothing had been made better, easier or improved during this time, and reported a sense of feeling abandoned.

National networks, such as TIG, helped coordinate information at sector and leadership level, bringing together insight and experiences across partners, and providing a space to share good practice, insights and learning. In line with this, examples of emerging practice during Covid-19 have been collated by TLAP, as part of Covid-19 adult social care provision: stories of promise. TLAP's directory of innovations in community-centred support was set up to demonstrate how care and support can and is being provided in person-centred and community-based ways; organisations on the directory have shared how they have responded to Covid-19.

<sup>&</sup>lt;sup>9</sup> SCIE's guidance was developed through engagement with national bodies including LGA, ADASS and TLAP with over 40 interviews with commissioners and providers from a broad range of organisations and a survey of commissioners and people who use services and carers.

### 4. CONCLUSIONS

The rapid evidence review was inevitably not comprehensive, in that it did not capture the experience of everyone accessing care and support during the early phase of the pandemic. Nor did it answer questions around the extent to which people were impacted by CAE in those areas where councils 'switched on' the easements. Neither does it build up a consistent picture of community support during the crisis and how, and to what extent, this helped fill any gaps in regular care and support.

However, it is clear that the research conducted and presented in this report presents a vivid picture of the wider impacts of Covid-19 upon people's lives. The early research revealed the many and specific ways that the pandemic – and the government response to it – disrupted routines, removed taken for granted freedoms, and unleashed uncertainty about the future. This was undoubtedly an anxious – if not frightening – time for everybody, but it specifically impacted upon those who accessed care and support and the people who provided the care.

Most importantly, the research provides a snapshot of a fast moving and fluid situation, as the impact of the pandemic unfolded on a week by week basis. Several of the concerns highlighted in the research have already been addressed (specifically around guidance and PPE). The research has also helped to highlight things that worked well and less well over this period and revealed some building blocks of promise. These insights can help as we continue to live with Covid-19 or any other pandemic. Importantly, they should also help inform the re-design and reform of social care, where personalised and community-based responses must be the essential feature. The final chapter of this report outlines a series of recommendations based on this report, which can and should lead to change.

# 5. RECOMMENDATIONS AND PROPOSED KEY ACTIVITY

This report – as per the wider TIG role - was intended as stimulus to change. As such, the table below contains a series of recommendations which have been agreed by members of the TIG. These are based on analysis of the research and information submitted by partners to the TIG, combined with the intelligence and insight from discussion at TIG meetings. Whilst they are interrelated and there is inevitably some overlap, they distinguish strands of key activity and the proposed leadership for taking them forward which will also need to involve a broader constituency of the wider TLAP partnership and beyond.

Inevitably some recommendations will require changes to system and process. But at their heart they depend on a willingness to develop and implement policies and practices in co-productive ways that put people front and centre, as exemplified by <u>Making it Real</u>, which sets out what good personalised care and support looks like.

Ther	ne	Issues	Solutions	Who
1.	All themes	Ensure the learning from TIG is shared with Directors of Adult Social Services.	Undertake a programme of meetings with each of the nine ADASS regions to share the learning from the TIG, identify what support can help preparations for a possible second wave of the pandemic (or similar) and to inform and influence the re-design of care and support in local areas.	TIG
2.	Guidance	A large amount of guidance, produced rapidly, especially emergency guidance, which limited opportunities for coproduction; therefore not able to address fully the perspective of those people who access care services. Lengthy guidance overwhelming for council staff and other target audiences.	Put in place structures to ensure that meaningful guidance can be co-produced rapidly with clear style guide (plain English, short, bullet points).	DHSC

Then	ne	Issues	Solutions	Who
3.	Communications at local level	People reported anxiety created by lack of information or no information from local councils regarding how their care would be affected.	Councils to ensure they have in place an up-to-date system for communicating with people who use care and support services; nominated key workers /phone numbers for particular issues e.g. direct payment holders, people in care homes.  Make sure that there is a strong culture of expectation over practitioners engaging proactively with the people they support.  Have in place co-production groups who can advise on issues arising.	Councils  Healthwatch England
4.	Co-production	a) People with lived experience contributed to the national Covid work, often within very short timescales; the extent to which their contribution was reflected in the final published guidance was unclear.  c) Only pockets found of coproducing responses to Covid at the local level.	a) Embed co-productive approach within DHSC and across wider government, building on the approach now adopted for direct payments guidance.  b) establish a protocol for a co-productive approach to producing emergency guidance that recognises the need to work at pace.  c) Councils to strengthen co-production.	a) DHSC* b) DHSC/TLAP c) Councils

Ther	ne	Issues	Solutions	Who
5.	Care Act Easements	Concern over how decisions to use the easements were communicated locally whilst councils using them felt singled out for criticism. People reported negative experiences of assessment and changes to care and support in council areas where easements had not been enacted (stages 3 &4).	Identify themes and learning from councils who used the easements and those that did not alongside feedback from people with lived experience. Look to retain less bureaucratic more efficient process around assessments, support planning and reviews, providing they remain Care Act compliant. Revised DHSC Easement guidance published on 1st September	DHSC  ADASS  LGA  Healthwatch England
6.	Commissioning	A mixed commissioning response. Financial and other support (e.g. PPE, infection control advice) made available to familiar providers such as care homes and home care; concern over impact on VCSE providers (especially smaller organisations and BAME groups). Signs of creative approaches to commissioning in partnership with providers.	Spread better commissioning practice in partnership with citizens and providers, focused on health and wellbeing, not time and task.	LGA ADASS TLAP SCIE

<sup>\*</sup> Healthwatch England can support this recommendation through collating feedback from people accessing health, care and support gained from local Healthwatch

Ther	ne	Issues	Solutions	Who
7.	Addressing inequality	Disproportionate impact of the pandemic on people from BAME communities and other disadvantaged groups, highlighting existing patterns of inequality.	Convene the care and support sector to develop a programme of action to systematically address inequalities in care and support, through coproduction with the groups and communities in question. Tackling inequalities to be an explicit objective in all of the key activities in this TIG response. Changing/unmet needs as lockdown relaxes, disaggregated by protected characteristics.	All
8.	Support for carers	Unpaid family carers took on significant additional caring responsibilities, leading to increased stress, financial burden and risk of burn out. Families with a relative living in a care home experienced loss of contact and fears for their loved one's safety.	Restoration of care and support, carer support, and community-based activities at the earliest point (see also mobilising communities). Capitalise on flexible approaches that should be retained; develop: a new 'carers offer'.	DHSC LGA ADASS Carers UK

Then	ne	Issues	Solutions	Who
9.	A better deal for direct payment holders	National guidance late in coming, reflecting an absence of a voice for direct payment holders at national level. Locally, experience of direct payment holders fell into two broad camps. Reported problems of poor communication from councils, access to PPE, confusion on employing PAs (particularly furloughing), and restrictions on use of their direct payment. Others reported proactive communication and support from councils and support to use their budgets flexibility.	Co-production at national and local level to re-set the direct payment 'offer' so they are flexible, as intended in the Care Act, and in line with the good practice of leading councils. Develop a consensus on how to support a voice for direct payment holders and their employees (personal assistants) at local, regional, national levels.	Re-Imagining SDS Group (convened by TLAP)  Social Care Innovation Network
10.	Addressing mental health	People with existing mental health needs reporting difficulty in accessing support (including urgent care). Changes and (sometimes) reduction as services transferred to digital, reinforcing existing digital exclusion for some; erosion of personalisation. Rising anxiety amongst other groups from self-isolation, social distancing and disappearance of community-based support. Some evidence of creative responses from providers with supportive commissioners.	Building back support through innovative partnership across commissioners, providers and people with lived experience based on learning and shared objectives, responding to increasing and changing need; interdependency with NHS.	DHSC AMHP

Ther	ne	Issues	Solutions	Who
11.	People living in care homes and families	Incredibly anxious time for people living and working in care homes and their families.  Multiple concerns over infection control, access to PPE, testing, transfers of people from hospital, access to health advice, managing movement in and out of homes. Contact with loved ones severely hindered.	Immediate action being taken forward by the Social Care Covid Task Force. Opportunity to re-think care homes and build up alternatives such as Shared Lives, which proved largely resilient.	DHSC ADASS TLAP SCIE
12.	Mobilising communities	We have seen communities come together to look out for one another with the rapid flourishing of mutual aid groups, whilst at the same time people reported feeling left isolated and struggling to get hold of essentials such as food and medicines. Some councils worked cooperatively alongside mutual aid groups, others more distant or sought direct control.	Develop a better understanding of the community response and what the state (national and local) and business should be doing to create the conditions for it to flourish, so that everyone and every place is included. Urgently attend to re-opening the myriad forms of support in the community, from universal services (e.g. libraries, recreation, arts and culture) through to neighbourhood activity. Link to re-design of formal service provision (e.g. day care), to be more resilient, adaptive and personalised.	Social Care Innovation Network  LGA  ADASS  Healthwatch England

Then	ne	Issues	Solutions	Who
13.	Going digital	Rapid acceleration of digital technology to transact business (e.g. assessments) and compensate for cancelled face to face support (e.g. peer support, day services); different impacts on different groups.	Establish what aspects of digital technology should be retained, based on understanding benefits and limitations for particular groups to avoid exacerbating existing digital divide. Overcome barriers to address digital exclusion e.g. provision of training to go online; universal faster broadband as an equality measure.  Consider what amount of national and local coordination is required to avoid plethora of competing digital initiatives.	DHSC  LGA  Healthwatch England
14.	Develop the workforce	All parts of the workforce needed to rapidly change how they worked e.g. remote working, re-deployment, delivering hands on support in stressful circumstances, where infection control and access to PPE has been a recurring issue. A struggle to achieve parity with NHS and issues to do with who should legitimately be regarded as a key worker e.g. personal assistant.	Take the opportunity to grow the social care workforce with increased recognition and status making sure to include personal assistants. Look at workforce development through the lens of wellbeing. Use Making it Real to embed personalised approaches to providing support.	DHSC ADASS LGA Skills for Care
15.	Further research and learning	TIG insights rapidly assembled in a fast-moving fluid context. Risk now of an uncontrolled explosion of research activity, not well coordinated and therefore of limited use.	TIG (if continuing) to act as conduit for sharing and dissemination of insight and resources. Convene roundtable with DHSC, academics, TLAP partners and people with lived experience to set priorities for research and evaluation in the context of Covid.	DHSC TLAP

## **APPENDIX 1: STATUS OF RESEARCH**

Table 1 Research and data used in the Rapid Evidence Review

Organisation	Cohort	Key research questions/objectives	Data type	Status of data
Association of Mental Health Providers	VCSE MH providers and staff - to understand impact on people with mental conditions, including those in the CJS and from BAME communities and upon the provider landscape	Identify learning from and issues addressed to form the basis of a proposal for an action plan to sustain & improve access to VCSE mental health services & support via digital, both during & beyond C-19  Understand the effects and impact of CAE & Mental Health Act 'adjustments resulting from the Coronavirus legislation  Understand and help colleagues manage and respond to some of the emerging challenges for mental health providers and the people they serve	Conversations with members  Webinar with partners  Online session for members	Supporting mental health in communities during the coronavirus crisis  Covid-19 and the VCSE Mental Health Sector
Association of Directors of Adult Social Services	Directors of Social Services in 8 councils that used the Care Act Easements and 5 other councils	To identify reflections and learning from the perspective of directors	Interviews with Directors	Early themes and learning reported to TIG 7th July 2020. Full report to be published

Organisation	Cohort	Key research questions/objectives	Data type	Status of data
Carers UK	Carers and former carers (c. 5k)	Understanding carers experiences during C-19	Survey	Report published and shared with TIG  Carers UK Behind Closed Doors April 2020
Carers UK	A recovery plan for Carers		Briefing	Recovery plan for carers
Covid-19 Be Human RACA: In Control and Disability Rights UK	All age, all impairments		National Register of Experience	Interim report shared with TIG
CQC	Experts by Experience (across England)	Experience of Care Act Easements upon care and support received during Covid-19	Feedback from Experts by Experience	Headlines shared with TIG
CQC	250 people from register	Experience of Care Act Easements upon care and support received during Covid-19	Survey	Headlines shared with TIG
CQC	250 people from register	Experiences of the Mental Health Act amendments	Survey	Headlines shared with TIG
CQC	250 people from register	Explore online and innovative care during Covid-19	Survey	Headlines shared with TIG
CQC	250 LGBTQ+ people from register	Experiences during Covid-19	Survey	Headlines shared with TIG
CQC	200 BAME and 50 White people from register	Experiences during Covid-19	Survey	Headlines shared with TIG

Organisation	Cohort	Key research questions/objectives	Data type	Status of data
CQC	People who access care and support	Experiences of care and support during Covid-19	Survey	Headlines shared with TIG
Healthwatch	Local authorities enacting easements	Impact of local councils enacting easements  Impact of Covid-19 on those accessing care and support including Care Home residents, staff and carers	Local initiatives – surveys Future intelligence gathering is planned	Headlines shared with TIG
Healthwatch, National Voices, Traverse and supported by PPL	49 people across an online platform with 20 telephone interviews	Patient experience of remote and virtual consultations	Rapid qualitative research study	Report shared with TIG  The Doctor will Zoom you now
Healthwatch Leeds	Wellbeing of Care Residents during Covid-19	Interviews with the relatives of residents (while enter and view visits were paused) to highlight important experiences and issues	Interviews	Report shared with TIG  Covid Care Homes  Residents Report:
Inclusion London	Covid-19 and Disabled people		Briefing paper	Report shared with TIG  Abandoned, forgotten and ignored
NCAG	People with lived experience with visual impairments	Covid related experience for visually impaired people	Intelligence from peer support group	Headlines shared with TIG

Organisation	Cohort	Key research questions/objectives	Data type	Status of data
Research Institute for Disabled Consumers (RiDC)	Disabled and older people	Experiences and opinions of disabled older people during lockdown	Survey	Report published
NHS England and Improvement Public Participation team	People who are shielding	Understanding the experiences of Covid-19 upon people who are shielding	Sessions with patient and community organisations	Headlines shared with TIG  Contact <u>england</u> . <u>engagement@nhs.net</u> for more information
SCIE 30 Apr - 19 May	Social workers from all settings	Explore the key challenges facing social workers and identify ways to overcome them	Survey	Headlines shared with TIG
SCIE 14 May – 29 May	Commissioners and providers	Explore the key challenges facing commissioners and providers and identify ways to overcome them	Survey	Headlines shared with TIG
SCIE	Commissioning and Covid-19: advice for social care		Guidance and practical examples	Commissioning and Covid 19
Shared Lives Plus	Shared Lives Members	Explore the key issues facing members during Covid-19	Surveys Webinars	Headlines shared with TIG

Organisation	Cohort	Key research questions/objectives	Data type	Status of data
Skills for Care April 2020	Employers and the ASC workforce	How Skills for Care can support recovery in social care  Identify immediate and medium-term workforce needs in adult social care  Provide a clear indication of areas for attention in 'multiple future' scenarios  Pose a distinct set of hypotheses for Skills for Care response	Conversations with care providers (100)  Collated and responded to queries	Headlines shared with TIG
TLAP	Covid-19 adult social care provision: stories of promise		Information and examples of emerging practice during the coronavirus pandemic	Stories of promise
VODG	Local authorities	Impact of councils that have notified easements	Structured FOI access requests	FOI access requests shared with TIG
UNISON	Unison vision for social care		Briefing	Report shared with TIG  Care after Covid
Wiltshire Centre for Independent Living	Disabled people and their carers	Life under lockdown during Covid-19 outbreak  Evidence to provide a snapshot of how the current restrictions are affecting and impacting on the lives of disabled people in Wiltshire	Survey	Report published and shared with TIG Experiences during Covid-19

Table 2 - Research and data gathering that was not yet available for inclusion in this report

Organisation	Cohort	Key research questions/objectives	Data type	Status of data
ADASS	Directors of Adult Social Care	Reflections and learning from Directors	Written statements	Awaiting final report
BASW	Social workers	Information from social workers	Survey	Awaiting findings
CQC	DCA and supported living services	Impacts of community- based services in Solihull	Survey	In process – findings not currently available
EngAgeNet and Legal & General	Older people	Understand how older people are disproportionately affected by lockdown; by a higher risk of serious infection; how many are themselves carers for other family members	Survey	In process – findings not currently available
Healthwatch	Network of Patient Experiences during hospital discharge	Gather intelligence from the wider network on patient experiences of hospital discharge during the outbreak. Some of the feedback may relate to the impact on local social care services following the changes	TBC	In process – findings not currently available
In Control	Health and Social Care direct care and support workers		Survey	In process – findings not currently available
In Control	Lost Loved Ones survey: end of life all age, all groups	Experience of end of life for all age groups, including those who lost loved ones	Survey	Survey launch early June

Organisation	Cohort	Key research questions/objectives	Data type	Status of data
NCAG	People with lived experience	Feedback from NCAG Ministerial Meetings How Covid-19 has impacted those who access care and support	Feedback from NCAG Ministerial Meetings	Awaiting findings
NHS England and Improvement Public Participation team	Marginalised groups	Understanding the impact on marginalised groups from Covid-19	Telephone survey	Research being undertaken Contact england. engagement@nhs.net for more information
NHS England and Improvement Public Participation team	BAME young people	Experiences of BAME people during Covid-19 and views of what to change for a positive experience in future	NHS Youth Forum feedback	Research being undertaken Contact england. engagement@nhs.net for more information
Skills for Care, LGA and Care Providers Alliance	Adult social care employers	Recruitment and retention good practice - helping employers to overcome staffing shortages relating to COVID-19  Examples of recruiting people returning to work in social care, students in their final year of study who are starting their career in social care early, volunteers and people coming from other sectors	Collating responses from the sector via email	Safe and Rapid Recruitment In process. Findings on www.skillsforcare.org. uk

Organisation	Cohort	Key research questions/objectives	Data type	Status of data
Skills for Care	Registered Manager Network		Facilitating conversations	SfC continue to liaise with the RM networks, but the reports are for SfC internal use only. They won't be published
Skills for Care	BAME care workers	The survey is open to anyone from a BAME background and we are interested in understanding the challenges from both BAME employers and BAME employees  The survey is part of a piece of work which will include a series of webinars and peer coaching, to find out more about the experiences of social care workers from a BAME background during the pandemic	Survey and webinars	In process. The responses will help shape Skills for Care's work  Survey for BAME care workers



#### **TLAP Insight Group members**

- ADASS (Association of Directors of Adult Social Services)
- AMHP (Association of Mental Health Providers)
- BASW (British Association for Social Work)
- Carers UK
- Chief Social Workers
- CQC (Care Quality Commission)
- CSA (Care and Support Alliance)
- DHSC (Department of Health and Social Care)
- Healthwatch England
- In Control
- LGA (Local Government Association)
- Race Equality Foundation
- SCIE (Social Care Institute for Excellence)
- Shared Lives Plus
- Skills for Care
- TLAP (Think Local Act Personal)
- TLAP/NCAG (National Co-production Advisory Group)
- VODG (Voluntary Organisations Disability Group)

Think Local Act Personal is a partnership working to promote personalisation and community-based approaches across social care, health and housing.

thinklocalactpersonal.org.uk info@tlap.org.uk @tlap1

Think Local Act Personal, October 2020