Module 6 Preliminary Written Statement on behalf of National Care Forum, Homecare Association and Care England

1. Introduction

1.1. This is the written preliminary statement for module 6 of the Covid-19 Public Inquiry made by the National Care Forum, Homecare Association, and Care England.

1.2. The National Care Forum is the membership body for not-for-profit care and support organisations in England, although our members have services in all parts of the UK. Formally constituted in 2003 and building on more than 10 years of experience as the Care Forum, the National Care Forum has been promoting quality care through the not-for-profit sector for 30 years. The National Care Forum has over 176 members, providing care and support to over 265,000 people and who employ over 139,000 staff. Our members provide a wide spectrum of services – everything from services for older people, such as residential and nursing care and specialist dementia care to offering home care, extra care housing, supported living and specialist services for people with a learning disability and autistic people and people with enduring mental health conditions or other complex needs. Some also offer homelessness, substance misuse and resettlement services. Many also offer supported housing, day services, employment support and other types of non-CQC registered care and support services.

1.3. The Homecare Association is the UK's only membership body exclusively for homecare providers. It is a private company limited by guarantee and was established as a not-for-profit Association in Autumn 1989. Founded by 75 homecare providers to represent the interests of the homecare sector, the original aims were to advocate for the sector, develop quality standards and campaign for regulation. Up until 2003, the Homecare Association's (previously UKHCA) Code of Practice was the only quality standard in homecare. Non-Executive Directors are all homecare providers, elected by the Homecare Association's members, representing small, medium, and large providers in both the state-funded and self-funded market. The Homecare Association represents members across England, Scotland, Wales, and Northern Ireland. We currently have over 2,300 members, representing about one-third of registered regular domiciliary care providers. 94% of our members are based in England, 3% in Scotland, 2% in Wales and 1% in Northern Ireland. The Homecare Association uses its trusted voice to bring people together in shaping and advancing homecare.

1.4. Care England, a registered charity, is the largest representative body for residential independent adult social care providers in England. Care England members provide a variety of care services, amongst them single care homes, small local groups, national providers and not-for-profit voluntary organisations and associations, as well as private providers, for a variety of service users including older people, those with long-term conditions, learning disabilities and mental health problems. Of our membership, broadly, 60% of care providers provide care to older adults, whilst 40% provide care to adults under 65, namely individuals with a learning disability and autistic people, people with acquired brain injuries, and those with mental ill-health. Our members run and manage approximately 4,000 care services and provide over 120,000 beds. Care England's mission brief is to serve as a unified voice for our members and the care sector aimed at supporting a united, quality-conscious, independent sector that offers real choice and value for money.

1.5. Our preliminary statement addresses the following:

- The current scope of module 6 and our concern about an unintended discriminatory approach.
- The areas the Inquiry should cover to adequately explore the impact of the pandemic on social care.
- The selection of appropriate experts to give insights into adult social care.
- Public funding.

1.6. In our closing statement as core participants for module 2, we drew attention to the general neglect and misunderstanding shown towards social care. These concerns still stand for module 6 and can be expressed in three ways:

i. Social care was overlooked in key decision-making moments.
ii. Social care was misunderstood (it was seen as care homes for older adults, rather than a diverse system of care and support services for all ages, with a workforce of 1.6m, larger than the NHS).
iii. Social care was disadvantaged, especially in comparison to the NHS. Indeed, the focus of decision-making appeared to be protecting the NHS rather than citizens in all communities.

2. The Inquiry's Provisional Outline of Scope for Module 6

2.1. The provisional outline of scope for module 6 as it currently stands appears to reflect a misunderstanding about the nature of the diversity and overlap of adult social care services (particularly with the exclusion of day services and supported housing) and potentially opens the way to a discriminatory approach which focuses on the experiences of older adults to the exclusion of working-age adults who may draw on social care for a number of reasons: learning disabilities, autism, acquired brain injuries, mental ill-health, addiction, physical disabilities etc. The Inquiry risks making the same mistakes and assumptions key decision makers and policymakers made during the pandemic, as reflected in module 2 of the Inquiry.

2.2. National Care Forum, Care England and the Homecare Association are happy to assist the Inquiry team in understanding these nuances through our involvement as core participants. However, we are concerned that without public funding we will be constrained in the evidence and representations we can present on behalf of our members and those they employ and provide care for and in turn the assistance we will be able to give to the Inquiry. We return to this in section 5 below.

2.3. Our comments at paragraph 2.1 are demonstrated by paragraph 20 of the note from the Counsel to the Inquiry[1] which states:

> *"At the outset though, given the public concern about the discharge decisions and the fact that this policy primarily affected adult patients, the Inquiry does not intend to examine children in care in this module (aspects of the impact of the pandemic on children and young persons will, in any event, be considered in a later module.) In addition, although there are a number of different settings in which adult social care is delivered it will not be possible or proportionate to examine all the settings – the Inquiry considers that by focussing on adult care and residential homes and care provided in the home, the Inquiry will have a sufficiently broad evidence base upon which to make meaningful recommendations. In the event that the evidence suggests that other adult social care settings need to be considered the Inquiry will keep these decisions under review."*

2.3.1. First, there is a focus on *"discharge decisions"* to residential settings in paragraph 20 and in the provisional scope. The majority of people drawing on care and support, young and old, during the pandemic were not 'patients' discharged from hospital. Many were people living in their own homes, including housing with care, shared lives schemes and supported living. They were nevertheless still impacted by the decisions taken around things such as lockdown, shielding and Do Not Attempt Cardiopulmonary Resuscitation (DNACPRs). Examining decisions taken around discharge to care homes will be important, but it won't tell the full story or range of experiences from which we must learn.

2.3.2. Second, we are concerned that the Inquiry's focus on residential care homes and what appears to be a narrow interpretation of care provided in the home will not create the '*sufficiently broad evidence base upon which to make meaningful recommendations"* it thinks it will. The

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[1] Dated 1 March 2024.

problem here is that supported housing, supported living, housing with care, shared lives schemes, people employing personal assistants and other similar models are based on the very premise that the individual receiving care is renting or owns the house/apartment they live in – they are literally living in their own homes and as such where needed, **receive care in their own home**. Multiple types of care overlap and cannot be disentangled as easily as the Inquiry seems to suggest. Regulated care is regularly delivered in these settings alongside more informal models of support. These therefore should be included in any inquiries for those *'provided care in the home'.* It doesn't make sense for the inquiry to exclude this cohort from its scope.

2.3.3. Third, by only focusing on residential care homes, a rigid definition of *'care in the home'* and an emphasis on hospital discharge, the Inquiry is neglecting an entire cohort of people, young and old, with learning disabilities and autism – one of the most heavily impacted groups. There were 180,000 deaths from Covid-19 March 2020 to end-July 2022 in England and Wales. Those most impacted were not just older adults, but many other groups accessing and working in adult social care. Mortality rates were higher among people with a self-reported disability or a learning disability – the risk of death from Covid-19 in England was 3-4 times higher in more-disabled people compared with non-disabled people.[2] People with learning disabilities or autism are more likely to have been accessing community services, housing with care, supported housing, supported living, shared lives schemes and employing personal assistants during the pandemic – as well as home care and support workers in these settings. By removing these services from scope, the Inquiry is inadvertently discriminating against the vulnerable groups of people who had the least voice or media attention. The scope of module 6 must encompass the full diversity of adult social care services and not just regulated care for older adults.

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[2] The King's Fund - Deaths from Covid-19 (coronavirus): how are they counted and what do they show? https://www.kingsfund.org.uk/publications/deaths-covid-19.

Comments on the Provisional Outline of Scope

2.4. Module 2 showed there was a concerning lack of understanding of social care by policymakers, leading to an unhelpfully narrow focus on care homes for older people, with little consideration of the breadth and diversity of care and support settings and services, which all needed help and support. There was a particular lack of understanding of home-based and community services, despite these making up more than half the workforce and millions of citizens. The preliminary scope of module 6 currently reflects this narrowness of focus and must be widened.

2.5. *"The impact of the pandemic on people's experience of the Care Sector. This will focus on residents and their loved ones and those working within the Care Sector and will include consideration of the unequal impacts on them."* The use of the word residents implies that the inquiry is only considering the impact upon care home residents. As pointed out in 2.1 and 2.3, the scope of module 6 must be broadened to reflect those living in their own homes as many more older and disabled people live in their own homes than in care homes. This should include supported housing, supported living, housing with care, shared lives schemes, people employing personal assistants and other community models. They too were impacted by the pandemic and the decisions of policymakers and the operationalisation of guidance.

2.6. *"The structure of the Care Sector and the key bodies involved in the UK and Devolved Administrations at the start of and during the pandemic. This will include staffing levels and bed capacity immediately prior to the pandemic."* This is framed in such a way to suggest that the Inquiry is only concerned with staffing levels in care homes, alongside bed capacity. Again, the scope must be broader to consider the wider social care workforce – including homecare workers, support workers and others based in the community – and wider sector capacity.

2.7. "*The key decisions made by the UK government and the Devolved Administrations in respect of the Care Sector, including the decisions relating to the discharge of people from hospitals into adult care and residential homes in the early stages of the pandemic."* The Inquiry must recognise that people requiring care and support were also discharged to other social care settings, not just care homes – the decisions and consequences surrounding this should also be examined. It is also important that the Inquiry goes beyond the issue of hospital discharge and looks at wider decisions relating to the formulation of guidance, the scaling back of access to clinical expertise and community health services, local versus national decision-making, access to key data and access to resources such as PPE and tests, among other key decisions.

2.8. *"The management of the pandemic in adult care and residential homes. This will include the measures preventing the spread of Covid-19, such as infection prevention and control measures, testing for Covid-19, the availability and adequacy of personal protective equipment (PPE), restrictions on access by/to healthcare professionals and visits from loved ones."* This will be a very important area for the Inquiry to explore. The Inquiry will also want to consider the management of supported housing, supported living, housing with care, shared lives schemes, people employing personal assistants, alongside home care and other community services, to get a proper understanding. Often, care providers operate more than one type of these services and people working and accessing these services move between them – it makes no sense to look at them in isolation or ignore some of them. It is also essential that the management of care in all setting is considered in the context of wider decision making, funding, guidance from PHE/UKHSA, DLUHC and DHSC and the nature of support from health professionals.

2.9. *"The use of Do Not Attempt Cardiopulmonary Resuscitation (DNACPRs) and communication with residents and their loved ones about the resident's condition and treatment including discussions and decisions about DNACPRs."* The use of the word resident implies that the inquiry is only considering the impact upon care home residents. The Inquiry should note the

DNACPRs were also used in care settings other than care homes, including people receiving care at home, supported housing, supported living, housing with care, shared lives schemes, people employing personal assistants and other similar models. Concerns in relation to the blanket adoption of DNACPRs and effective communication with those in receipt of care arose across a range of equality groups, including older people, people with dementia and people with a learning disability. As outlined at paragraph 2.3.3, people with a learning disability are much less likely to receive care in a care home. Failing to extend the scope of the inquiry, beyond 'residents' of care homes, to consider care in the full range of care settings once again risks an unintended discriminatory approach.

2.10. *"The changes to the regulatory inspection regimes within the Care Sector."* This is a very important line of inquiry. In England, providers' relationship with the Care Quality Commission changed significantly in a wide number of areas and the impact of this upon the sector needs to be examined carefully.

2.11. *"Deaths related to the infection of Covid-19 including deaths of residents and staff."* The use of the word 'residents' suggests the Inquiry is thinking only of residential care homes for older adults. It must widen its scope to look at deaths of people drawing upon care and support in in wider social care settings. As pointed out in paragraph 2.3.3, many working-age adults with learning disabilities, autism, mental ill-health, acquired brain injuries, physical disabilities, and addiction drawing on social care were impacted by the pandemic and are much less likely to receive care in a residential care home. The scope of the Inquiry must be sufficiently wide to examine and consider the deaths of people receiving care in all settings, to avoid inadvertently excluding people from particular equality groups. The same applies to ethnic minorities, who comprise a greater section of the social care workforce than wider economy.[3] Mortality rates were higher among some ethnic minority groups – particularly Bangladeshi, Pakistani and Black Caribbean groups.

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[3] https://www.skillsforcare.org.uk/Adult-Social-Care-Workforce-Data/Workforce-intelligence/documents/State-of-the-adult-social-care-sector/The-State-of-the-Adult-Social-Care-Sector-and-Workforce-2023.pdf#page=87

Mortality rates were also 2.6 times higher in the most deprived than the least deprived tenth of areas. People working in social care had significantly higher rates of death involving Covid-19 than the population among those of the same age and sex. [4]

2.12. *"Infection prevention and control measures for those providing care in the home, including by unpaid carers."* As outlined in 2.3 above, the Inquiry must consider supported housing, supported living, housing with care, shared lives schemes, people employing personal assistants and other similar models in the definition of 'providing care in the home'. To do otherwise will deny an entire group of people the opportunity to have their voices heard and lessons learned.

3. The areas the Inquiry should cover to adequately explore the impact of the pandemic on social care

3.1. Below we have outlined what we think the key areas of investigation are for module 6. These overlap and build on some of the comments we have made about the outline of scope in section 2 and reflect our overall observation about the neglect of adult social care.

3.2. There was a disregard for the people drawing on care and support from government and the wider health system - For those living in care settings and for those who need care and support in the community, there was a lack of understanding of their needs and circumstances. This lack of understanding and the lack of understanding of the social care sector as a whole, especially the breadth and diversity of it and those who use it, manifested itself as an apparent disregard for the people relying on care and support during the pandemic. This is demonstrated by the following:

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[4] The King's Fund - Deaths from Covid-19 (coronavirus): how are they counted and what do they show? https://www.kingsfund.org.uk/publications/deaths-covid-19.

a. PPE supply for the social care sector was particularly chaotic during the first wave.
b. The importance of testing across social care did not appear to be recognised by policymakers for a significant period, and whole home routine testing for all care homes was not reliably available until September 2020. Testing was not widely available for homecare and other community settings until January 2021.
c. Some of the most important policy decisions relevant to the social care sector, including the policy of discharge from hospitals, withdrawal of community health services, and the imposition of visiting restrictions, were taken without appropriate consultation with the sector itself.
d. Scientific and operational expertise in social care was excluded from the main SAGE group – noting that at a later stage the SAGE care working group was eventually established.
e. There was blanket decision making around do not attempt cardiopulmonary resuscitation decisions (DNACPR) by NHS colleagues for people with a learning disability and older people without involving people or their families or taking into account each person's individual circumstances.
f. Guidance in relation to visiting showed a lack of understanding of the practicalities of the sector, and those supported within it, particularly when it came to people with learning disabilities and autistic people.
g. The decision to instantly withdraw community health services for the social care sector at the beginning of the pandemic brought significant risks to people's health and may well have precipitated a decline in their overall health and wellbeing.
h. Care Act 'easements', allowing local authorities to cease formal Care Act assessments, applications of eligibility and reviews were made available very promptly in the early pandemic and enabled Local Authorities to abandon some of their responsibilities to people under the Care Act.
i. Moving through the different phases of the pandemic, it was clear that as restrictions eased for wider society, there was confusion across

government about how this easing might work for those using care and support services.

3.3. **There was a disregard for the people <u>working</u> in social care from government and the wider health system -** Priorities and guidance should be developed in partnership between health and social care services. Within this partnership, independent sector care providers should be seen as long-term legitimate partners instead of being used to overcome short-term pressures. This is demonstrated by the following:

a. Very significant delays to essential practical support for the care and support sector, including timely and reliable access to PPE or testing.
b. There were early issues in evidencing keyworker status for care workers and the associated support and prioritisation for services such as access to childcare, schooling etc., and access to financial assistance to implement the necessary absences for isolation and enhanced sick pay.
c. The implementation of the Vaccination as a Condition of Deployment policy (VCOD) for those working in care homes against the guidance of senior leaders in social care who repeatedly shared their expertise in the best policy approaches for encouraging vaccine uptake and overcoming vaccine hesitancy, as well as the likely negative outcomes of the policy. The proposal for extending VCOD to homecare, though averted at the eleventh hour, also had a negative impact on workforce numbers.

3.4. **Guidance flow and communication from government and key stakeholders was poor and chaotic throughout the first and second phase of the pandemic.** Changes in guidance were often communicated last minute, sometimes over bank holiday weekends and often late on Friday nights, making it hugely challenging to implement promptly. Particularly chaotic guidance changes were linked to PPE, Infection Prevention and Control, isolation of those receiving care and support following a positive Covid-19 test and visiting the different types of settings in which care and support is provided. Lack of understanding of the settings where care is provided led to policies that were unworkable in practice and required substantial change at short notice, adding to the chaos. Furthermore, easy read versions were often not provided for a considerable period after publication, meaning communicating complex guidance changes to many in receipt of care was challenging, and added to the anxiety felt by those utilising and working in the sector. Often, policy changes were communicated by press release/daily briefings, sometimes days before the final guidance was issued, leading to a mismatch between public understanding of the situation and the action that care providers were being instructed to take. By way of example, restrictions upon visits to care settings by friends and relatives were, understandably, a highly emotionally charged issue. Government announcements that restrictions were being reduced created an expectation that increased access would be allowed with immediate effect. The ensuing delay in issuing the guidance necessary to allow care providers to implement those changes caused immense frustration and anxiety to those expecting that the change in restrictions would be implemented immediately.

3.5. **The chain of command and communication were unclear, particularly the role of national vs. local decision-makers.** The divergence in guidance produced, and differences in how guidance was interpreted at a local level, were challenging for all social care providers. For example, District Nurses were told they didn't need to wear masks any longer, whilst homecare workers did.

3.6. **Throughout the pandemic response, there was a concerning lack of understanding of social care by policymakers,** leading to an unhelpfully narrow focus on care homes for older people, with little consideration of the breadth and diversity of care and support settings and services, which all needed help and support. The nuances of the sector, including fundamental differences between older person care homes and services for people with learning disabilities and autistic people were not recognised. The importance of co-production and joint strategic planning were crucial yet overlooked during the pandemic. The views of care sector representatives need to be afforded the same level of attention as the views presented by Public Health bodies. Whilst the latter is able to present theoretical data, the former is able to present empirical evidence from real-world experience.

3.7. **There was a lack of understanding of home-based, housing with care and community services in social care.** Home-based, housing with care and community services in social care involve more than half of the workforce and millions of citizens. Officials, Ministers, and other relevant parties, e.g., UKHSA need to understand the care sector, and ensure it receives the guidance, funding, and other resources it needs.

a. Operational guidance was typically written for NHS services without consideration of relevance to the setting and service type, resulting in guidance that was often unworkable and, in some cases, counterproductive.
b. PPE supplies were diverted to the NHS ignoring homecare, housing with care and wider community social care services.
c. There were delays in access to asymptomatic testing for homecare; and challenges with the Covid-19 vaccine roll-out in homecare.
d. When issues with guidance related to homecare were identified, it was not acted on quickly enough. It could take significant time to get relatively simple changes made to guidance.
e. The additional costs of managing infectious diseases for the sector were not well understood by the Government. For example, assumptions were initially made that homecare employers could cover the cost for all the time staff spent testing, without any additional funds.

3.8. **There was limited understanding of the broader community provision** that many providers offer alongside regulated care services. There was also limited understanding of the needs of those who use care and support services – for example, the needs of those with dementia or those with learning disabilities or enduring mental health issues. Additional services such as day centres for adults of all ages were stopped during the pandemic, and many were unable to reopen due to a lack of funding.

3.9. **The drip feeding of funding support was unhelpful, insufficient, inefficient and bureaucratic –** Whilst all funding was greatly needed and appreciated, it came after very significant advocacy from the sector and was provided only in the form of emergency short term time limited funding. This short-termism meant providers were unable to put long-term protective measures in place, or plan for the future accordingly. Funding was driven through local authorities, with significant grant conditions, leading to excessive administration and bureaucracy in relation to accounting and reporting. It is also worth noting that the emergency financial support designed to address additional demands placed upon the sector stopped in March 2022, but associated guidance remained in place for several months in relation to testing and isolation requirements, placing continued financial pressure on employers regarding pay and sick pay.

3.10. **The collection and use of data were highly problematic throughout the pandemic for social care** – The Capacity Tracker became the 'pandemic data capture tool' and was then regularly amended, with many additional questions to require and capture a wider range of data from the wider adult social care sector to inform the emergency response to Covid-19. The final tool created a daily burden for care providers, did not always eliminate duplication of data requests and was regularly changed with little notice. For many providers, there was little perceived benefit to sharing data as it did not result in any discernible change in decision making by those in receipt of the data reflecting the impact of the pandemic that was being reported. Providers who entered the data were then not able to see the wider emerging trends in their collective data, which would have given them greater warning of the expected impact of new variants or the anticipated need for additional capacity.

3.11. **The regulator of adult social care services, the Care Quality Commission (CQC) approach changed significantly during the pandemic.** Providers' relationship with CQC was impacted during this period in a number of ways.

a. In March 2020 on-site inspections were stopped and CQC staff worked remotely. That was followed by a move to a risk-based model for inspection and regulation, effectively resulting in the withdrawal of CQC oversight from adult social care services for the duration of the pandemic. As a result, there are adult social care services that have not had an inspection since the pandemic began and, in some cases, for over 6 years. Outdated ratings caused issues for providers accessing insurance cover and in securing public sector contracts at crucial points in the pandemic and, in many cases, still are.
b. CQC was the only body which held data on deaths of residents in care homes, but this information was not made publicly available or accessible in the early stages of the pandemic.
c. CQC spent considerable time and money competing with the NHS and NECS Capacity Tracker on systems to collect data submitted by providers on various metrics. Ultimately, the NECS Capacity Tracker prevailed.
d. Despite the risk of asymptomatic spread, during the majority of 2020, CQC inspectors were not required to access regular testing when they conducted on-site inspections.
e. The regulator was slow to act on serious concerns about clinical practice and decisions relating to social care. For instance, on 31 March 2020, CQC signed a joint statement on advance care planning and DNACPR with the Care Provider Alliance, British Medical Association and Royal College of General Practice but it took until March 2021 for CQC to publish the result of its investigations into the practice.
f. Given its practical knowledge, position and powers, consideration should be given to whether CQC should have taken a leading role in the preparation of guidance to the social care sector, which

arguably would have ensured more realistic and practical guidance that gave providers greater confidence that in following that guidance they were meeting both their obligations in relation to infection prevention control and in relation to wider care quality.

4. Expert Witnesses and Research Specialists

4.1. Paragraph 33 of the note from the Counsel to the Inquiry[5] provisionally outlines several areas where expert evidence is likely to assist in examining matters set out in module 6's provisional outline of scope.

4.2. The Nuffield Trust[6] and the King's Fund[7] are two organisations which will be able to provide the Inquiry team with the expertise required on the structure and capacity of the Adult Social Care Sector across the UK. In particular, the Nuffield Trust has carried out a series of pieces of work comparing the social care system across the devolved nations and beyond.

4.3. The Health Foundation[8] has produced a Covid-19 policy tracker for 2020 and has done a series of analyses about the costs required to keep adult social care services stable and reform them.

4.4. The International Long-Term Care Policy Network (LTC Covid)[9], part of the London School of Economics' Care Policy and Evaluation Centre can provide expertise on the nature of Covid-19, infection prevention and control and the international perspective.

4.5. For the reasons set out in section 2, it is very important that the Inquiry pays particular attention to the impact of the pandemic on those with specific conditions which commonly underpin the need for social care – this must include the types of setting they receive care in. This must include the full

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[5] Dated 1 March 2024.
[6] https://www.nuffieldtrust.org.uk
[7] https://www.kingsfund.org.uk
[8] https://www.health.org.uk/
[9] https://ltccovid.org

diversity of care and not just care homes and rigidly *defined 'care provided in the home'*. To avoid marginalising anyone's experience, the expert(s) appointed by the Inquiry will also need to explore the experiences of people drawing upon care and support in supported housing, supported living, housing with care, shared lives schemes, people employing personal assistants and wider community models of care. Regulated care is regularly delivered in these settings alongside more informal models.

4.6. Paragraphs 38 to 43 of the note from the Counsel to the Inquiry[10] outlines the proposed approach to the listening exercise, the Key Lines of Enquiry (KLOEs) for researchers and the potential audience groups that should be included in the sampling for the qualitative interviews. We have responded to this in a separate submission dated 7 March 2024, but we want to reiterate our points here.

4.7. For the reasons we have outlined in section 2 above, the KLOEs must go beyond care homes and a rigid definition of care in the home. The questions for the latter should also be asked to those who access supported housing, supported living, housing with care, shared lives schemes, people employing personal assistants and other community models of care.

4.8. Likewise, paragraph 42 of the note from the Counsel to the Inquiry[11] has worryingly omitted people in the receipt of care in their own home and the wider diversity of settings listed in 4.6 above. If this is the approach the Inquiry takes, it will be another example of inadvertent discrimination in valuing the views of older adults over those of working age or with learning disabilities and/or autism. We welcome the inclusion of the other proposed audience groups in paragraph 42 of the note from the Counsel to the Inquiry[12].

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[10] Dated 1 March 2024.

[11] Dated 1 March 2024.

[12] Dated 1 March 2024.

5. Public Funding

5.1. The time and effort involved as core participants for module 2 was significant due to the refusal of the Inquiry team to grant public funding to enable full legal representation to equip us with the resource to analyse over 56,000 pieces of evidence. As such, we were significantly constrained in our ability to respond to module 2, particularly in comparison to other organisations such as the UK government and the NHS, as well the CQC, which appears to have spent £1.8m on its preparations despite not being called to give evidence so far[13].

5.2. We anticipate the level of participation required for module 6 will be far greater than that required for module 2, which we struggled to keep up with due to lack of funding and resources. We are well placed to assist the Inquiry in understanding the impact of the COVID-19 pandemic upon the care sector and to consider this when reaching conclusions and making recommendations. We are concerned that without public funding we will be constrained in the evidence and representations we can present on behalf of our members and those they employ and provide care for and in turn the assistance we will be able to give to the Inquiry. A refusal of public funding will only reinforce the neglect of adult social care we have seen throughout the pandemic. We understand that public funding will be the subject of a separate application but wanted to be clear what the implications would be of not receiving funding.

6. Concluding Remarks

6.1. The provisional outline of scope for module 6 as it currently stands appears to reflect a misunderstanding about the nature of the diversity and overlap of adult social care services and potentially opens the way to a discriminatory approach which focuses on the experiences of older adults to the exclusion of people with learning disabilities and autism.

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[13] CQC – Corporate performance report (cover paper) 29.11.23: https://www.cqc.org.uk/event/board-meeting-29-november-2023

6.2. The focus *“discharge decisions”* to residential settings in the provisional scope neglects the fact that the majority of people drawing on care and support, young and old, during the pandemic were not ‘patients’ discharged from hospital. Many were people living in their own homes, including housing with care, shared lives schemes and supported living - they were nevertheless still impacted by the decisions taken around things such as lockdown, shielding and DNACPRs. Examining decisions taken around discharge to care homes will be important, but it won’t tell the full story or range of experiences from which we must learn.

6.3. The Inquiry’s focus on residential homes and care provided in the home will not create the ‘*sufficiently broad evidence base upon which to make meaningful recommendations”* it thinks it will. The problem here is that supported housing, supported living, housing with care, shared lives schemes, people employing personal assistants and other similar models are based on the very premise that the individual receiving care is renting or owns the house/apartment they live in – they are literally living in their own homes and as such where needed, **receive care in their own home**. Multiple types of care overlap and cannot be disentangled as easily as the Inquiry seems to suggest. Regulated care is regularly delivered in these settings alongside more informal models. These therefore should be included in any inquiries for those *‘provided care in the home’.* It doesn’t make sense for the inquiry to exclude this cohort from its scope.

6.4. By only focusing on residential care homes, a rigid definition of *‘care in the home’* and an emphasis on hospital discharge, the Inquiry risks neglecting an entire cohort of people, young and old, with learning disabilities and autism – one of the most heavily impacted groups. Mortality rates were higher among people with a self-reported disability or a learning disability – the risk of death from Covid-19 in England was 3-4 times higher in more-disabled people compared with non-disabled people.[14] People with learning disabilities, autistic people, people with mental ill-health, acquired brain injuries, physical

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[14] The King’s Fund - Deaths from Covid-19 (coronavirus): how are they counted and what do they show? https://www.kingsfund.org.uk/publications/deaths-covid-19.

disabilities and addiction are more likely to have been accessing community services, housing with care, supported housing, supported living, shared lives schemes and employing personal assistants during the pandemic – as well as home care and support workers in these settings. By removing these services from scope, the Inquiry risks inadvertently discriminating against the vulnerable groups of people who had the least voice or media attention. The scope of module 6 must encompass the full diversity of adult social care services and not just regulated care for older adults.

6.5. Unless the scope of the module is widened to include the provision of care in all settings, the Inquiry is in danger of reinforcing the general neglect and misunderstanding shown towards social care by key decision makers during the pandemic and its aftermath. This still can be expressed in three ways:

i. Social care was overlooked in key decision-making moments.
ii. Social care was misunderstood (it was seen as care homes for older adults, rather than a diverse system of care and support services for all ages, with a workforce of 1.6m, larger than the NHS).
iii. Social care was disadvantaged, especially in comparison to the NHS. Indeed, the focus of decision-making appeared to be protecting the NHS rather than citizens in all communities.