

Written evidence from VoiceAbility (COV0246)

About VoiceAbilityⁱ

VoiceAbility is a registered charity in England and Wales (1076630) and Scotland (SC050036) and one of the UK's largest providers of advocacy and involvement services. We have been supporting people to have their say in decisions about their health, care, and wellbeing for almost 40 years.

VoiceAbility supports people to be heard in decisions about their health, care, and wellbeing. We believe everyone has a right to:

- be heard and respected
- have the same choice, control, and freedom as any other person
- be safe from violence, discrimination, harm or abuse

We submit this evidence based on our experience of delivering advocacy during the coronavirus pandemic and our work with people who may struggle to be heard when decisions are made that affect them and the fulfilment of their rights to healthcare, housing, liberty, private and family life, and protection from abuse or harm. This submission seeks to address the Inquiry's interest in the measures taken by the government, the impact of these measures on human rights, and whether any impact disproportionately affects specific groups or individuals. With this in mind, this submission references Article 2 (right to life), Article 3 (freedom from torture and inhuman or degrading treatment), Article 5 (right to liberty and security), Article 8: (respect for private and family life), Article 14 (protection from discrimination).ⁱⁱ

The need for action

To uphold the human rights of people with disabilities, people living in care, supported living or hospital settings, people with learning disabilities, and people with ongoing health and mental health conditions, the government must act. The Secretary of State for Health and Social Care and Care Services Minister should be accountable for driving action forward. Later in the submission, we share the context and insight which brings us to make this demand of government.

As priorities, the government should:

- **Fully and meaningfully involve people in decisions that affect them.** Advocacy plays a critical role in ensuring people's voice is heard and that their rights are respected. Advocacy relates to all Articles referenced in this submission. Covid-19 is not a reason to take decisions without involving the person affected.
 - Referral to advocacy must be considered whenever a person needs support to be heard in important decisions. This message must be delivered to front-line services. Referral to advocacy is often a legal requirement and this obligation has not been removed by the Coronavirus Act.
 - Staff in care homes, residential care, supported living, and hospital settings must facilitate access to advocacy services. Where a person can make use of digital communication tools and their privacy can be guaranteed, such tools should be actively used; where this is not practical because of a person's particular needs, visits must be facilitated. The significant risk of a breach of people's rights through a lack of advocacy must be recognised alongside any risk of Covid-19.

- **Address the health inequalities experienced by Black and minority ethnic people and people with a disability or learning disability**, in consideration of Article 14. New and evolving measures in response to the pandemic must address these inequalities, including the intersectional nature of discrimination and the adverse experiences people may have of Covid-19 restrictions or enforcement of those restrictions due to their ethnicity and/or disability.
 - **Ensure existing guidance on equal access to quality healthcare is followed** and blanket decisions to not provide healthcare or DNA-CPR orders are fully eradicated. This is especially important when it relates to active treatment and hospital admission should someone become seriously ill with Covid-19.
 - **Appropriate support for people with learning disabilities and autism.** NHS England produced well-considered guidance for clinical staff on supporting people with learning disabilities and autistic people in relation to Covid-19. It is unlikely that this was fully disseminated and embedded into practice, given the length of the guidance and extreme pressures at the time. It should be revisited.
 - **Addressing health inequalities and increased mortality due to the wider impact of coronavirus.** The increased difficulty in accessing healthcare during the pandemic will disproportionately affect people who already experience health inequalities. Where routine health checks and reasonable adjustments have stopped, these must restart immediately. They must be accompanied by proactive outreach by primary care and hospital teams. We must urgently prioritise the most at-risk population groups for routine health checks, flu vaccinations, and medication reviews.

- **Gather reliable information and statistical data and take action based on it** so that the Government and responsible institutions can ensure full compliance with Article 14. The Government have published statistics about the number of people who have died. However, it is critically important that accurate and comprehensive information about the direct and indirect impact of coronavirus on the lives of people living in care homes, people with autism, people living with disabilities and learning disabilities, and people with mental health conditions is gathered, published, and acted on.

- **Take concrete steps to actively protect the lives of people living in care homes, supported living, hospital settings, and residential care**, to fulfil the rights specified in Articles 2 and 14. In particular, the government must:
 - **guarantee the supplies of personal protective equipment.** It is unacceptable that there remain issues about access to PPE for staff and carers irrespective of whether the people they support live in care homes, in their own homes, or with their families.
 - **provide easily accessible coronavirus tests, with necessary protections to ensure full and informed consent**, for people living in and working in care homes, supported living, and hospital settings, and to those who work as carers. This must be consistently applied across the country and not be restricted on basis of age, ability, or capacity.
 - **protect people moving into and between care settings** by ensuring decisions about people moving into and out of care homes, especially people who are discharged from hospital, are clear and that they fully inform and involve the individual.

- **consider whether people will be safer in other settings.** For people who live in large homes or who are supported by a large team of staff, difficult decisions may be needed about whether it is safer and better for people to move. The risks of moving to the person's health and lifestyle and the risk of spreading the virus to others must be duly considered. The person's views must be sought, and their decisions and wellbeing must be paramount. Given that people who live in settings with a large number of people may be most at risk, as a long-term legacy of the pandemic, there should be a review of the use of large care settings, which increase people's risk of experiencing human rights breaches.
- **put plans in place to manage potential outbreaks and risks in large care settings.** Many older people and people with learning disabilities and autism live in large settings for in-patient mental health. Prevention of and response to potentially major outbreaks in these settings must be urgently planned for.
- **Recognise that the restrictions currently in place for many people present greater risk to their health and wellbeing than Covid-19 itself,** in that they are at risk of mental, physical, and emotional decline and distress through lack of contact with family and friends. This relates to Article 8. Thus, the government must
 - **Ensure that restrictions meaningfully take into account the differing needs of individuals who need more support,** particularly when they relate to safety and wellbeing and the risk of breaches to their human rights. For people living in care home or hospital settings, restrictions should be eased as far as possible and as soon as possible, to allow family contact and for the easier delivery of key statutory services, such as advocacy.
 - **Take steps to support people to access digital services** to have contact with family, friends, and social interaction. Ensure that supported living, care homes, and hospital settings have suitable devices and internet connectivity that allows for access of advocacy services where meeting in-person is not possible.
 - **Ensure the full dissemination and adoption of national guidance which states clearly that advocates are key workers** and thus, that access to clients should be facilitated by those managing supported living, care homes, and hospital settings, including in-person contact when this is appropriate.
- **Review what is in the best interests of people subject to deprivation of liberty,** with consideration of Article 5. In 2018-19 there were 150,000 applications to authorise a person living in a care or nursing home in England under the Deprivation of Liberty safeguards. Deprivation of liberty decisions must be made based on the person's best interests. Coronavirus shifts the balance of best interest, as many larger care settings may be more dangerous than people's own or their family's homes. This must be taken into account in decisions regarding deprivations of liberty.

Ensuring people's rights & vital advocacy (Articles 2; 3; 5; 8; 14)

The UN Office of the High Commissioner for Human Rights set out clear guidelines for responding to the coronavirus pandemic:

"People have a right to participate in decision-making that affects their lives. Being open and transparent, and involving those affected in decision-making is key to ensuring people participate in measures designed to protect their own health. [...] Physical distancing, self-isolation and other emergency measures, need to take account the needs of persons with disabilities who rely on support networks

essential for their survival and some of whom may experience significant stress with confinement. [...] When restrictions on movement impede existing family and social support networks, they should be replaced by other services. [...] [D]ecisions on the allocation of scarce resources (e.g. ventilators) [should] not [be] based on pre-existing impairments, high support needs, quality of life assessments, or medical bias against persons with disabilities."ⁱⁱⁱ

Advocacy services are crucial to ensuring that the above guidance can be acted on and that any conditions to which an individual is subject are in full compliance with human rights. Statutory rights to an advocate under the Mental Health Act 1983, Mental Capacity Act 2005 and Care Act 2014 are unchanged by the Coronavirus Act. Advocates are classified as keyworkers and advocates have a legal duty to meet with a client privately whenever this is reasonable (Mental Health Act) or practicable and appropriate (Care Act, Mental Capacity Act). It follows that service providers must facilitate this to the greatest extent possible.

Deprivation of Liberty Safeguards – DoLS (Article 5; 14)

Where care or treatment arrangements in a care home or hospital deprives a person of their liberty, and they lack the capacity to consent to those arrangements, a formal process is needed to ensure that their human right to liberty and security is protected, known as DoLS. The obligation of the State to ensure that an individual can challenge their deprivation of the liberty remains unchanged. In order to challenge their detention, many people will need the support of an advocate.

However, according to a July report by the Care Quality Commission, there has been almost a third (31%) and two-thirds (65%) drop in DoLS applications in adult social care and hospitals, respectively. Specifically, it states that “poor understanding of DoLS has remained a fundamental issue. This together with the delays and uncertainty over the progress of LPS may mean there is an increasing risk of people being deprived of their liberty without the proper authorisation.”^{iv} This presents a serious risk to human rights and suggests that people may have been deprived of their liberty without the appropriate process and safeguards in place.

Access to advocacy (Articles 2; 3; 5; 8; 14)

Access and the lack of access to advocacy continues to be a fundamental issue. Data gathered from a sample of advocacy providers across the country suggests that reported referrals for statutory advocacy were 32% lower in the three month period March-May 2020 than March-May 2019.^v This suggests that it is highly likely that people are not being referred for the advocacy to which they are entitled.

A lack of advocacy for some individuals presents a very serious risk to their human rights, health, and wellbeing. In many of these cases the balance of risk falls in favour of contact despite the coronavirus pandemic. Advocates have expressed concern about an increased risk to abuse of human rights because of the current restrictions and a lack of access to clients which raises very serious safeguarding concerns. From a survey of advocates undertaken during the pandemic, 75% of people thought that their clients human rights were not being fully upheld and almost half (49%) of advocates assessed that on balance people’s rights under the Human Rights Act had not been respected.^{vi}

Once referred, regardless of the setting, all practicable steps must be taken to ensure that a person is able to meet with their advocate. However, there are significant challenges particularly in relation to the switch to digital and telephone communication. Internet access is not universal, internet enabled devices are not always available, and a person may need additional support to use digital communication tools. For some individuals remote contact will not ensure the privacy and confidentiality required and a face-to-face visit is the only practicable option to ensure their rights.

The lack of access to or difficulty in using digital communications has a disproportionate impact on those in residential care, hospital, and supported living settings, who have learning disabilities, autism, or dementia and thus in some cases may relate to breaches of Articles 8 and 14, in that there is a discriminatory impact on those groups and they are prevented from having their rights to family life and privacy upheld.

The latest guidance of 22 July 2020 eases restrictions on visits to care homes, however, people living in care homes continue to face significant restrictions in relation in-person visits. As decisions will be taken by individual providers, the guidance risks being open to a range of interpretation.^{vii} Additionally, guidance on the wearing of masks at all times, may disproportionately impact hearing impaired individuals who use lip-reading to communicate and this is not recognised in the guidance.

The situation for people in supported living is confusing and the government has not made clear guidance available. Providers do not know if they should be using PPE, whether regular testing of staff should be in place, or how to balance the risks of visits from family and friends with the impact that isolation may have on an individual's ability to maintain independent living. The latest guidance on visits to care homes of 22 July 2020 referred to guidance being "in development" for supported living settings.^{viii} This guidance has been in development for a number of months. At the time of writing, Rook Irwin Sweeney LLP are acting on behalf of a 24 year-old man who lives in supported living accommodation and have outlined a proposed claim for Judicial Review of the lack of guidance in such cases, arguing that it is "irrational, discriminatory, and result in a breach of [...] human rights."^{ix}

Health inequalities, excess deaths, and discrimination (Articles 2; 14)

The Inquiry must critically reflect upon the excess deaths and the disproportionate impact on people living in care homes, people with disabilities and learning disabilities, people with autism, and Black people and people from an ethnic minority background. The government must show leadership to address structural inequalities and discrimination that have led to the avoidable deaths of people who already experience significant health inequalities.

There were at least 20,457 excess deaths in care homes between 20 March and 7 May 2020.^x Whilst many may not be confirmed Covid-19 deaths because these occurred prior to testing at-scale, it is reasonable to assume that the majority of these excess deaths are due to Covid-19. Disproportionate deaths have also been linked to disability. A study by the Office of National Statistics shows that males aged nine to 64 years-old whose activities were "limited a lot in 2011" had a rate of death involving Covid-19 over six times higher than people without a disability, and for females it was 11.3 times greater.^{xi}

While statistical uncertainties remain, much of the data does not take account of the indirect impact of Covid-19 on mortality rates for people who already experience poor health outcomes due to inequality and discrimination. People with learning disabilities die, on average, about two decades younger than the general population. According to the latest report from the NHS LeDeR Programme, people with learning difficulties are twice as likely to die an avoidable death.^{xii}

Deaths from Covid-19 of Black people and people of South-Asian ethnicity have been disproportionately high. Whilst statistics that fully reflect the intersection of ethnicity, disability, and many other health conditions, with deaths from Covid-19 are not available we already know that Black people and people from an ethnic minority face discrimination across society. As is reflected upon by Public Health England, "[i]t is clear from discussions with stakeholders that COVID-19 in their view did not create health inequalities, but rather the pandemic exposed and exacerbated longstanding inequalities affecting BAME groups in the UK."^{xiii}

The widespread reporting of blanket Do Not Attempt CPR (DNA-CPR) notices exposes the discrimination which many experience; older people and people with disabilities do not receive the same standards of care as younger people or people without disabilities. Blanket decisions must always be made individually. This is a legal requirement which has been highlighted by all relevant national organisations.^{xiv} Blanket decisions breach Articles 2 and 14 in that these decisions are not taken with full respect for an individual's life and that discrimination on basis of age, ability, and capacity, are at the forefront of these actions.

Care Act easements (Articles 3; 5; 8; 14)

The Coronavirus Act and accompanying guidance on Care Act easements allow a local authority to trigger easements to the Care Act. Government guidance is clear that local authorities should only trigger easements if it is essential that they do so. The government's stated expectation is that even after triggering the easements, local authorities will do everything that they can reasonably do to continue to meet need as they would under the Care Act.

However, there have been reports of people left in conditions which may amount to breaches of human rights, due to Care Act easements or alleged de-facto, unlawful easements. Individuals have been left without vital care support that has a severe impact on their health and wellbeing.^{xv} It is thus essential that advocates can support clients to ensure that the local authority fully uses its powers to provide necessary support.

Conclusion

Serious concerns are raised in this submission alongside proposals for concrete action to address them. The common thread of discrimination that runs through this submission makes clear that inaction tackling inequalities and discrimination risks people's human rights.

Advocacy plays a vital role in tackling the many issues highlighted in this submission and we would encourage the Inquiry to recognise the importance of advocacy in supporting people to be listened to, meaningfully involved in decisions that affect them, and to ensure their human rights are respected and upheld.

We conclude by thanking the Committee members for their work on this Inquiry.

22/07/2020

ⁱ For more information about VoiceAbility, visit <https://www.voiceability.org>

ⁱⁱ As taken from European Convention of Human Rights and the Human Rights Act 1998

ⁱⁱⁱ United Nations Office for the High Commissioner of Human Rights, 'Covid-19 Guidance', <https://www.ohchr.org/EN/NewsEvents/Pages/COVID19Guidance.aspx>, accessed 14 July 2020

^{iv} Care Quality Commission, 'Covid-19 Insight', Issue 3, July 2020,

<https://www.cqc.org.uk/sites/default/files/20200715%20COVID%20IV%20Insight%20number%203%20slides%20final.pdf>

^v This is based on data gathered from advocacy services working across 33 Local Authorities, with a total of 7402 referrals received across period in 2019 compared to 5036 received in 2020. The data has been gathered from a number of advocacy providers as part of a cross-sector collaboration to address issues arising as a result of the Covid-19 pandemic.

^{vi} This data is from a survey carried out by NDTi together with a group of organisations, including VoiceAbility, who are working together to lead advocacy through the Covid-19 pandemic. A fuller analysis of the findings of the survey will be published in due course, and this can be made available to Committee members.

^{vii} Department of Health & Social Care, UK government, 'Guidance: Update on policies for visiting arrangements in care homes', published 22 July 2020

^{viii} Ibid.

^{ix} Rook Irwin Sweeney LLP, 'Challenge to lack of COVID-19 guidance for people in supported living'

<https://rookirwinsweeney.co.uk/challenge-to-lack-of-covid-19-guidance-for-people-in-supported-living>, accessed 17 July 2020

^x Public Health England, *Disparities in the risk and outcomes of COVID-19*, June 2020

^{xi} Office for National Statistics, *Coronavirus (COVID-19) related deaths by disability status, England and Wales: 2 March to 15 May 2020*, published 19 June 2020

^{xii} University of Bristol, LeDeR Programme Annual Report 2019, June 2020

^{xiii} Public Health England, *Beyond the data: Understanding the impact of COVID-19 on BAME groups*, June 2020

^{xiv} NHS England, Royal College of GPs, BMA, CQC and NICE have reiterated that blanket decisions are unacceptable.

^{xv} As reported: *The Guardian*, 'A phone call can't make tea: how UK's lack of social care is hitting disabled people in lockdown', 30 June 2020 <https://www.theguardian.com/society/2020/jun/30/a-phone-call-cant-make-tea-how-uks-lack-of-social-care-is-hitting-disabled-people-in-lockdown>; *The Guardian*, 'Stop using coronavirus powers to neglect care duties, UK councils told', 7 May 2020, <https://www.theguardian.com/society/2020/may/07/stop-using-coronavirus-powers-to-neglect-care-duties-uk-councils-told>