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Executive Summary

People who face discrimination are at the sharp end of inequality and poverty. The Covid-19 (coronavirus) pandemic has brought existing inequalities into stark relief. Those of us who are most negatively affected by inequality have also been most negatively affected by the pandemic.

Across health and social care, people came together to respond to the pandemic and to continue to support people as much as possible, despite restrictions and despite the wholly unprecedented nature of the situation we all faced. Advocacy was no different. A core tenet of advocacy is to redress inequality so that people's rights are upheld and they are respected as individuals who are listened to and understood irrespective of who they are or any health condition or diagnosis they may have. Advocacy has a vital role to play in improving people's health and wellbeing that must not be overlooked.

This report brings together findings from a survey of 435 advocates working across England and Wales that was carried out in June 2020. Advocates shared urgent concerns which reflect not only the restrictions that the pandemic brought but also the wider attitudes towards people who have additional support needs.

There are widespread and profound concerns about the impact of the pandemic on the human rights of people who use health and social care services. Responses indicated frequent failures to provide people with the support which they are legally entitled

to, and weaknesses in the safeguards needed to prevent and address these increased risks of abuse and harm.

What did we find?

Advocates worked together across the sector to respond to the needs of the people they support in the context of an exceptionally unusual situation. The right to advocacy remained unchanged by the Coronavirus Act and restrictions enacted by government. For some people, this meant good support continued but for others the restrictions meant they could not get the support they needed, when they needed it.

People's needs were not being met or assessed and people's statutory and human rights continue to be at risk, despite legal obligations on local authorities being broadly unchanged. Three quarters (76%) of advocates felt the human rights of the people they support were not being fully upheld.

There is a consistent failure to implement the Mental Capacity Act which means people who are unable to make decisions are not being listened to and their interests are being ignored. Nearly a third (31%) of advocates had seen Do Not Attempt Cardio Pulmonary Resuscitation orders (DNACPRs) being placed on the people they support without regard to the person's feelings, wishes, values or beliefs, and without formal capacity assessments or consultation with family. One in five reported that people were being blanketly denied healthcare.

Blanket decisions about access to treatment and visitors are being taken without clear justification, including enforced confinement, denying access to outdoor space or gardens, and preventing leave for people who are on mental health wards. Half of advocates reported care providers had stopped all visits and almost half (47%) reported that people were being confined to their rooms.

People are at greater risk of abuse, self-harm, and suicide because of the impact of the restrictions and the removal of essential services. Rights to advocacy have remained unchanged and advocacy organisations have worked together to maintain services during the pandemic. However, over a quarter of advocates experienced a care provider trying to prevent access to advocacy. Advocates also highlighted a lack of care planning, discharge planning, and support.

People with the greatest needs are hardest hit by changes made in response to coronavirus. People who do not communicate verbally or who have cognitive impairments are being increasingly left out by the shift to digital communication. While some people find digital communication can be as effective as meeting in person, for many others, it is not comparable and means they are not getting the support they need which risks further entrenching health inequalities.

What next?

The survey findings demand a rethink of our approach to health and social care and make it clear that the time to act is now. In concluding, the report sets out concrete recommendations for government, health and social care providers and local authorities. As we face a second wave of the pandemic, lessons must be learnt to avoid a repetition of some of the worst impact. We must improve our public health strategy in response to

second or third waves. In the medium- and long-term, we must develop, embed, and properly resource programmes that address health and social care inequalities.

Integral to this is not just a system change but a culture change. There must be a reinvigorated focus on human rights that recognises individual choice and control. We must make sure those responsible for planning, commissioning and providing health and social care support comply with the Care Act and Mental Capacity Act. The 2018 independent review of the Mental Health Act emphasises that people should have greater choice and autonomy, and people should be seen and treated as individuals. Importantly, the independent review recognises the role of advocacy in achieving this. Those recommendations must be enacted through parliamentary legislation as a priority.

It must be an urgent priority to reinforce rights and improve support for people who rely on social care. Addressing health and social care funding is necessary but not sufficient alone. There needs to be a new political and public consensus so that we are all supported to live full lives in our communities. We have an opportunity to overhaul our health and social care systems so that there is an inclusive vision to support people beyond the coronavirus pandemic.

Methodology

In June 2020, organisations with expertise in independent advocacy worked alongside the National Development Team for Inclusion (NDTi) to carry out a survey of advocates and gather evidence of the impact of the Covid-19 (coronavirus) pandemic.

The survey collected evidence on the accessibility and quality of advocacy and the pandemic's impact on people who are entitled to advocacy. The survey also looked at the present challenges and what was working well in response to the pandemic and the restrictions in place.

Figure 2: Responding advocates location(s) of work (multiple choice) ¹.

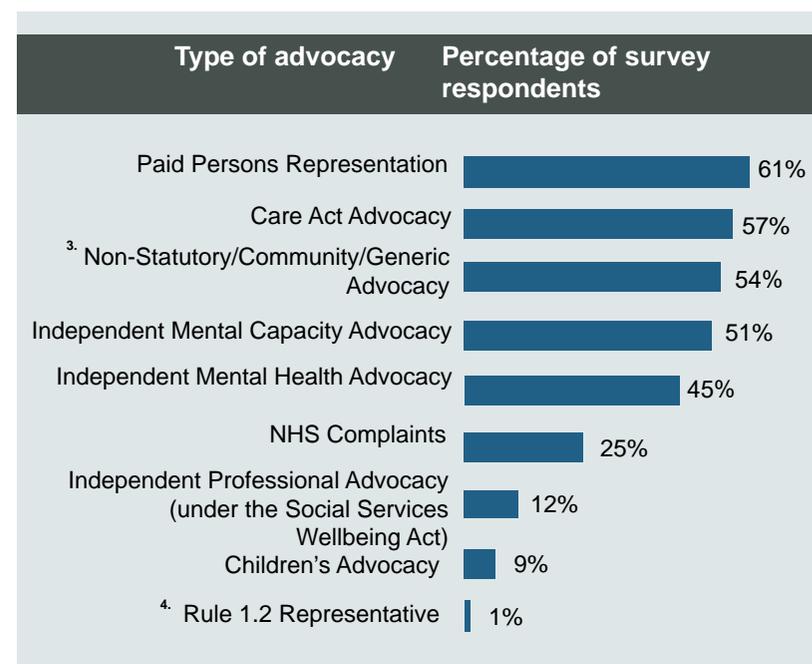


1. 453 advocates participated in the survey. Some advocates work across multiple regions and therefore will have selected more than one region.

2. Statutory advocacy is provided in England under the Mental Health Act, the Mental Capacity Act, and the Care Act and in Wales under the Mental Health (Wales) Measure, Mental Capacity Act, and the Social Services and Wellbeing (Wales) Act. There is also some statutory requirement for advocacy under the Children Act. For some of these Acts the legislation and guidance differs between England and Wales.

In total, 435 advocates completed the survey from across different regions of England and Wales with a breadth of advocacy experience, often across multiple areas of statutory and non-statutory advocacy.²

Figure 1: Type of advocacy practiced by respondents (many advocates are qualified and practice multiple advocacy types)



3. Non-statutory advocacy included family and parental advocacy, victims of crime/hate crime advocacy, litigation friend, veterans and carers advocacy.

4. A Rule 1.2 Representative is an independent representative of a person who has been assessed to lack capacity to consent to their care and support arrangements.

Introduction

People who face discrimination are at the sharp end of inequality and poverty. While the NHS Long Term Plan sets out to improve the health and wellbeing of those who are most negatively affected by inequality, the coronavirus pandemic has brought these inequalities into stark relief and made many of them worse.

It is increasingly evident that there has been avoidable loss of life. Many people have experienced dreadful conditions, in part due to a falling away of measures designed to protect people's rights and wellbeing, despite tremendous efforts of people working in health and social care. Overwhelmingly, people who already found it harder to have their voices heard have suffered greatest in the pandemic.

Advocacy has a vital role to play in improving people's health and wellbeing. A core tenet of advocacy is to redress inequality so that people's rights are upheld and they are respected as individuals who are listened to and understood irrespective of who they are or any health condition or diagnosis they may have.

Advocates have a unique and crucial perspective with independent expertise through their work with some of the people who are most excluded and overlooked by society and supporting people to assert their rights.

This report offers insight into the challenges people face having their rights upheld and being listened to during the pandemic. These challenges are not always new but have been exacerbated by the restrictions in response to the coronavirus pandemic. This report sets out key findings from the survey, provides context for these findings and makes pressing recommendations for national government, local authorities, and health and social care providers.



Rights breached and non-compliance

Human rights failures

People's statutory entitlements and respect for their human rights are at risk. The public health response has seen vital health and social care services stripped back, non-compliance with legal duties, severe ongoing restrictions on people's liberty and private and family life which for many people represent a threat to their human rights. Over three quarters (76%) of advocates reported that people's human rights were not being fully upheld during the pandemic.



Safeguarding risks

Advocates raised concrete examples of individuals whose safeguarding risks had increased, in part because of the limitations placed upon them. These concerns included increased risk of suicide, suicidal thoughts, and atypical behaviours. Some of these cases were linked to a wider restriction on care and support that left people in very difficult situations. Reduced access to advocacy, the limitations of

remote communication tools, and the lack of privacy during advocacy meetings made it harder for advocates to play their role in safeguarding people from harm and abuse.

After the care home had closed the common areas, and asked residents to self-isolate in their rooms, she began to be agitated and shouted at staff and slammed doors. She then told staff she wished she was dead and threatened to kill herself [...]. [This was completely out of character for her.]

From our own data analysis, we found a 45% reduction in safeguarding alerts raised by advocacy services during March to May 2020 compared to the same period last year.⁵ Visits by family, friends, and CQC inspectors were stopped, which meant the safeguarding role these people often play was also taken away. Without people from outside their living environment visiting, the mechanisms people might use to report concerns are removed and it is much harder for them to communicate any issues of abuse or neglect. In particular, this adversely affects those who need additional support to communicate, lack capacity, or use non-verbal communication and rely on others to raise concerns on their behalf.



5. This is based on data gathered from advocacy services working across 11 local authorities. The number of safeguarding alerts advocacy services raised during the period March – May 2020 was 45% lower than the previous year.

Services were unable to carry out usual checks and contact because of restrictions and the client is under coercive control so unable to seek privacy.

Suicide was not the only risk highlighted by advocates. Many noted concerns about increased risk of domestic violence, including examples of people being isolated with an abuser, and increased risk of people with learning disabilities who live alone being subject to abuse or coercive control because of a reduction in contact and wider support.

Advocates also raised concerns about increased risk of neglect, including in care homes and supported living, particularly due to staff shortages or a scaling back of support for people due to the pandemic.

Blanket decisions

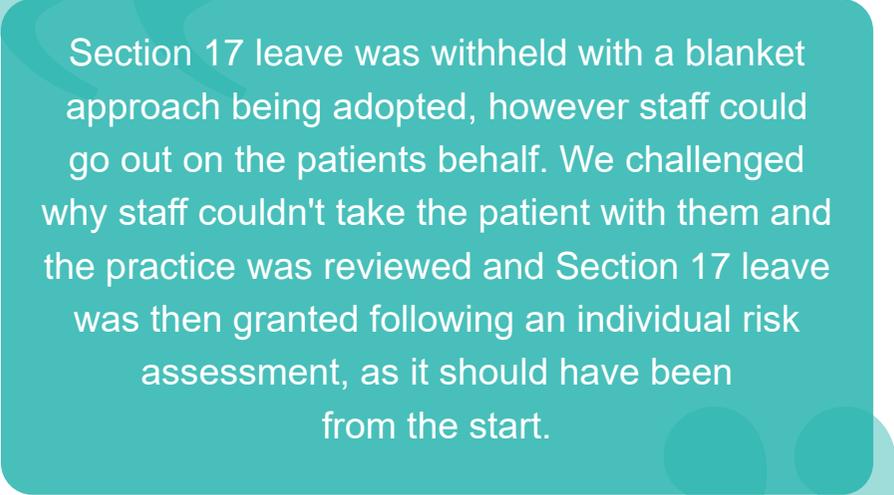
Advocates provided detailed examples of how people's rights had not been upheld. Many examples referred to blanket decisions, including those related to healthcare and Do Not Attempt CPR orders (DNACPR), which are now subject to a review by the Care Quality Commission. Almost a third of advocates reported blanket decisions of DNACPRs and one in five said they were aware of blanket restrictions around hospital admission and withholding of treatment.

Blanket decisions did not just relate to medical care. They also led to restrictions on visits and access. 47% of advocates reported people being confined to their rooms under blanket decisions.



Residents in care homes have been locked in their rooms and not allowed out into secure grounds despite no cases in the home.

27% of advocates reported blanket decisions stopping Section 17 leave under the Mental Health Act.⁶ However, there is also evidence that when appropriately challenged, these decisions were changed, underscoring the important role advocacy plays as a check and balance on mental health wards, enabling rights and compliance with legislation.



Section 17 leave was withheld with a blanket approach being adopted, however staff could go out on the patients behalf. We challenged why staff couldn't take the patient with them and the practice was reviewed and Section 17 leave was then granted following an individual risk assessment, as it should have been from the start.

6. When detained under the Mental Health Act, a person may be able to leave the hospital if authorised by the clinician in charge of their care. This leave is often referred to as Section 17 leave.

Reduced referrals

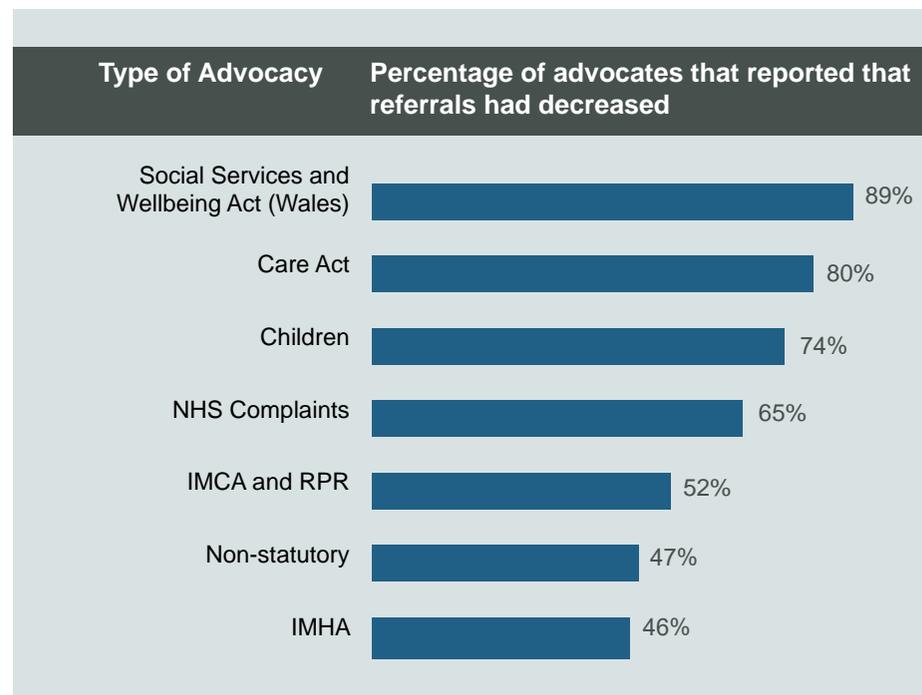
From the survey and our additional research across 33 local authorities, we found that advocacy referral rates have dropped across nearly all advocacy types by a third. Overall, reported referrals for statutory advocacy were 32% lower in the three-month period March to May 2020 than March to May 2019.⁷ Recognising the drop in referrals, advocacy organisations worked hard to facilitate access to advocacy and encourage referrals developing an ‘Advocacy Mythbuster’⁸ and increasing awareness that advocacy services were continuing and people could still get support.

While more advocates reported a decrease in referrals for non-statutory advocacy than for statutory, there was still a perceived significant drop in referral numbers across all statutory advocacy. This was particularly pronounced in relation to the Social Services and Wellbeing Act (Wales) where 89% of advocates said there had been fewer referrals, under the Care Act where 80% of advocates reported that referrals had decreased and Children’s Advocacy where 74% said they had seen a decrease in referrals.

7. This is based on data gathered from advocacy services working across 33 local authorities. (7402 referrals received in 2019 compared to 5036 received in 2020). Reductions were seen in every type of statutory advocacy. An increase was seen to the number of reported paid RPR instructions - this saw an increase in 9% in the same period.

8. Advocacy Mythbuster: <https://qualityadvocacy.org.uk/wp-content/uploads/2020/04/Coronavirus-Advocacy-Mythbuster.pdf>

Figure 3: Percentage of advocates reporting a decrease in referrals by advocacy type



Under the Care Act, Mental Capacity Act, Social Services and Wellbeing Act (Wales), and Mental Health Act, people have the right to an advocate and this remained unchanged by the emergency powers in the Coronavirus Act. Advocates raised cases of individuals who had not been referred for their entitled advocacy or had not been able to access advocacy support, some of which represent non-compliance with legislation. One advocate shared that “[i]nitially it felt as though a suspension of the Mental Capacity [Act] had happened. It felt as though people's rights were not being upheld, people not being consulted with, few referrals.”

Many advocates reported frontline local authority workers behaving as if rights to advocacy had been suspended and



We have had a reduction in the number of Care Act advocacy referrals. The council has not used easements, so you would expect the number of referrals to remain consistent.

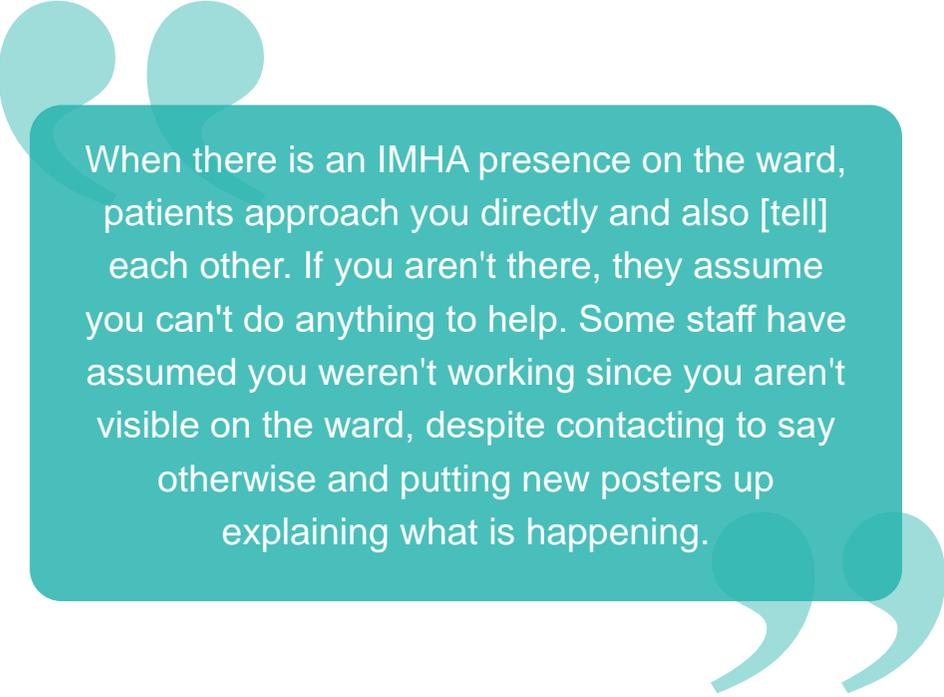
even being told “we don’t have to refer anymore because of the easements.” The drop in referral rates is a pressing concern and does not tally with any evidence to suggest there was parallel drop in the need for advocacy. This paints a stark picture that people are being detained under the Mental Health Act, moved in and out of hospitals and care homes, and having decisions made about their capacity and understanding without their rights being fulfilled, representing not just a breach in statutory duties but also a potential violation of human rights.

Advocacy awareness

Many people find out about their rights to advocacy through word of mouth, seeing an advocate on a ward, or by spotting information on posters in hospitals, care homes, and other community places. When asked about the reasons for a reduction in referrals, one in five (20%) advocates responded that it was in part due to a lack of understanding of advocacy statutory duties, and that for a period of time advocacy has become less visible during the pandemic.

Most people in mental health hospitals have a right to advocacy. An advocate’s presence on the ward is vital to make people aware of that right. Unlike under the Care Act or Mental Capacity Act where there is an obligation that an advocate is provided, in England under the Mental Health Act this is an opt-in right, meaning people are not provided advocacy by default. Because advocates were prevented from spending time on mental health wards as they normally would, people were not able to see advocates working and were not prompted to ask about advocacy for themselves.⁹ This is particularly problematic where the person lacks capacity to request an advocate and results in advocacy being less available for this group who arguably need it the most.

9. For Wales, under the Mental Health Measure (Wales), advocacy is opt-out for those eligible.



When there is an IMHA presence on the ward, patients approach you directly and also [tell] each other. If you aren't there, they assume you can't do anything to help. Some staff have assumed you weren't working since you aren't visible on the ward, despite contacting to say otherwise and putting new posters up explaining what is happening.

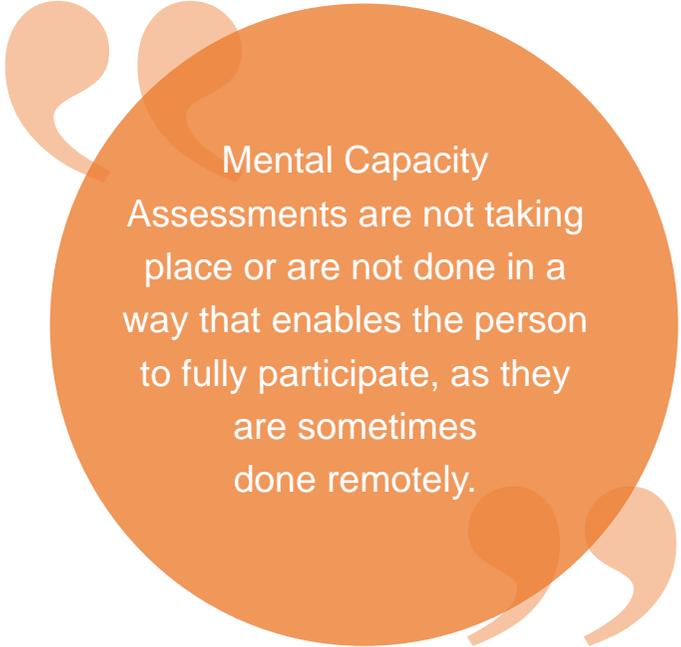
While the Mental Health Act Review led by Sir Simon Wessely recommends that advocacy becomes opt-out in England, we are still waiting for the government to publish its response to the review and move forward with this vital reform. In the meantime, as we respond to a second wave of the pandemic, we need people to know about their right to advocacy and take steps to make sure that people get the support they need. Advocacy organisations have outlined what they will do to increase awareness in *Upholding Rights and Valuing Voices: Advocacy principles for coronavirus and beyond*¹⁰. Increased awareness of advocacy and statutory duties is vital to ensure people's rights during and after the pandemic.

10. *Valuing voices and respecting rights: Advocacy principles for coronavirus and beyond*, published 14 September 2020 and endorsed by 20 organisations at time of writing. <https://www.voiceability.org/news/upholding-rights-and-valuing-voices-advocacy-principles-for-coronavirus-and-beyond>

Understanding the Mental Capacity Act and Care Act

A lack of understanding of people's rights under the Mental Capacity Act (MCA) is a common thread through many responses. Advocates reported serious concerns that people who do not have capacity were not being appropriately assessed. Best interest meetings and decisions were not being taken in line with the MCA. Further, some reported "restraint used unlawfully" and people being "threatened with restraint" when distressed or not wanting to be tested for coronavirus.

Concerns were shared by advocates that MCA assessments were rushed, incorrectly completed, or overlooked, suggesting that people's rights were being breached. A lack of understanding of the MCA by hospital and care staff is a consistent challenge and more must be done to address this knowledge gap.

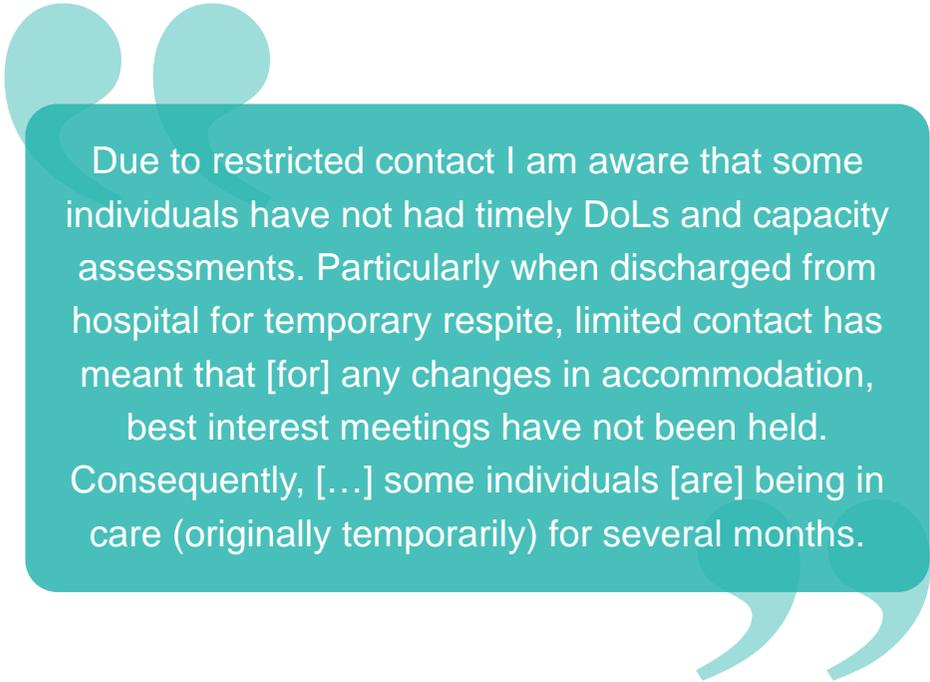


Mental Capacity Assessments are not taking place or are not done in a way that enables the person to fully participate, as they are sometimes done remotely.



Care Act Assessments [have been] delayed or option to assess [was] not offered due to Covid but without easements in place.

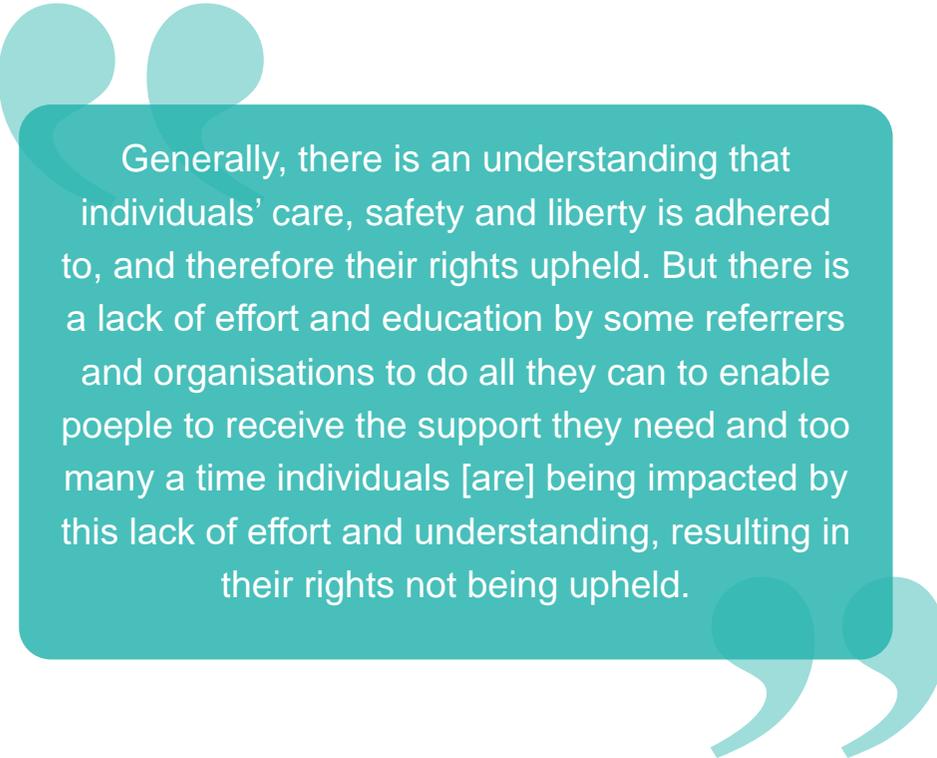
Alongside non-compliance with the Mental Capacity Act, advocates raised concerns that adherence to the Care Act had been reduced without easements being formally triggered. The Coronavirus Act and accompanying guidance on Care Act easements allow a local authority to trigger easements to the Care Act. Government guidance is clear that local authorities should only trigger easements if it is essential and under very specific circumstances and for a limited period. Further, the government's stated expectation is that even after triggering the easements, local authorities must do everything they reasonably can to continue to meet needs as they would under the Care Act.



Due to restricted contact I am aware that some individuals have not had timely DoLs and capacity assessments. Particularly when discharged from hospital for temporary respite, limited contact has meant that [for] any changes in accommodation, best interest meetings have not been held. Consequently, [...] some individuals [are] being in care (originally temporarily) for several months.

Many advocates reported local authority workers behaving as if rights to advocacy had been suspended and even being told 'we don't have to refer anymore because of the easements' when easements were not in place. 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'. This meant people were not getting assessed as they were entitled to or supported as they should be and for some people this has had a severe impact on their health, wellbeing and safety. ¹¹.

11. 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>



Generally, there is an understanding that individuals' care, safety and liberty is adhered to, and therefore their rights upheld. But there is a lack of effort and education by some referrers and organisations to do all they can to enable people to receive the support they need and too many a time individuals [are] being impacted by this lack of effort and understanding, resulting in their rights not being upheld.

Unlawful deprivation of liberty

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 make sure their rights are protected, known as Deprivation of Liberty Safeguards (DoLS). A person's right to challenge their deprivation of liberty remains unchanged and many people will need the support of an advocate to do this.

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."¹² This presents a serious risk to human rights.

Locked in, while locked down

The pandemic has resulted in rapid changes to the lives of people who rely on social care and health services and the emergence of new issues, risks, and concerns. It has increased the need for people to receive the independent skilled support that advocacy provides. There has been a lack of care and discharge planning, and reduced access to healthcare and support. This is particularly an issue for older people. There are examples of people being denied choice when discharged from hospital or forced into a care home against their and their family's wishes.



Person [was] not discharged to chosen accommodation due to lack of care package, discharged to family member who restricted person's access to advocate and to other family members.

12. 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>



Several people have had marked deterioration in their mental health leading to self-harm because usual activities and sources of support not available.

The wider scaling back or wholesale withdrawal of non-statutory support has had a very serious impact on some individuals. Advocates shared examples of how people have felt overlooked and left out on a limb because of a lack of support. For some people this has had knock-on effects on their ability to communicate and keep themselves safe, and on their mental health. In community and residential settings advocates have also seen people lose out on the support which enabled them to go out and do the same things other people were permitted to do during and after the peak of the restrictions such as shopping and exercising.

Nearly half of advocates supported people who have been confined to their rooms in care homes or residential settings. People in care homes have been subject to much greater restrictions to their movement, that in some cases might amount to a deprivation of liberty.

When asked about coronavirus-related safeguarding risks, advocates mentioned the impact of social isolation and loneliness on people's mental health and wellbeing. Many people had very limited or no contact with friends or family for many months, due to a lack of access to technology or being unable to use technology. For many people, a face-to-face visit is the only way to support them. As the pandemic continues, endemic loneliness and isolation must not be its legacy. For further waves, we must establish ways to make sure people are not isolated and do not experience overly harsh and overreaching restrictions to their liberty.



We have raised a safeguarding alert for all of the people living in a supported living service, as they were being locked in the house and unable to go out for any reason, including exercise or shopping.

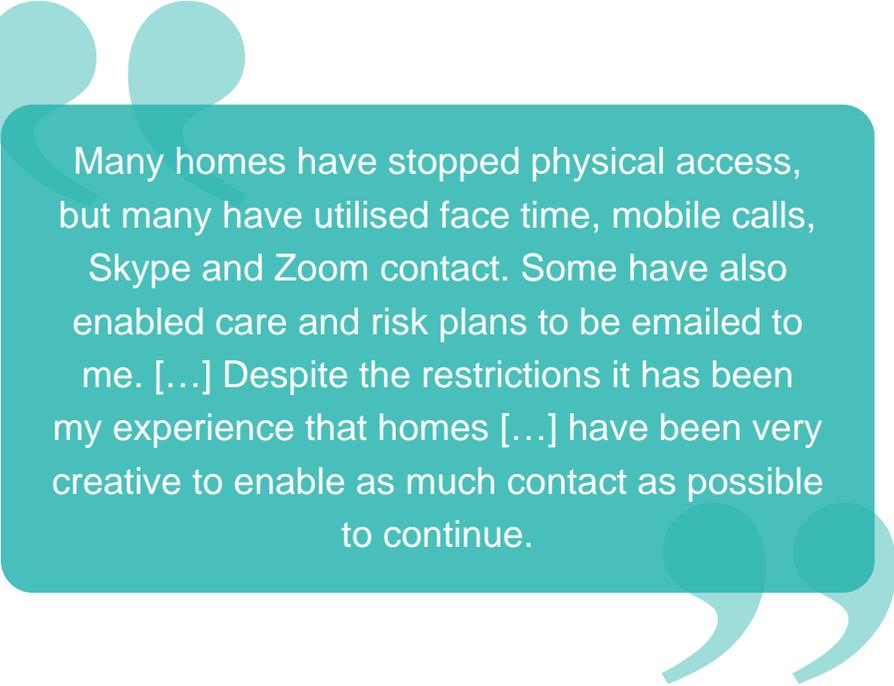
Delivering advocacy during the Coronavirus pandemic

Despite the restrictions, advocates made use of digital communication tools and other methods to continue to support people. As a result of these efforts, 76% of advocates reported they felt that the advocacy support they provided was somewhat effective. However, only 12% of advocates reported they were able to deliver fully effective advocacy support during the pandemic. Over half reported their level of effectiveness working remotely makes them feel 'dissatisfied' or 'very dissatisfied'. This is a warning sign that people may not be getting the quality of advocacy support they need despite many advocates' best efforts and therefore people's statutory rights may not be fulfilled.

Meeting with people

Similar to other health, social care, and voluntary services, in March 2020 the way advocacy was delivered had to shift dramatically almost overnight. Through creativity on the part of advocates, flexibility of people who use advocacy services, and practical assistance of staff and unpaid carers who support them, advocacy has continued. Meetings between people and their advocates have taken place, in line with government guidance on social distancing, by using digital communication tools as an alternative to in-person meetings and using face coverings and personal protective equipment (PPE) when meeting in person.

Access to places where people live or stay has been highly restricted. Only 7% of advocates reported being able to fully access the places where people live or stay and as a result said



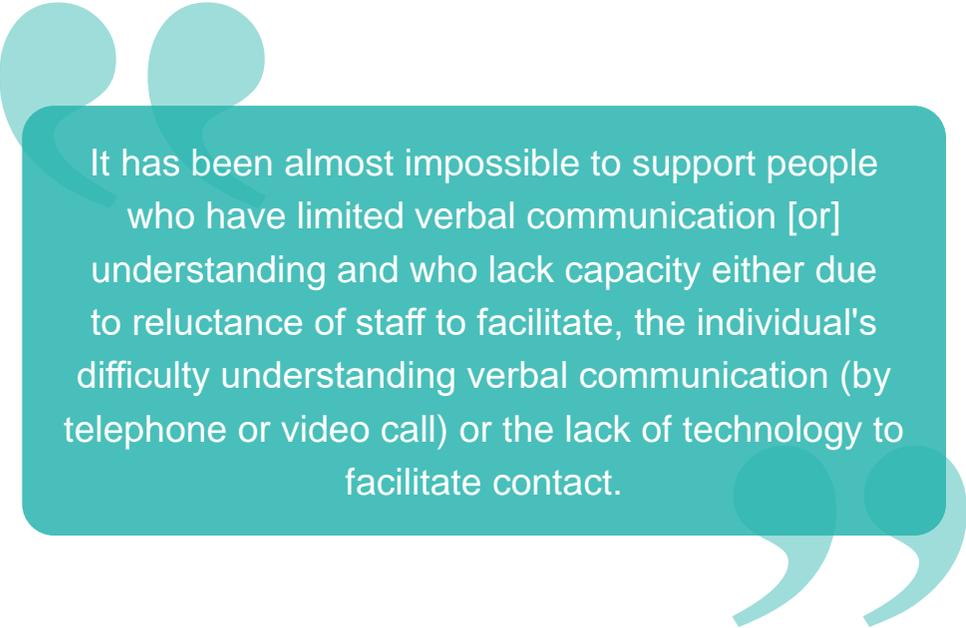
Many homes have stopped physical access, but many have utilised face time, mobile calls, Skype and Zoom contact. Some have also enabled care and risk plans to be emailed to me. [...] Despite the restrictions it has been my experience that homes [...] have been very creative to enable as much contact as possible to continue.

their ability to communicate with people has been negatively affected. The findings were consistent across different settings suggesting widespread and blanket restrictions negatively affected people's access to the advocacy they are entitled to. Nearly half of advocates (48%) reported not being able to meet with their clients at all. Over a quarter of advocates had experienced a care provider (including hospitals) trying to prevent access to advocacy in all forms, despite rights to advocacy remaining unchanged.

Advocacy organisations made concerted efforts to facilitate access to advocacy safely, including in-person. Advocates continued to meet with people during the first wave of the pandemic and after the first wave, advocates further increased in-person visits. In our response to the second wave, we must not go backwards from the lessons learned and the progress made. In-person visits remain essential for many people and we must establish ways of working that mean people can get the support they need. Advocacy organisations are responding by making sure risk assessments are robust and that they follow infection control protocols so they can continue to make visits. Advocates are key workers: their ability to carry out their role must not be hindered.

Communication at the heart of advocacy

Effective communication is at the heart of advocacy. Many advocates support people who need additional support to communicate or who use non-verbal communication techniques

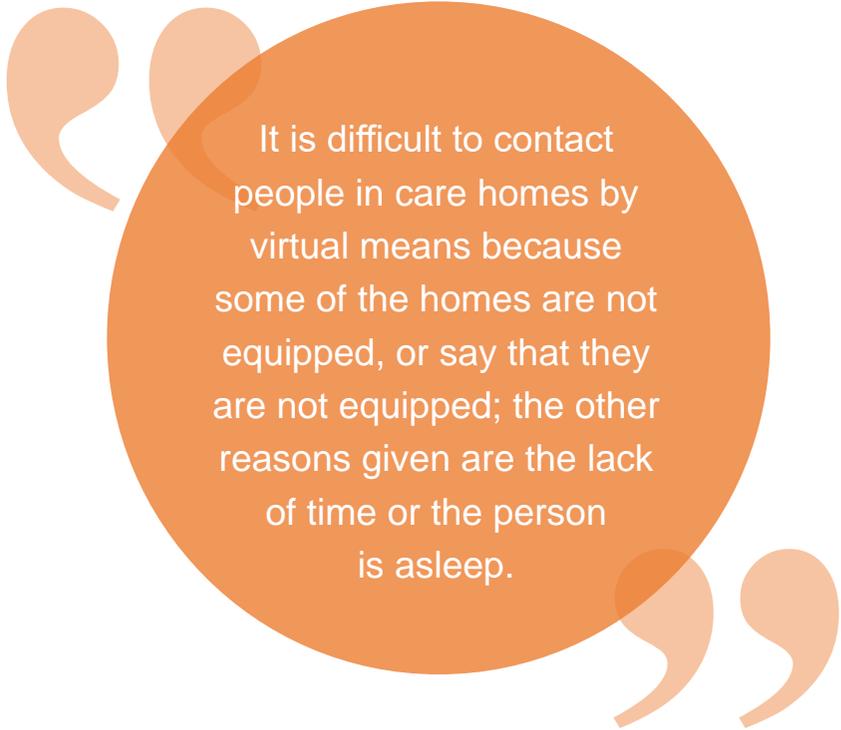


It has been almost impossible to support people who have limited verbal communication [or] understanding and who lack capacity either due to reluctance of staff to facilitate, the individual's difficulty understanding verbal communication (by telephone or video call) or the lack of technology to facilitate contact.

to make themselves understood. Advocates shared insight into the challenges of communicating with people remotely and not being able to read a person's non-verbal cues.

Practical concerns

Once referred, regardless of the setting, all practical steps should be taken to ensure that a person is able to meet with an 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. This has been further compounded by having to rely on busy care staff to act as mediators for communication which is not always effective. People with a wide range of needs cannot be adequately served by remote working alone.



It is difficult to contact people in care homes by virtual means because some of the homes are not equipped, or say that they are not equipped; the other reasons given are the lack of time or the person is asleep.

Impact on people who need additional support to communicate

When asked about who it was harder to support through the pandemic, advocates explained that the lack of access or difficulty in using digital communications has a disproportionate impact on those in residential care, hospital, and supported living settings, and on people who have learning disabilities, autism, or dementia. This may, in turn, have a discriminatory impact on these groups.

Advocates particularly drew attention to people with dementia and learning disabilities who struggled to communicate or understand how to communicate via telephone or video calls. It was also reported that it was more difficult to support some people with mental health conditions and for advocates to pick up on non-verbal cues such as a person's "body language and micro-expressions to facilitate further conversation."

Whilst contact by videoconference, telephone, or email enables effective support to some people, in some circumstances, this is often not the case. Restrictions on in-person meetings disproportionately affect people who most benefit from advocacy, including people with the most complex needs and who experience the greatest communication barriers.

Privacy and confidentiality

Advocates raised that it was difficult to support people who do not have privacy. While some places recognised the requirement for privacy and the need to facilitate a person's access to advocacy, others were more restrictive in their practices.

Together with effective communication, confidentiality and privacy are crucial to deliver person-centred advocacy. Privacy ensures an advocate understands a person's genuine views and allows them to express themselves fully and independently. In many contexts, privacy is a statutory requirement for advocacy. It is more difficult for an advocate to establish clearly what is happening to a person and to ensure privacy through remote tools. Advocates also highlighted not being able to communicate with people who they suspect may be subject to abuse at home which brings to the fore serious concerns about safeguarding.



One RPR client requested to speak to me in private, so the care staff did leave the i-Pad in the client's room and stepped outside. Some homes have been very cooperative with allowing and enabling access to speak to my clients via the phone or video call but some have made it difficult and don't appear to understand that the person is entitled to independent advocacy.

Services are unable to carry out the usual checks and contact because of restrictions and the client is under coercive control so unable to seek privacy.

Issues when trying to gain communication with some children is that the conversations are not private, phone calls are put on loud speaker, children are being influenced by others in the room.

Personal Protection Equipment

In the early weeks of the pandemic, the approach to PPE was inconsistent, partly reflecting the inconsistent guidance and supply challenges across the country. Less than half of advocates (44%) reported to have access to Personal Protective Equipment (PPE). 64% of advocates had not had training in using PPE at the time of the survey, while just over a quarter had received training. Half of advocates (52%) felt they had the knowledge and skills to use PPE effectively. This situation has changed since June and we are not receiving reports that availability of PPE is a major issue in relation to providing advocacy.

Developing consistency

In response to a need for consistent guidelines and reports of restrictive practices and access issues, advocacy organisations have defined their own clear guidance that allowed them to continue their essential duties as keyworkers.¹³ The law makes clear that advocacy must continue and the government have also emphasised that such essential health and social care support for people must not be stopped. As we look to deliver advocacy through second and potential third waves, advocacy organisations are now well placed to respond effectively and consistently and are already doing so.

13. Advocacy Mythbuster: <https://qualityadvocacy.org.uk/wp-content/uploads/2020/04/Coronavirus-Advocacy-Mythbuster.pdf>

Moving forward

Advocates were asked about ways of working differently during the pandemic that they would like to continue. 39% of advocates wanted to continue with some virtual meetings and over one in five liked the flexibility of working from home. Others also referred to having learnt more about how technology can be used creatively and that for some people this can have a positive impact. As noted through this report, digital technology has its place and for some can be a good option but for too many people it presents problems. As we move forward, we must consider how we use digital platforms when it is genuinely effective but also protect the primacy of being able to deliver advocacy in person.

Some advocates said they hoped the advocacy sector would continue to push for greater cooperation to “share experience and good practice (at advocate level not just managers)”, “ensure we remain a valued support by policymakers and those in power”, and to “work in partnership/coproduction with outside agencies [...] to raise awareness of people’s rights [...] to access advocacy services.”

Such cooperation is already happening among the many organisations who have been involved in the survey and this report. Advocacy organisations came together in immediate response to the survey findings to set out five principles that would drive forward their response to the challenges outlined in the survey. *Upholding rights and valuing voices: Advocacy principles for coronavirus and beyond* sets out how



For some clients working virtually has worked well for them and they have really liked it citing greater flexibility, reduced stress of encounter / going to meetings, less of a power imbalance. But it doesn't work for everyone. Providing advocacy virtually should be just one of the ways we can provide advocacy going forward if it meets the person's needs - and it may not be right every time for that person either.

advocacy organisations will hold themselves accountable for delivering effective advocacy, through the pandemic and beyond, with a particular focus on making sure advocacy reaches people who need it most and who experience the worst health inequalities.¹⁴ By sharing learning, insights, tools and developing joint publications, guidance, and resources, we will continue to collectively increase our effectiveness across the advocacy sector.

Advocates shared their vision for the future. Around a quarter said how important it is to raise awareness of the value of advocacy through collecting and sharing evidence, and training for professionals. Others talked about the need for health and social care services to be more ambitious in embracing a fully person-centred approach.

Advocacy is independent and firmly on the side of the person who uses the service. This makes advocates well-placed to identify systemic practices and attitudes which disproportionately impact people's rights and wellbeing. By harnessing this insight, advocacy organisations can inform commissioners and providers where things are not working for people or where poor practice threatens people's safety and wellbeing. By having an impact on public policy, advocacy organisations can make a difference that delivers long-term change to even more people.

14. *Valuing voices and respecting rights: Advocacy principles for coronavirus and beyond*, <https://www.voiceability.org/news/upholding-rights-and-valuing-voices-advocacy-principles-for-coronavirus-and-beyond>

Massive training drive for all health sectors; hospitals, doctors, social workers and care providers on what advocates do and that it is a legal requirement for people to have access to us. Also, for those services to be trained/ regulated in being more person centred.

Valuing voices and respecting rights: Advocacy principles for coronavirus and beyond

1. Make sure that people are heard and their rights are respected
2. Communicate effectively, and safely meet with people in person
3. Make sure that people can access advocacy
4. Take positive anti-discrimination action
5. Work together to promote systemic change

Conclusion

Undoubtedly, the coronavirus pandemic is an unprecedented global event. Many people in health and social care made enormous efforts in the early days of the pandemic to respond to a very complex and challenging situation and figure out ways to support people as best they could. Many of us have learnt from our experiences in the spring and are better equipped to support people. As we enter a second wave of the pandemic, we must take these lessons forward to avoid a repetition of some of the worst impact on people's lives. There can be no backward steps.

The survey responses have exposed systemic flaws in health and social care. Legislation to protect people most at risk of being marginalised or abused is not consistently embedded within local authorities and health and social care providers, and at times is ineffectual. If rights were embedded, and if decision-making culture fully recognised each person as an individual, we would not have seen blanket decisions about people's daily lives at scale we have witnessed, and over three quarters of advocates would not be reporting that people's human rights have not been upheld.

There must be a reinvigorated focus on human rights that recognises individual choice. Those responsible for planning, commissioning and providing health and social care support must comply with the Care Act and Mental Capacity Act. The 2018 independent review of the Mental Health Act emphasises that people should have greater choice and autonomy, and people should be seen and treated as individuals. Importantly,

the report recognises the role of advocacy in achieving this. The report recommendations must be enacted through parliamentary legislation as a priority.

The survey findings demand a rethink of our approach to health and social care and make it clear that the time to act is now. We must improve our public health strategy to respond to future waves of the pandemic. In the medium and longer-term, we must develop, embed, and properly resource programmes that better address health and social care inequalities.

It must be an urgent priority to reinforce the rights and to support the wellbeing of people who rely on social care. Addressing social care funding is necessary but not sufficient alone. There needs to be a new political and public consensus on how we are all supported to live full lives within our communities. Integral to this is not just system change but culture change. We have an opportunity to overhaul our social care system so that there is an inclusive vision for social care and support for people with long-term health conditions beyond the coronavirus pandemic.

Recommendations

Supporting people effectively and ensuring their rights through advocacy

The principles set out in *Upholding rights and valuing voices: Advocacy principles for coronavirus and beyond* are shared commitments by advocacy organisations to ensure people's access to advocacy and that advocacy is effective, including for those who experience the greatest health inequalities.

- Advocacy organisations have committed to:
 - Make sure their advocacy services are known about, accessible, person-centred, and provide effective advocacy whether through remote tools or face to face meetings
 - Harness our insight and expertise to influence policy and practice, at an individual level through challenging decisions, and at the wider level of systemic change.
- Local authorities must urgently address the knowledge gap of their health and social care providers, the drop in referrals, and the subsequent risk to statutory and human rights. This requires:
 - Clear leadership communication that the Mental Capacity Act continues to apply and the Care Act and Social Services and Wellbeing Act (Wales) remain fully in force unless the authority has formally exercised easements.

- Action to make sure people's legal rights to advocacy are enforced, including through effective communication with professionals regarding their duty to refer and the active auditing and monitoring of referrals, advocacy uptake, and advocacy reach
- Enhanced understanding of human rights and domestic law across the health and social care system, including targeted training on statutory duties, the Equalities Act, and the Human Rights Act
- Increased clarity and communication by health and social care agencies that decisions about restrictive practices and healthcare must be made individually, other than where specifically lawful
- Promotion of both face-to-face advocacy (with measures to assess and reduce risk) and remote advocacy via telephone or video call
- Embedding the actions outlined in the Adass paper 'Advocacy during Covid-19 and beyond' that set out what local authorities, commissioners, and managers could do to make better use of advocacy ¹⁵.
- Local authorities who face back-logs in care assessments, care planning or Deprivation of Liberty Safeguards assessments must give urgent priority to addressing these especially in view of second or third waves, paralleling

15. Adass, 'Advocacy during Covid-19 and beyond', <https://www.adass.org.uk/advocacy-during-covid-19-and-beyond>

the plan for the third phase of the NHS's response to coronavirus.

- Local authorities must prioritise active engagement by safeguarding teams, enhanced awareness of potential indicators of abuse and increased readiness to act on concerns, which may need to err further on the side of caution when interpreting of thresholds to make safeguarding enquiries.
- Rapid local system reviews must be properly resourced. This means external insights and recommendations can help local authorities improve how health and social care needs are met, notwithstanding the pressures of coronavirus.
- Professional visitors, including advocates, must be able to meet with people in-person. There should not be blanket restrictions that prevent advocates accessing where people are, including care homes and hospitals. If asymptomatic testing is required for advocates to access where someone lives or is staying, this should be easily available.
- Endemic isolation and loneliness must not be the legacy of the pandemic. It is not acceptable that people who live in care homes or supported living should face enduring bans on visitors. The government must address this and make sure people are able to have social contact with their loved ones alongside protecting them from the risks of coronavirus.

Digital when effective and nobody left behind

Digital services can be effective and can offer greater flexibility and accessibility of services for some people.

- Digital services should be developed where desirable and genuinely addressing people's needs.
- Health and social care services that are digital first must not become digital by default where there is risk of excluding people from access who cannot use digital services.
- When digital services are developed, people who have difficulty using digital services and those at risk of harm or abuse must always be offered in-person support.

Reconsider the Liberty Protection Safeguards

People's rights in the context of decisions around their liberty and capacity are very fragile. With the timetable for the implementation of the Liberty Protection Safeguards (LPS) now pushed back by almost two years, there is an opportunity for the government to make sure the Regulations and Code of Practice are clear, practicable, person-centred, and put people's rights, autonomy, and wellbeing at the core of any process.

However, LPS in their current form risk reducing rather than enhancing people's protections. For any new arrangements to work, the following must be incorporated.

- Local authorities have specific duties to make sure human rights are upheld. They must have full, proper, and independent oversight of providers, and hold providers to account to all statutory legislation and human rights law.
- Increased, easy access to independent advocacy to make sure people's rights are protected.

Reform the Mental Health Act

The independent review of the Mental Health Act led by Sir Simon Wessely made clear recommendations to improve the experiences of people detained under the Mental Health Act.

The government should:

- Prioritise parliamentary time as soon as possible to reform the Mental Health Act, including enhancing provisions to advocacy by making it opt-out so people can get the support they need, when they need it and extend advocacy entitlements to informal patients in England
- Implement recommendations that increase people's choice and control over their care through advance planning, easier access and enhanced rights to an advocate, more scope to challenge decisions they disagree with, and a crucial focus on the need for culturally competent care and support.

A vision for the future of health and social care

Social care is in urgent need of overhaul. It is not fit-for-purpose to serve people who need additional support to live fulfilled and healthy lives and does not make the contribution to everyone's wellbeing at individual and community level that it needs to in the future.

The government has a leadership role to deliver a social care system that combines investment with improved standards, and attitude and culture change. This requires a person centered vision that embeds individual rights and respect, and must be a shared endeavour.¹⁶

The government must:

- Look to user-led organisations and experts by experience to fully understand what people want from the future of health and social care and what makes the greatest difference to them.

- Build a shared political and public consensus that offers us health and social care that is person-centred, redresses imbalance by shifting power to people and communities, and better recognises the positive impact good healthcare, social care, and community support has on everyone, whatever our needs.
- Start the promised cross-party talks on the future of social care as soon as possible and make sure steps are taken to seek consensus and ensure reform is fit for purpose for the long-term, not just a sticking plaster. Changes to social care must be delivered with both a medium- and long-term vision that lives beyond the life of one or two parliaments. Legislation and frameworks must strengthen people's rights, and enable transparent accountability so individuals and organisations are able to challenge decisions, rectify mistakes, and learn for the future.
- Develop a meaningful approach to co-production with community groups, people with lived experience, and the health and social care and voluntary sectors. Subject matter and lived experience experts have crucial roles to play in making sure social care models are fit-for-purpose and serve those most affected by health inequality.
- Sufficiently resource and empower local authorities to increase their focus on co-producing future plans for social care with disabled people and communities, with a focus on supporting citizenship and inclusion.
- Support and resource co-produced initiatives that address the urgent need for greater and faster culture change, particularly regarding attitudes towards Disabled People, people with learning disabilities, autistic people, people with mental health conditions, and older people.

16. For insight into what a vision for social care might look like, if it were more inclusive, Social Care Future is a movement that is pushing for wholesale overhaul of social care. <https://socialcarefuture.blog>

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Jacqui Jobson Consulting
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People First
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Swan Advocacy
The Advocacy People
The Advocacy Project
VoiceAbility

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