

Valuing Voices in Wales: Protecting Rights Through the Pandemic and Beyond



Executive Summary

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

A core tenet of advocacy is to redress inequality so that people's rights are upheld and that 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 in improving people's health and wellbeing that must not be overlooked.

This report brings together findings from a survey, carried out in June 2020, of 72 advocates working across Wales. Advocates shared urgent concerns which reflect not only the restrictions that the pandemic brought but also the wider societal and cultural belief systems and attitudes towards people who are supported through advocacy. The sample size might appear small but it represents a significant number of advocates working across Wales who are in a unique position to identify weaknesses in systems and blanket abuses of rights.

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 to which they are legally entitled, increasing risks of abuse and harm and weaknesses in the safeguards needed to prevent and address these.

What did we find?

People's needs are not being met or assessed and people's statutory and human rights are at risk, despite legal obligations on local authorities being

unchanged. Eighty-five percent (85%) 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 that people who are unable to make decisions are not being listened to and their interests are being ignored. A third (33%) of advocates had experienced Do Not Attempt Cardio Pulmonary Resuscitation orders (DNACPRs) being placed on the people they support without any regard to the person's feelings, wishes, values or beliefs, and without formal capacity assessments or consultation with family. Almost one in five (17%) reported that people were being denied healthcare or treatment in a blanket way.

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. Over forty percent (43%) of advocates reported care providers had stopped all visitors and almost a third (31%) 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 and the absence of independent safeguards in the settings where people live. Advocacy organisations have come together to ensure people's access to advocacy. However a lack of care planning, discharge planning, and support were highlighted with over a quarter of advocates (28%) having experienced a care provider seeking to prevent access to advocates despite rights to advocacy remaining unchanged.

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 most people it is not comparable. It means that they are not getting the support they need and this 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. As we face a second wave of the pandemic, lessons must be learned to avoid a continuation and 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.

It must be an urgent priority to reinforce the rights and improve the support of people who rely on social care. Addressing the health and social care funding gap is necessary but not sufficient in and of itself. 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.

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 and reinforces compliance with legislation such as the Social Services and Well-being Wales Act and the Mental Capacity Act by those responsible for assessing, planning, commissioning, and providing health and social care support. Further, the recommendations of the Independent review of the Mental Health Act, including those which recognise the inherent value of advocacy in securing people's rights and wellbeing must be enacted through parliamentary legislation as a priority.

Acknowledgements

We would like to recognise the input, help and support that has been received in order to produce this important report into advocacy during the Covid-19 pandemic. It has been a very difficult time for the people who use advocacy, for the advocacy sector and for wider society as a whole. This has made us all the more grateful to the advocates who took the time out to complete the survey. The response was fantastic from Welsh colleagues who fed back their experiences at this challenging time.

We would also like to thank all the advocacy network members in Wales who have supported this work and contributed to the thinking that made it come alive. Included in this is the small advisory group were NDTI, Advocacy West Wales-Eiriolaeth Gorllewin Cymru, Age Cymru, Alzheimer's Society, Dewis CIL and North Wales Advice and Advocacy Association, who have met on many times during the development of the survey to review the analysis of the results and find ways to bring the advocates' stories to life.

This wouldn't have been possible at all without the tremendous work of the team at NDTI who have spent many days developing the survey, reviewing and analysing data, and writing the report. Thank you to Charlotte Gill of Voiceability (original combined report draft), Natasha Fox of Advocacy West Wales-Eiriolaeth Gorllewin Cymru and Gail Petty of NDTi (Welsh specific report drafting) for the time they have spent in preparing the report and to all advocacy providers who have contributed to the writing of the report.

Thank you also to Age Cymru for funding the development of the report.

Methodology

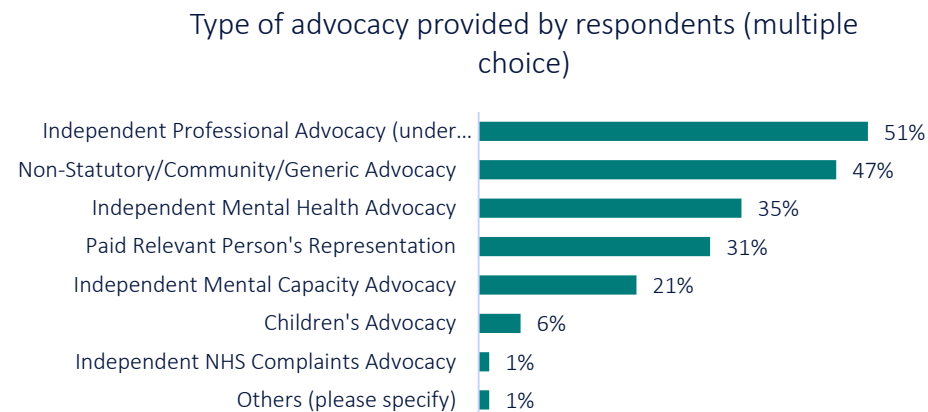
In June 2020, organisations with expertise in independent advocacy services worked alongside the National Development Team for Inclusion (NDTi) to carry out a survey of advocates and gather evidence of the impact of the Covid-19 (coronavirus) pandemic.

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

In total, 72 advocates completed the survey from across different regions of Wales with a breadth of advocacy experience, often across multiple areas of statutory and non-statutory advocacy.¹ Over half (51%) of respondents in Wales provided Independent Professional Advocacy, nearly half (47%) provided community advocacy and over a third (35%) provided Independent Mental Health Advocacy. Children's Advocacy was under-represented in the survey.

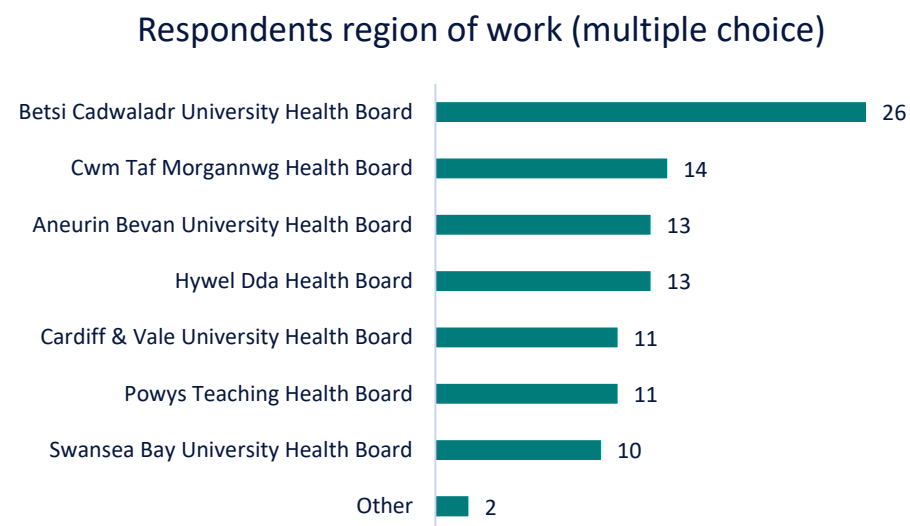
¹ Statutory advocacy is provided in Wales under the Mental Health Act and Mental Health (Wales) Measure, Mental Capacity Act, and the Social Services and Wellbeing (Wales) Act. There is also some statutory requirement for advocacy under the Children's Act. For some of these Acts the legislation and guidance differs between England and Wales.

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



*'Other' types of advocacy provided – 1 response only; litigation friend.

Figure 2: Respondents region of work (multiple choice)



The average completion rate was 79% and the average time taken in completing the survey was 18 minutes. The survey was available in English and Welsh. However, no respondents completed the survey in Welsh.

The findings represent the views and experiences of independent advocates who work alongside people across Wales.

This report is allied with a combined report produced from data and analysis of survey responses from 435 advocates across England and Wales.

Advocates support people to say what they want, secure their rights and obtain services they need. Where the people they support lack capacity to make key decisions in their care for themselves, advocates ensure the unique views and preferences of the person are heard. They ensure that the person's rights and entitlements are upheld and that their views and preferences are kept at the centre of decision making when health and social care professionals are making decisions affecting their lives.

Advocacy organisations and advocates work in partnership with the people they support; taking their side, promoting social inclusion, equality and social justice: Definition taken from the - Advocacy Charter 2018, NDTi <https://qualityadvocacy.org.uk/resources/advocacy-charter/>).

Introduction

People who face discrimination are at the sharp end of inequality and poverty. While the Public Health Wales Long Term Strategy 2018-30 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 the safeguards and measures designed to protect people's rights and wellbeing, and despite the tremendous efforts of people working in health and social care to support people. Overwhelmingly, those of us who already found it harder to have our 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 as independent experts who work with some of the people most excluded and overlooked by society. This report offers insight into the challenges that people face in having their rights upheld and being listened to when decisions affect them during the pandemic. These challenges are not always new but have been exacerbated by the restrictions and the public and political response to the coronavirus pandemic.

The report sets out the key findings from the survey and provides some additional context for these findings. The report also makes pressing and timely recommendations for national government, local authorities, and health and social care providers.

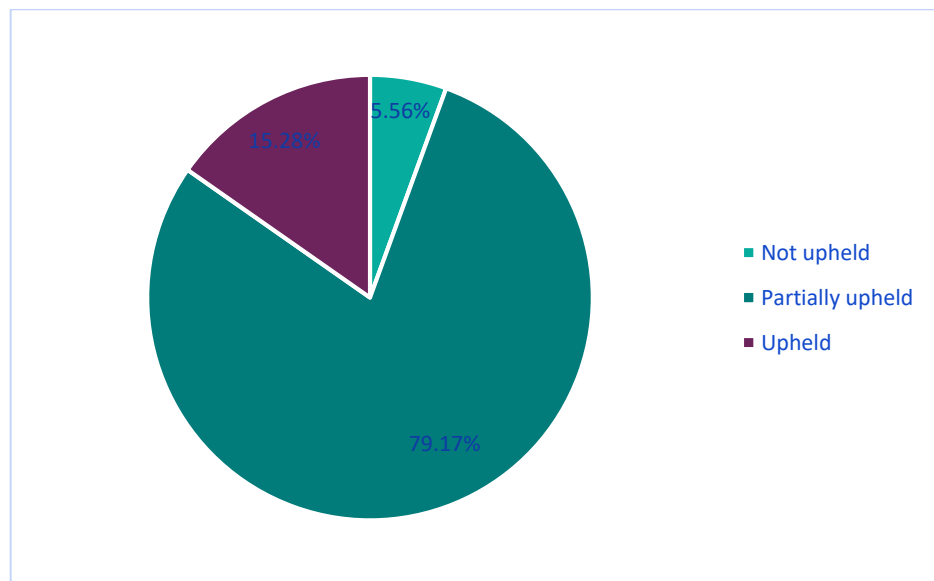


Rights breached and non-compliance

Human rights failures

The fulfilment of people’s statutory entitlements and respect for their human rights are at risk. The public health response has seen the stripping back of vital health and social care services and severe and ongoing restrictions on people’s liberty, and private and family life which for many people represents a very real threat to their human rights. More than 8 out of 10 (85%) of advocates reported that people’s human rights were not being fully upheld during the coronavirus pandemic. In respect of individual pieces of legislation, advocates reported that people’s rights had most been respected under the Children and Families Act (83%) and least respected under the Human Rights Act (39%).

Figure 3: The extent to which advocates feel the human rights of the people they support have been upheld during the pandemic



Safeguarding risks

Over twenty percent (21%) of advocates reported experiencing a safeguarding situation arising as a direct result of Covid-19 restrictions.

Advocates raised concrete examples of individuals whose risk had increased, in part because of the restrictions and limitations placed upon them. Advocates gave examples of people being discharged to unsafe accommodation, discharge to family member who restricted the person’s access to other family and advocacy, a person being forced to self-isolate with a known abuser and an older person transferred out of area without their family being informed. These concerns also included increased risk of suicide and 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 and which a lack of access to advocacy exacerbated. Reduced access to advocacy, the limitations of remote communication tools, and the lack of privacy to meet with many clients made it harder for advocates to play their role in safeguarding people from harm and abuse. The absence of independent safeguards in many settings during this time has raised concerns regarding safeguarding people at risk of harm or abuse.

“Not being able to get out and exercise or see family led to a major increase in incidents and regular use of PRN medication which wasn’t the case prior to lockdown”

“Patients across our area have been moved out of area.”

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.

“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.”

About a person isolated with an abuser

Advocates also raised concern 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

The data paints a stark picture in terms of how blanket decisions have impacted people.

Nearly all respondents (96%) reported to have experienced some kind of blanket decision being applied to people during this period. Advocates were able to give detailed examples of how people’s rights had not been upheld. Many examples referred to blanket decisions, including those related to access to healthcare and treatment and Do Not Resuscitate or Do Not Attempt CPR orders, the proliferation of which was well documented in the press at the time. A third of advocates (33%) reported blanket decisions of DNACPRs and advocates said they were aware of blanket restrictions around hospital admission (15%) and the withholding of care or treatment (17%). One respondent specifically reported that patients of mental health services in the community were discharged and told to refer back to their GP once the pandemic was over.

Do Not Resuscitate Orders (DNACPRs) were reported as being applied to all individuals living within certain care settings without consultation, advocacy support or consideration of the consequences, not least the impact of such a decision on people’s mental health.

There were also some reports of medical professionals and care homes interpreting laws and guidance in their own ways with negative consequences; for example, the implementation of blanket DNACPRs without local doctors seeing or speaking to individuals and taking decisions without due consultation, e.g. not carrying out video meetings to discuss best interest matters.

“There have been too many blanket approaches to community access and family contact which have caused harm, not applying the MCA and best interest principles for people with complex needs”

“At the beginning of lockdown, a GP surgery in our county sent a letter requesting that those most vulnerable to COVID-19 to sign DNRs to protect emergency and health staff. They did not consider that some recipients with learning disabilities living independently would not be able to process the gravity of such a letter. The right to life is a basic human right, just because a person may be vulnerable to the virus, doesn't mean they don't have aspirations beyond their conditions”

However, blanket decisions did not just relate to hospital care and treatment. Blanket decisions also led to restrictions on visits and access. Over half of respondents reported advocacy organisations stopping visits in response to the crisis, with nearly a third (28%) stating that hospitals and care providers had stopped advocates from visiting and over forty percent of care providers or hospitals (43%) had stopped any form of visiting. 31% of advocates reported people being confined to their rooms under blanket decisions.

26% of advocates reported blanket decisions stopping Section 17 leave under the Mental Health Act.² However, there is also evidence that when

² 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".

appropriately challenged, these decisions were changed, underscoring the important role advocacy plays in a check and balance context 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.”

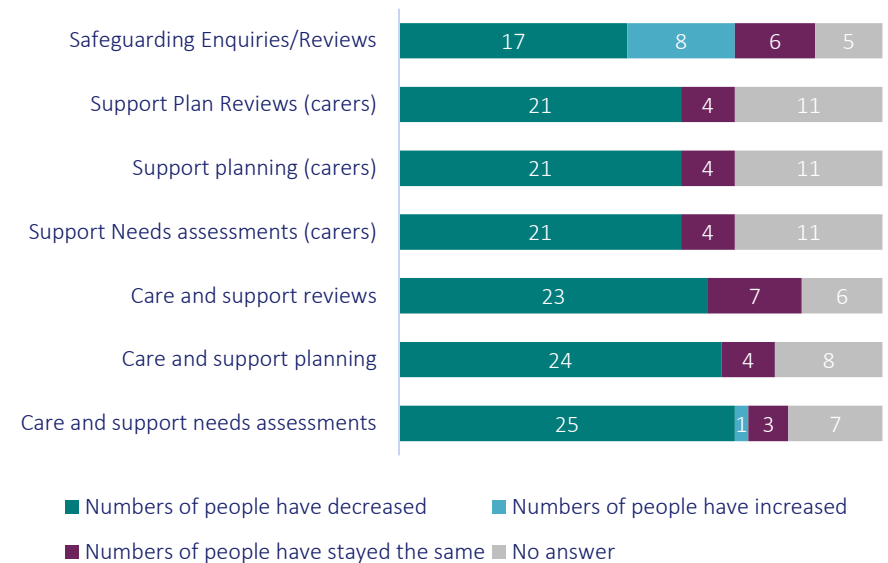
Reduced referrals

From the survey and our additional research across the local authorities in Wales, we have 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-May 2019 than March-May 2020.³

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.

“Referrals to advocacy are much lower and indicate rights to advocacy not observed.”

Figure 5: Decrease in reported referrals for IPA advocacy across Wales by issue



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 cases represent non-compliance with the relevant legislation. Under the 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 Coronavirus Act and its emergency powers. 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.”

“Lower admissions to wards. Some wards stopped referring for a while thinking, despite assurances to the contrary, that IMHA was suspended by the CA2020. Also, not involving an independent can mean they are able to make decisions they want as professionals rather than what clients would want if supported to ask.”

³ This is based on evidence from advocates completing the survey and data gathered from advocacy services working across health board areas in Wales. Reductions were seen in every type of statutory advocacy.

“My client group are mental health in-patients. Patient turnover has been low. Without visiting in person, staff do not always refer patients.”
IMHA Advocates about referrals to IMHA services

The drop in referral rates is a pressing concern and does not tally with any evidence to suggest that there was a parallel drop in the need for advocacy. This paints a stark picture that people are being detained under the Mental Health Act, put on care plans, 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 and posters in hospitals, care homes, and other community places. When asked about the reasons for a reduction in referrals, one in three advocates (33%) responded that it was in part due to a lack of understanding or awareness of advocacy statutory duties, and that advocacy has become more “invisible” during the pandemic.

In Wales any person in hospital being treated or assessed for their mental health, of any age, and whether detained under the Mental Health Act or in hospital voluntarily, is entitled to support from an Independent Mental Health Advocate. An advocate’s presence on the ward is vital to make people aware of their right to advocacy because in Wales advocacy is an opt-in service and people are not provided an IMHA advocate by default.⁴ 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.

While the Mental Health Act Review led by Sir Simon Wessely recommends that advocacy become opt-out, we are still waiting for the UK and Welsh governments to publish their responses to the review and move forward with this vital reform. In the meantime, as we respond to a second

⁴ For Wales, under the Mental Health Measure (Wales), advocacy is opt-in for those eligible - both detained and voluntary patients.

wave of the pandemic, we need people to know about their right to

“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.”

“People are excluded to participate due to digital exclusion”.

“Capacity assessments are being made over the phone and using Skype. These are questionable [due to] difficulty on the phone or via IT, particularly those with hearing issues.”

“The discharge process for people who are deemed to lack capacity is rushed and sometimes the MCA guidelines and principles have not been adhered to.”

advocacy and take steps to make sure that people who need support, get support. Advocacy organisations are stepping up to the plate with the production of Upholding Rights and Valuing Voices: Advocacy Principles for Coronavirus and Beyond and increased awareness of advocacy and statutory duties is recognised as vital to ensure people’s rights during and after the pandemic.

“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.”

“Lack of understanding from care providers around MCA and best interests, for example no assessments or best interest paperwork in place regarding COVID specific issues, for example testing for people who lack capacity to consent; particularly in instances of 'blanket testing' as opposed to considering the best interests of each individual.... Some (problematic) managing authorities that were reluctant in working with Paid RPR's prior to lockdown have become less forthcoming in terms of contact and information sharing since unannounced face to face visits have been unable to take place due to COVID.”

Understanding the Mental Capacity Act and Care Act

Concerns were shared by advocates that MCA (Mental Capacity Act) assessments were rushed, incorrectly completed, or overlooked suggesting that people's rights were being breached in such cases. 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.

Alongside non-compliance with the Mental Capacity Act, advocates raised concerns that adherence to the Social Services and Well-being (Wales) Act has been suspended inappropriately. The Coronavirus Act and accompanying guidance provided by Welsh Government (<https://gov.wales/adult-social-services-during-covid-19-pandemic.html>) states that: "Local authorities should continue to do everything they can to continue meeting their existing duties prior to the 2020 Act provisions coming into force" and that changes to assessment, care planning and support should be made as a last resort, in specific circumstances and for the least possible time.

However, there have been reports of people left in conditions which may amount to breaches of human rights, due to suspension of duties or alleged de-facto, unlawful suspensions. This meant people were not getting assessed as they were entitled to or supported as they should be, including referral to advocacy, and for some people has had a severe impact on their health, wellbeing and safety.⁵

"care assessments have been restricted for urgent cases only. Support planning has continued but with restrictions, making this less accessible for clients."

"[social care] professionals are meeting less people for the 1st time so what needs are required are going unassessed."

⁵ 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*

"Social Workers not adhering to the act and offering the service to individuals and their rights to an independent advocate."

"Less contact with advocacy and friends/family has made people more isolated and vulnerable."

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 ensure that their rights are protected, known as Deprivation of Liberty Safeguards (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.

"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."

"Capacity tests that were scheduled before lockdown have not been conducted. This has led to serious negative consequences for some individuals."

"There has been an initial delay in the DoLS assessments, meaning some people have been illegally deprived of their liberty."

Our survey responses show that during this period there has been a drop in DoLS applications and subsequent referral for advocacy in adult social care and *Fig 6: Reported current concerns (June 2020) for people advocates support and represent:*

hospitals. This together with the delays and uncertainty over the progress of the new LPS (Liberty Protection Safeguards) may mean there is an

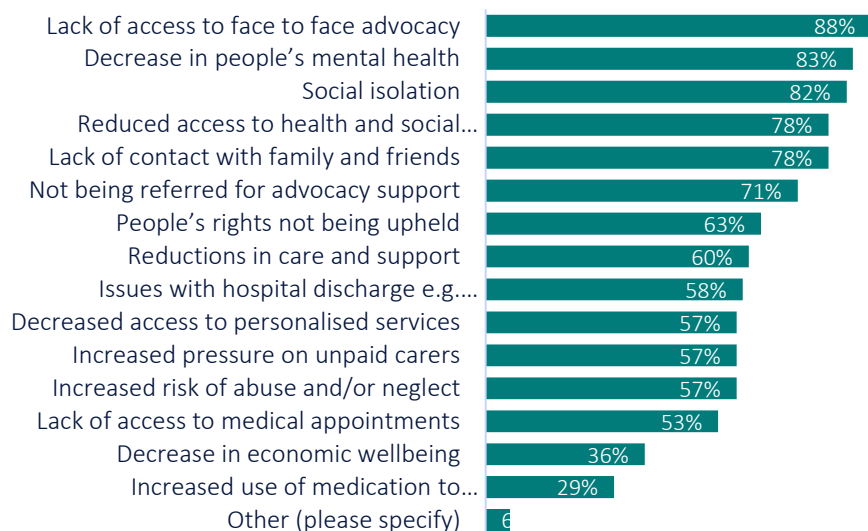
Guardian, 'Stop using coronavirus powers to neglect care duties, UK councils told', 7 May 2020, <https://www.theguardian.com/society/2020/may/07/stop-using-coronavirus-powers-to-neglect-care-duties-uk-councils-told>

increasing risk of people being deprived of their liberty without the proper authorisation.”⁶ 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.

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. There can be no doubt that it has increased the need for people to receive the independent skilled support that advocacy provides. The table below shows the nature of the issues impacting people supported by advocates and the level of concern:

Fig 6: Reported current concerns (June 2020) for people advocates support and represent:



There has been reduced access to healthcare and support and a lack of care planning and discharge planning. This is particularly an issue for older people and there are examples of their being denied choice on discharge from hospital or forced into a care home against their and their families’ wishes.

Change of accommodation has increased with referrals for clients being moved into temporary accommodation. Safeguarding referrals are consistently low.

Supervisory Body's which already had a backlog of DoLS authorisations are limited in what they are able to do as visits are not being conducted face to face in most instances. DoLS reviews and re-authorisations are being done based on previous assessments and not on a face to face basis.

Comment from an RPR working in Wales

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 for their mental health.

Nearly a third (31%) of advocates reported having clients 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 de-facto deprivation of liberty.

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

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 to engage. For many people, a face to face visit is the only way to visit someone and support them. There have been many incidences where advocates have not been able to meet the people they support privately, or they have relied upon support from carers or family to access advocacy via remote means. This calls in to question the independence of the advocacy and the client's ability to express themselves as openly as they might like were others not having to facilitate contact with the advocate. 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.

Delivering advocacy during the coronavirus pandemic

Despite the restrictions, advocates and advocacy providers made use of digital communication tools and other methods to continue to support people.

These restrictions impacted on advocates' sense of effectiveness, with just 3% reporting that they feel their advocacy is 'very effective' whilst they are not able to see everyone face to face. However, the majority (78%) feel their advocacy is 'somewhat effective' when delivered remotely. Nearly half of respondents (44%) reported that this reduced level of effectiveness makes them feel dissatisfied or very dissatisfied, with just 16% satisfied or very satisfied. There is a clear sense of frustration from advocates that they are not able to support their clients fully or in person.

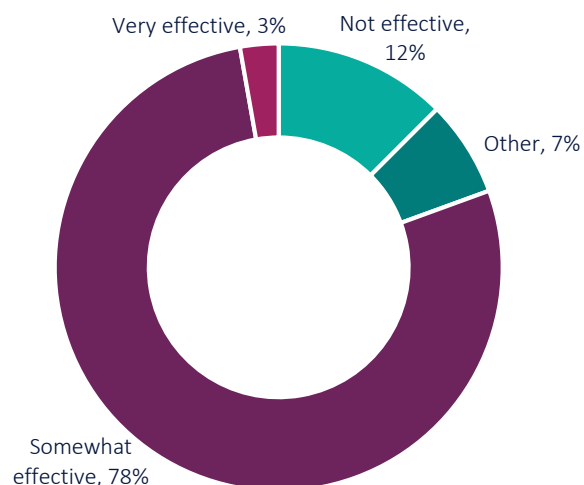
Meetings with clients

Similar to other health, social care, and voluntary services, in March 2020, almost overnight, the way advocacy was delivered had to shift dramatically. Through creativity on the part of advocates, the flexibility of people who use advocacy services, and the 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. However, many people have been unable to access advocacy in this way owing to cognitive or communication needs. Nearly eighty percent (79%) of advocates reported difficulty for various client groups to access advocacy as a result.

"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."

Access to places where people live or stay has been highly restricted. Only 22% of advocates reported being able to undertake face to face visits at the date of the survey (June 2020) although 28% reported that they were planning to do so in the near future. This inability to fully access the places where people live or stay has negatively affected advocates' ability to communicate with people. The findings were consistent across the different settings suggesting widespread and blanket restrictions negatively affected people's access to the advocacy to which they are entitled. Over forty percent of advocates (43%) had experienced a care provider (including hospitals) seeking to prevent access to advocacy in all forms, despite rights to advocacy remaining unchanged.

Figure 7: Advocate view of effectiveness of advocacy when not face to face:



As we moved on from the first wave of the pandemic, advocates began to meet with people more easily and make more 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 to this need by ensuring risk assessments are robust and that they follow infection control protocols so they can continue to make visits. Advocates are professional essential workers and thus their ability to carry out their role and ensure the rights of their clients must not be hindered.

Personal protection equipment and risk assessment for face to face visiting

⁷ [Advocacy Mythbuster](https://qualityadvocacy.org.uk/wp-content/uploads/2020/04/Coronavirus-Advocacy-Mythbuster.pdf): <https://qualityadvocacy.org.uk/wp-content/uploads/2020/04/Coronavirus-Advocacy-Mythbuster.pdf>

The approach to the use of PPE was inconsistent, partly reflecting the lack of and inconsistent nature of guidance and the supply challenges across the country at the pandemic peak. This situation has changed since June and we are receiving fewer reports of PPE being a major issue in relation to providing advocacy. We know that advocacy organisations are accessing PPE in a variety of ways, both through private supply and via local authority hubs. In June however fewer than

half of advocates (45%) reported to have access to Personal Protective Equipment (PPE). Of those who had access to PPE, it was provided by their employer or organisation. Of those who had been provided with PPE, 61% of advocates had also been given training in using PPE at the time of the survey and 86% of those advocates felt that they had the knowledge and skills to use PPE effectively.

Advocates were asked about risk assessment processes in preparation for face to face/in person visits. 86% of advocates reported that they undertake risk assessment for such visits using an organisational risk assessment with a manager or through discussion with a manager. Only 1 advocate reported having to assess risk without such support.

Inconsistency across the country

A lack of timely, clear, and consistent guidelines has been an issue throughout and continues to be an issue, leading to confusion, blanket decisions, and at times overly restrictive practices. Some of this inconsistency is reflected in the variety in responses and answers from advocates that show a range of approaches to advocacy across services and settings. In response to initial confusion, advocacy organisations have defined their own clear guidance that allowed them to continue their essential duties as keyworkers.⁷ The law makes clear that advocacy must

continue and the government have also made clear 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 be proactive, effective and consistent in their response.

Communication at the heart of advocacy

Effective communication is at the heart of advocacy. Many advocates work with people who have difficulty communicating their views or who use non-verbal communication techniques to make themselves understood. Advocates shared insight into the challenges of communicating with clients remotely and in being able to effectively support people to express their views and have their wishes respected. Difficulties for certain client groups were detailed and reproduced below:

Advocates particularly drew attention to people with dementia and people with 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 video-conference, 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 need and benefit from advocacy, including people with the most complex needs and who experience the greatest communication barriers.

Once referred, regardless of the setting, all practicable 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. For some individuals remote contact will not ensure the privacy and confidentiality required and a face-to-face visit is the only option that ensures their rights.

"My main concerns are not being able to engage on a one to one level with people in any setting and that people's voices and human rights will not be heard."

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, on people who have learning disabilities, autism, or dementia. This may, in turn, have a discriminatory impact on these groups.

"Older people who are not technology confident, people with dementia who are more engaged face to face than via video or phone, people with mental health conditions that make electronic contact difficult i.e. auditory hallucinations, paranoid anxiety etc, people with a learning disability that do not have access or skills to use technology for video calls or social media."

"Non-instructed advocacy that relies on observation in a person's home or care setting has been impossible to carry out."

"Older adults with mental health needs such as dementia and other degenerative cognitive disorders whereby they lack the ability to give instruction and lack capacity to make decisions about their care and treatment. 1:1 advocacy is vital in establishing and getting to know that person and understand what their wishes might be in relation to those types of decisions. Family can be consulted but in some situations what family wishes is not always consistent with the client."

"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."

“Due to the pandemic all services have had to adopt new ways and have had to be creative in the people they support. There have been positives to remote working as well as negatives. I am aware that these positives will have to be adopted for future working my fear is that services will not recognise this may have a detrimental effect on individuals who need communication support to understand and process information which they need to ensure that they understand their options which will enable them to make their own decisions on aspects of their life. My hope for the future is that all services have an understanding of what are the communication needs of each individual and consider/use creative ways to best support that individual so that the best outcome can be achieved for that individual.”

Advocates also raised the challenge to support people who do not have privacy. Together with effective communication, confidentiality and privacy are crucial to deliver person-centred advocacy. Privacy ensures understanding of a person’s genuine views and wishes 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.

“We have more skills to draw on being forced to work so remotely but would not want that to take over from quality face to face work as this is what clients value and need.”

“People who would benefit from advocacy and are not able to talk via telephone are slipping through the net. I also worry that advocacy is heavily reliant on the help of health staff to facilitate these meetings make us less independent.”

People with a wide range of needs cannot be adequately served by remote working alone. 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. Further in relation to this, issues were raised about advocates not being able to communicate with clients who they suspect may be subject to abuse at home which brings to the fore serious concern about safeguarding.

Moving forward

Advocates were asked about ways of working differently during Coronavirus that they would like to continue afterwards. 40% of advocates wanted to continue with some virtual meetings and over one in five (22%) 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 many it is lacking. As we move forward, we must consider how we use digital when it is genuinely effective but also protect the primacy of being able to meet in person with someone for the many reasons previously outlined.

Some advocates reported that they hoped that 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 of the 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*⁸ sets out how 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.

Here in Wales advocacy organisations have come together via their regional and All Wales networks to share knowledge, planning and risk assessment tools, technology and awareness-raising materials as well as training opportunities. By collaboration across the advocacy sector,

⁸ *Upholding Rights and Valuing Voices: Advocacy Principles for Coronavirus and Beyond*, published 14 September 2020 and endorsed by 20 organisations at time of writing.

including through sharing learning, insights, tools and the development of

“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.”

“My main concerns are not being able to engage on a one to one level with people in any setting and that people's voices and human rights will not be heard.”

“A concerted effort to live up to the possibilities [advocacy] provides for clients together as a sector would be excellent... Taking advocacy as seriously as it should be taken would be a good starting point”

“Some clients able to access support more regularly due to remote access but overall no-one wants it to replace in person advocacy.”

“Ensuring that we do not lose 1:1 face to face advocacy and the virtual world is used as a secondary not primary response or action of advocacy”

“Hopes - we have found new ways to get awareness out that will be useful in future and more varied ways to engage with clients. For those clients we have continued with it's clear they value us more so in this period as we have continued to work with people when other services have not. Concerns - financial stability long term due to impact of economic problems in the country on public service funding for advocacy. Getting back to where we were before - ie - getting professionals to refer again after a period when they haven't.”

“BDA [British Deaf Association] advocacy rely on lottery funding to keep this going. Need to shift to Health Social Care [to] commission this unique service for Deaf community (BSL).”

joint publications, guidance, and resources, we will continue to collectively increase our effectiveness.

Advocacy is independent and firmly on the side of the person who uses the service. This makes advocates well-placed to identify systemic practices, behaviours, and attitudes which disproportionately impact people's rights or their health and wellbeing. By harnessing this insight, advocacy organisations can inform commissioners, providers and Welsh

<https://www.voiceability.org/news/upholding-rights-and-valuing-voices-advocacy-principles-for-coronavirus-and-beyond>

Government 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.

Nearly a third (29%) of advocates shared a vision for the future that identified a continued need to raise awareness of the importance and value of advocacy through building the evidence base and through training for professionals. Others referred to the ongoing need to push services and systems to take on a person-centred approach across the health and social care sectors. The future of health and social care must be more ambitious and take this approach into better account.

Conclusion

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 second or third 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.

The survey responses have exposed the systemic flaws in health and social care and that legislation set up to protect people most at risk of being marginalised or abused is at times weak and ineffectual, but at a minimum, not consistently embedded within local authorities and health and social care providers. If these rights were fully embedded, and if the decision-making culture and attitudes within the system were person-centred and recognised each individual's human value, we would not have seen blanket decisions taken at scale about people's daily lives and over three quarters of advocates would not have witnessed people's human rights not being fully upheld.

It must be an urgent priority to reinforce the rights and to support the wellbeing of people who rely on social care. Addressing the social care funding gap is necessary but not sufficient in and of itself. There needs to be a new political and public consensus formed about how we are all supported to live full lives within our communities. 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.

Integral to this is not just a system change but a culture change. There must be a reinvigorated focus on human rights, personalisation, and compliance with statutory legislation and guidance by those responsible for assessing,

“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.”

planning, commissioning and providing social care support. We need to see the urgent adoption of the recommendations of the Independent review of the Mental Health Act, including those which recognise the inherent value of advocacy in securing people's rights and wellbeing and reframing of people's rights so they have more power over their care and treatment.

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. In particular, advocacy organisations have committed to:

- Make sure that the advocacy services they deliver are known about, accessible, person-centred, and provide effective advocacy whether through the use of remote tools or in face to face meetings
- Harness our insight and expertise to influence both policy and practice whether at an individual level through challenging decisions and supporting people or at a wider level to advocate 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 communicating that the duties under the Social Services and Wellbeing Act (Wales) remain in force except as a last resort and that the Mental Capacity Act continues to apply unchanged
- action to make sure that 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 through enhanced and targeted training regarding statutory duties, the Equalities Act, and the Human Rights Act

- increased clarity and communication by health and social care agencies that any decisions regarding restrictive practices must be taken on an individual basis, other than where specifically lawful, and that all healthcare and treatment decisions must be made individually
- promotion that advocacy that can be carried out both in-person and/or through telephone or video call contact, and promotion of the risk mitigation practices that can be in place to allow in-person advocacy for those who need support face-to-face, including at times of a second or third wave of Covid-19

Local authorities who may be facing back-logs in care assessments and planning or deprivation of liberty must give urgent priority to addressing these especially in anticipation of second or third waves – paralleling the expectation for the NHS in the third phase of the pandemic.

Local authorities must prioritise ensuring active engagement by safeguarding teams, clear communication about the need for enhanced awareness of potential indicators of abuse and increased readiness to act upon concerns raised, which may require more inclusive interpretation of thresholds to make safeguarding enquiries

There must be support and resourcing for rapid local system reviews to provide external insight and recommendations as to how local authorities are ensuring health and social care needs are met notwithstanding the pressures 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. However, digital services should only be developed where desirable and genuinely addressing an unmet need or a need that can be fully met through a digital service. Health and social care services that are digital first must not become digital by default where it risks leaving people behind.

Safeguards and mitigation must be put in place when digital services are developed to ensure that people who will have difficulty accessing digital

services are still supported and that people who are at risk, at increased risk of harm or abuse, or who have enhanced communication needs are always offered in-person appointments.

This applies also to advocacy services where the overwhelming evidence is that one to one in person advocacy, as part of a relationship of trust where the advocate works alongside the person, is the most effective advocacy for the majority of the people we 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 ensure that 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, the LPS in their current form risk reducing rather than enhancing people's protections. For any new arrangements to work there must be:

- Full, proper, and independent oversight of providers by local authorities who as state bodies have enhanced duties regarding compliance with human rights and the Human Rights Act. Providers must be held to account through external mechanisms or it risks establishing accountability merely by name. Meaningful and enforceable accountability is required when making such significant decisions about people's lives.
- Increased access and ease of access to independent advocacy that can ensure people's rights are protected

Reform of 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 of the Mental Health Act, including enhancing provisions to advocacy by making it opt-out so that people can get the support they need, when they need it. This will include enhancing funding to advocacy providers to ensure they are able to meet the increased demand.
- Implement recommendations that increase people's choice and control over their care and treatment through advance planning, enhanced rights and easier access to advocacy, more scope to challenge decisions with which people disagree, and a crucial focus on the need for culturally competent care.

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 the needs of people who require 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 drive forward improvements and reform to the social care system that combines resourcing and investment with improved standards, attitudes, and a culture change. However, the need is greater than simple reform and requires a broader person-centred vision that embeds individual rights and respect. Defining a vision for more inclusive health and social care must be a shared endeavour, not something that is drawn up within parliamentary walls. The government must work in collaboration with people with lived experience of being supported by the social care system and with the health and social care and voluntary sectors to deliver an ambitious and much improved framework for social care and vision for the future. The government must:

- Look to user-led organisations and experts by experience in the first instance to fully understand what people want from the future of health and social care and what makes the greatest difference to them.
- Build across society a shared political and public consensus that offers us health and social care that is person-centred, shifts power to people and communities redressing imbalance, and better recognises the

positive impact good healthcare, social care, and community support has on everyone, whether our needs are very little or are complex and severe.

- Start the promised cross-party talks on the future of social care as soon as possible and ensure that steps are taken to seek consensus and that reform is fit for purpose for the long-term, not just a sticking plaster. Cross-parliamentary engagement is vital – 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. Any legislation or framework must strengthen people’s rights and the accessibility and transparency of accountability mechanisms available to challenge decisions, to rectify mistakes, and to learn for the future.
- Develop a meaningful approach to co-production with community groups and people with lived experience and with 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 the needs of those most affected by health inequality
- Sufficiently resource and empowering 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 attitude and culture change, particularly attitudes towards people with physical disability, people with sensory impairment, people with learning disabilities, autistic people, people with mental health conditions, and older people.
- Professional visitors, such as advocates, must be able to continue to meet with people, despite any ongoing or increased restrictions on visitors. Any requirements with regards to testing must not directly or indirectly lead to advocates being prevented from entering care homes or meeting with people, including through any blanket decisions or restrictions.
- Endemic isolation and loneliness must not be the legacy of the pandemic and it is not acceptable that people who live in care homes or supported

living should face enduring or blanket bans on visitors. The government must address this and ensure that people are able to have social contact with their loved ones alongside protecting them from the risks of coronavirus.