The British Institute of Human Rights
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The Joint Committee on Human Rights Inquiry into the human rights implications of the UK Government's Covid-19 response:

Evidence from people with care and support needs, families, friends and carers

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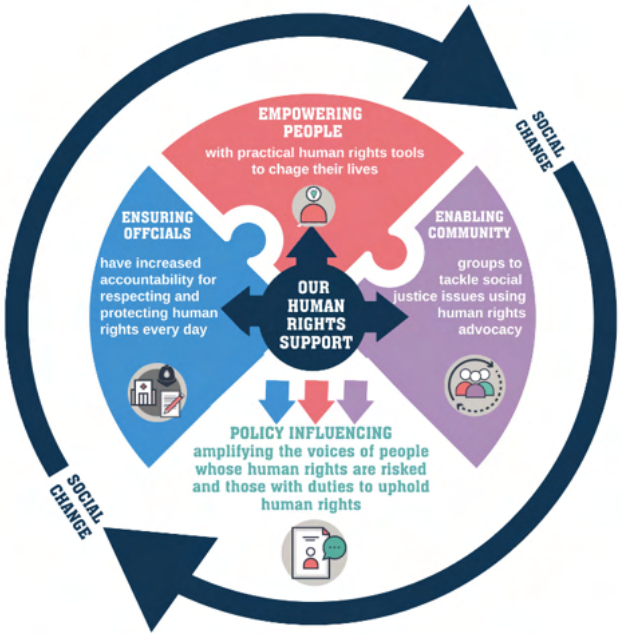
1. Executive Summary

The British Institute of Human Rights (BIHR) welcomes this opportunity to provide evidence to the Joint Committee on Human Rights (JCHR) as part of its inquiry into the human rights implications of the Government's response to Covid-19. Our policy responses are directly informed by people's real-life experiences of the issues, drawn from our work to support people to benefit from their human rights in their daily experiences. Our key findings are summarised below:

- Over 68% of people who responded to our call for evidence told us that their care and support (or that of their loved one) had got worse during Covid-19.
- Over 23% told us that they used to be involved in decision making about their care and support but since Covid-19 are no longer involved.
- Over 54% told us that they were not told how to challenge decisions made about their care and support during Covid-19.
- 60% were not told under what legal basis the change to their care and support was made during Covid-19.
- Over 69% were not provided with information that the duty to respect their human rights had not changed as a result of Covid-19.

2. Background

The initial Coronavirus Act was passed very quickly, and UK government has issued both law (Regulations) and guidance at speed, often with conflicting or confusing public messaging. There are some welcome references in the Coronavirus Act which make it clear that decisions to change care and support should not be incompatible with human rights. However, this was not accompanied by measures to enable people to understand what these human rights are and to ensure that frontline workers know how to make rights respecting decisions. Thus, there are two elements to accountability for the responses to Covid-19: a) central Government's response through law, policy, guidance and resourcing; and b) the implementation of these responses at local level, and therefore people's everyday experiences of risks to their human rights.



3. Methodology

The British Institute of Human Rights is a charity working in communities across the UK to enable positive change through human rights.

We work with three main groups across the UK:

1. People accessing (or trying to) access services, their family members and people who care about them.

2. Formal advocates (e.g. IMCA, IMHA, etc.), self-advocates, and other community, campaigning, and advocacy groups.

3. People with legal duties to respect and protect rights. Including those working in public services and those working in private, charitable, or voluntary bodies delivering public services.

a) BIHR's evidence submission

Since March 2020, our work has specifically focused on the impact of Coronavirus law and policy on people and its implementation through local decision-making. Across the UK, we have worked with over 400 people accessing public services including their families and those who care about them and over 950 people working in health and care services including advocates and campaigners.

From our work supporting people directly:

- **100% of those who completed our evaluation forms told us that they were more worried about their human rights as a result of Covid-19.**

- **Additionally, more than 57% felt less confident to raise concerns about their human rights with care and support staff and decision-makers as a result of the Covid-19 situation.**

The evidence gathered through our work informs our main concerns and suggestions for the steps that need to be taken to ensure that measures taken by the Government to address the Covid-19 pandemic are human rights compliant.

We have prepared an evidence submission for each of the groups we work with, so that the Committee members have access to the direct experiences of all three groups when considering the Government's response. **This submission focuses on the experiences of people accessing (or trying to access) care and support, their family members and people who care about them**. For the purposes of this JCHR report, the data will be shown as UK wide. We will be submitting nation specific data to devolved inquiries where appropriate.

Important demographics to note when considering the evidence contained in this report:

- **Where in the UK:**
  - 86.4% of those who responded to our call for evidence live in England,
  - 6.8% in Scotland and
  - 3.4% in Wales.
  - There were no responses identified from people living in Northern Ireland.[1]
  - 3.4% preferred not to say.

[1] BIHR has not conducted specific partnership sessions in NI yet, as our emergency response focused on responding to demand from our community partners. We will be discussing future NI collaborations in due course.

- **Disability and care and support needs:**
  - 47.5% consider themselves to be disabled (45.8% did not)
  - Over 50% receive care in their own home (either formally and/or informally)
  - 19% live in supported living arrangements
  - 12.8% live in residential living arrangements (for example, a care home)
  - 4.3% live in an inpatient setting for physical health needs, and
  - 2.1% were an inpatient setting for mental health needs.

- **People detailing experiences:**
  - 31% submitted evidence on behalf of themselves
  - 45.8% on behalf of a family member
  - 10.5% on behalf of someone they care about (not a family member)
  - the remainder selected an option not listed.

b) PANEL Approach

As a human rights organisation, we ourselves use a human rights approach. We have used the PANEL human rights framework endorsed by the United Nations in our evidence gathering and as the structure of our submission.

We take each principle in turn, sharing people's experiences and in doing so answer the questions the Committee is seeking views on through the lens of human rights:

What steps need to be taken to ensure that measures taken by the Government to address the COVID-19 pandemic are human rights compliant?

What will the impact of specific measures taken by Government to address the COVID-19 pandemic be on human rights in the UK?

Which groups will be disproportionately affected by measures taken by the Government to address the COVID-19 pandemic?

Click on the headings below to read the evidence for each human rights principle.

- Participation
- Accountability
- Non-discrimination
- Empowerment
- Legality

4. Evidence on the human rights impacts for people with care and support needs

a) Participation

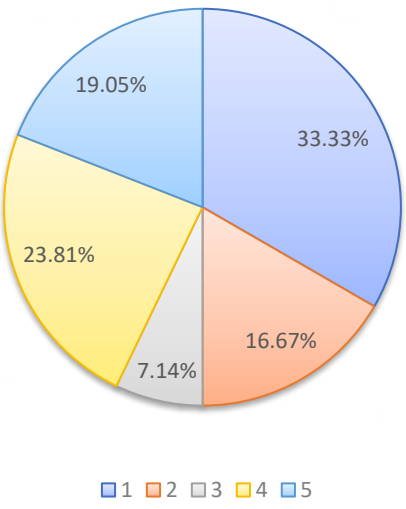
In order for the measures taken by the Government to address the Covid-19 pandemic to be human rights compliant: **People should be involved in decisions that affect their rights.** Autonomy is covered under Article 8 of the European Convention, brought into UK law in the Human Rights Act (1998), which also includes the legal duty on public authorities to respect and protect this right in their everyday functions.

In people's daily lives, this means that changes to care and support should be discussed with the individual, their family or other chosen person. Where the person has been assessed as lacking capacity to make specific decisions about care (or changes), the safeguards under the relevant capacity legislation must be met. These safeguards include, encouraging and enabling participation, considering past wishes and feeling, consulting anyone named by the person and much more.

What did people tell us about participation during Covid-19?

During Covid-19 we have seen an alarming reduction in people's involvement in decisions about their care and support.

a.1 We asked, "Since the start of Covid-19 have you been involved in decision-making affecting your care and support? Or has the person you care about been involved in decisions about their care and support during Covid-19?"



1. Yes. I am involved in decision-making. This has not changed. (33.33%)

2. Yes. I am involved in decision-making but not as much as I was before Covid-19. (16.67%)

3. Yes. I am involved in decision-making and I am involved more than I was before Covid-19. (7.14%)

4. No. I was involved in decision-making before Covid-19 but now I am not. (23.81%)

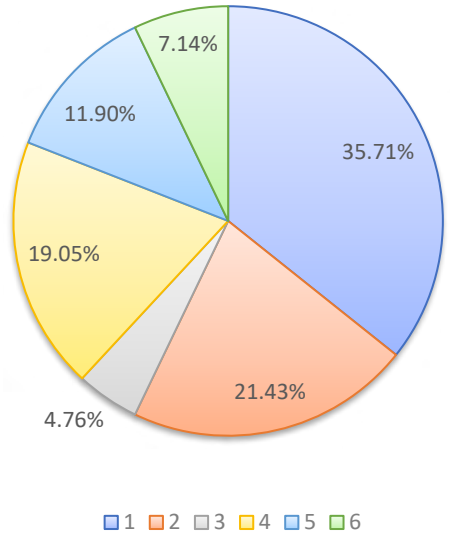
5. No. I was never involved in decision-making, even before Covid-19. (19.05%)

a.2 Further elaboration from people

"They don't even listen to and involve my parents who are my care and welfare deputies"

"Very limited understanding due to learning disability so he is only really involved in basic decisions (yes/no questions about activities, daily living)."

a.3 We asked, "When decisions have been made about your care and support during Covid-19 have you been told why the decision was made and how long it would last? Or has the person you care about been told this information?"



1. Yes- I am informed in the same way as I was before Covid-19. (35.71%)

2. Yes- I am informed but this has got worse since Covid-19. (21.43%)

3. Yes- I am informed and this has got better since Covid-19. (4.76%)

4. No- I am not informed and I wasn't informed before Covid-19. (19.05%)

5. No- I am not informed, this has only happened since Covid-19. (11.09%)

6. No decisions have been made since Covid-19 that affect my care and support (or that of my family member/ person I care about). (4.12%)

a.4 Further elaboration from people

"I had been receiving psychological treatment in another part of the country after notifiable safety incidents caused me psychological harm. Suddenly, without warning, I received an email last week explaining that the criteria for accessing their services have changed. I no longer meet the criteria and cannot continue my psychological therapy there. I was not involved in the decision - it was a decision made at meetings of the psychology department and NHS Trust. Patients were not part of that meeting. It has been devastating - and it is worse to start the treatment and have it taken away in a way that seems quite arbitary."

BIHR's recommendations for ensuring participation:

- The Government, both centrally and locally must make it entirely clear that all legal duties under the Human Rights Act (HRA) remain in place regardless of Emergency Coronavirus legislation. This includes the right to autonomy (having a say over your care) under Article 8 (HRA).

- It must be made clear that where a person's participation in decisions about their care and support is restricted, this restriction must follow the 3-stage test of lawful, legitimate, and (crucially) proportionate (the least restrictive option possible).

- Clarity must be provided around the use of Emergency Powers, it must be made clear that where any changes are made to a person's care and support, the person and their chosen family/friends (those who will be impacted) must be supported to be involved in decision making. Easements must be applied compatibly with human rights law.

- All public officials must be supported to recognise and respond to a situation in which a person's legally protected human rights are at risk. This is necessary during Covid-19 and beyond.

- The position of respect for human rights should be made clear as a central tenant of Government law, policy and guidance, rather than an optional extra.

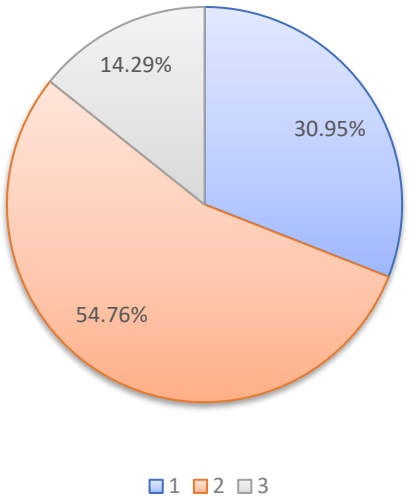
b) Accountability

In order for the measures taken by the Government to address the Covid-19 pandemic to be human rights compliant: **There should be monitoring of how people's rights are being affected, as well as remedies when things go wrong.**

The section 6 HRA duty places a legal duty on public officials (and those delivering a function of a public nature) to respect, protect and fulfil human rights. This duty is about every decision frontline staff make, the policies and protocols put in place by managers, and the strategic decisions of leadership. This does not change under Coronavirus law and policy.

What did people tell us about accountability during Covid-19?

b.1 We asked, "When a decision has been made about your care or support did workers or managers tell you about how you could challenge this decision? Or was the person you care about told this information?"



1. Yes (30.95%)

2. No (54.76%)

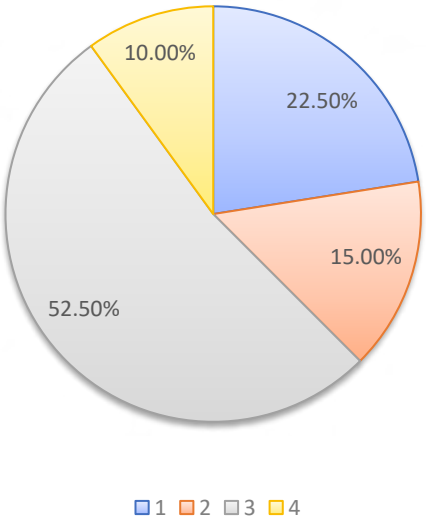
3. No but another organisation did (e.g. an advocacy group) (14.29%)

b.2 Further elaboration from people

"No. I received the email informing me of the decision. I cannot challenge it as far as I know. There should have been some preparation for such significant news..."

"Nobody in direct contact with me, just told what was happening. Yet I have full capacity. Family had issues discussed with them without my consent."

b.3 We asked, "If you raised your concerns or challenged a decision about care and support was this reviewed by the workers or managers? Or did this happen for the person you care about?"



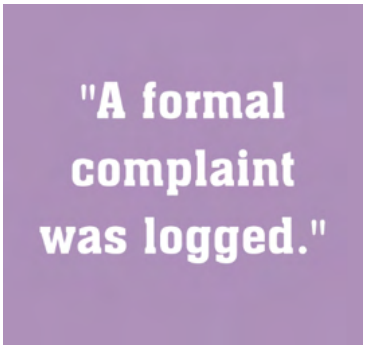
1. Yes, and I was happy with how it was handled (22.5%)

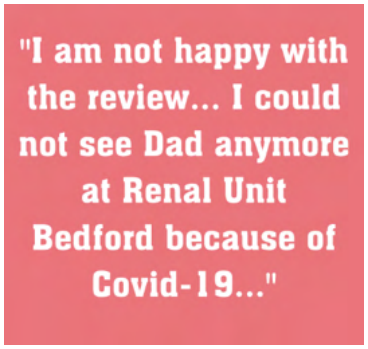
2. Yes, but I was not happy with how it was handled (15%)

3. No, there was no review (52.5%)

4. Would you like to tell us more (10%)

b.4 Further elaboration from people





BIHR's recommendations for ensuring accountability:

- There must be open and accessible processes for people, their families and those who care about them to raise issues with care and support during Covid-19.
- Where there have been changes to complaints processes as a result of Covid-19, they must be the least restrictive option available to the service (i.e. there cannot be a blanket suspension of complaints procedures, this is not a proportionate response). Staff should be made aware of these processes and be able to inform the people they support of how to raise an issue during Covid-19.
- People must be provided with easy to access, accessible information that enables them to understand what duties the Local Authority (or other public body) they are interacting with are bound by.
- There must be absolute transparency and clear communication both centrally and locally where Emergency Powers are being used across the UK. Please see our briefing on transparency issues in Scotland, here.
- Where Emergency Powers are in use (or have been in use but are "switched off") there must be monitoring both locally and centrally to ensure that these Powers are meeting intended outcomes and have not resulted in any unlawful interference with a person's human rights.
- People, their families and those who care about them must be consulted about their experiences. This enables informed decisions to be made about the continued availability of the Powers. In doing this, the Government can identify trends and concerns, including human rights flash points during the pandemic, as well as positive practice which others can learn from.
- Where the use of Emergency Powers has resulted in an unlawful restriction of rights, this should be independently investigated, using human rights as the central framework and remedies must be put in place.

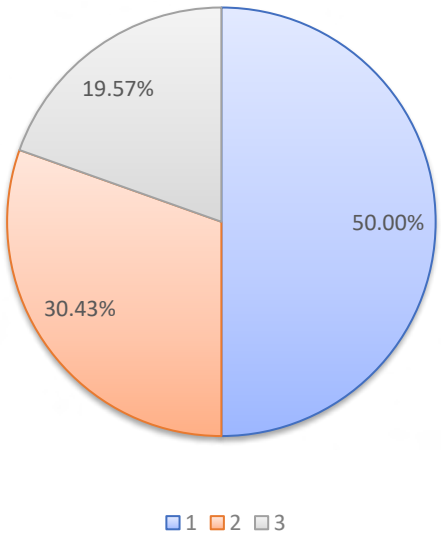
c) Non-discrimination

In order for the measures taken by the Government to address the Covid-19 pandemic to be human rights compliant: **Both direct and indirect discrimination must be prohibited, prevented and eliminated. People who face the biggest barriers to realising their rights should be prioritised.**

Article 14 of the Human Rights Act sets out that the enjoyment of rights and freedoms must be secured without discrimination on any grounds, including but not limited to sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status. Importantly, and differently to the Equality Act, this encompasses discrimination beyond the nine protected characteristics, and recognises discrimination based on combined or multiple factors, such as having Autism and living in a residential unit, or being an older person and living in a care home.

What did people tell us about which groups are disproportionately affected by measures?

c.1 We asked, "Do you think any of the problems you have experienced during Covid-19 have also been about treating you worse than other people because of a particular identity or characteristic you have? For example, this could be treating you worse because you are disabled or older. Or do you think the person you care about has been treated worse for one of these reasons?"



1. Yes (50%)
2. No (30.43%)
3. Not sure (19.57%)

c.2 Further elaboration from people

"Decision makers failed to designate psychiatric services as an essential service - these should never have been put on hold. They should have continued with appropriate PPE and social distancing. We were disadvantaged."

"Disability"

"Non-verbal young autistic man with learning disabilities and epilepsy"

"Race/ethnicity"

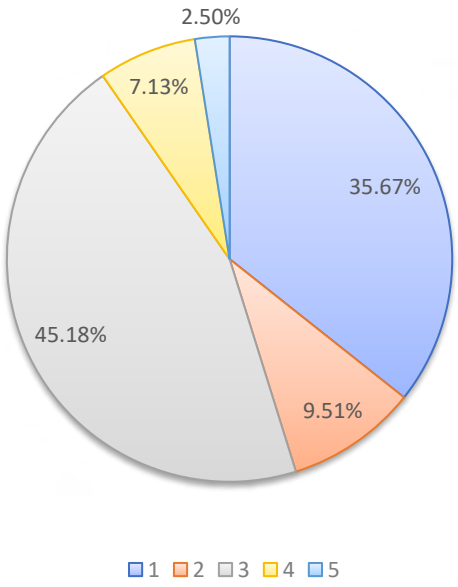
"Bisexuality"

"Discrimination over age"

"Denied equal medical treatment"

"Automatic DNR due to age, not my general health"

c.3 We asked, "Do you think people making decisions about your care and support during Covid-19 considered your specific characteristics or needs? This could include any disabilities, mental health or capacity issues, race or ethnicity, age, gender or other characteristics or needs. Or decision-makers thought about the characteristics or needs of the person you care about."



1. Yes, my characteristics were considered in a positive way (35.67%)

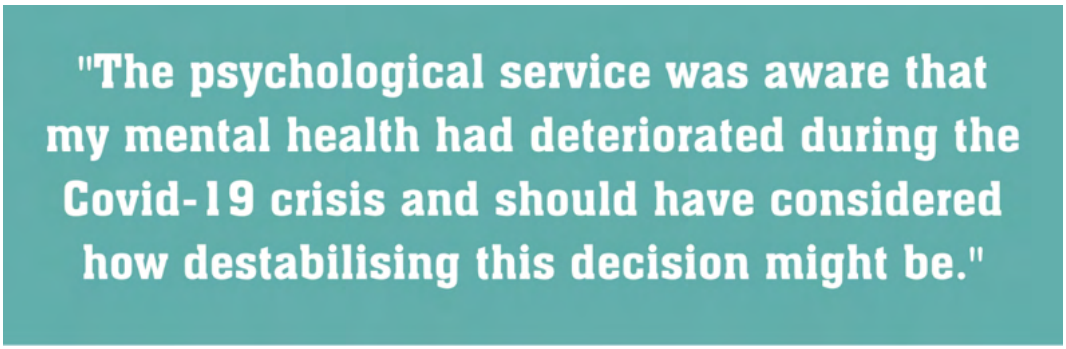
2. Yes, my characteristics were considered in a negative way (9.51%)

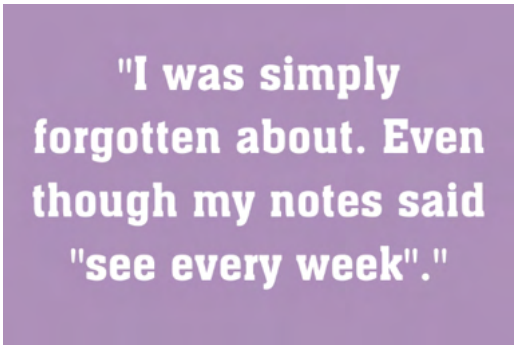
3. No, my characteristics were not considered (45.18%)

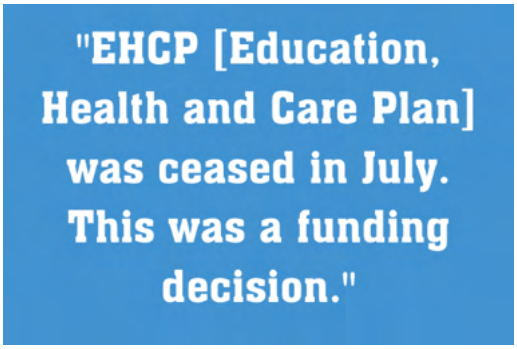
4. No decisions have been made since Covid-19 that affect my care and support (or the person's) (7.13%)

5. Other (2.5%)

c.4 Further elaboration from people







BIHR's recommendations for ensuring non-discrimination:

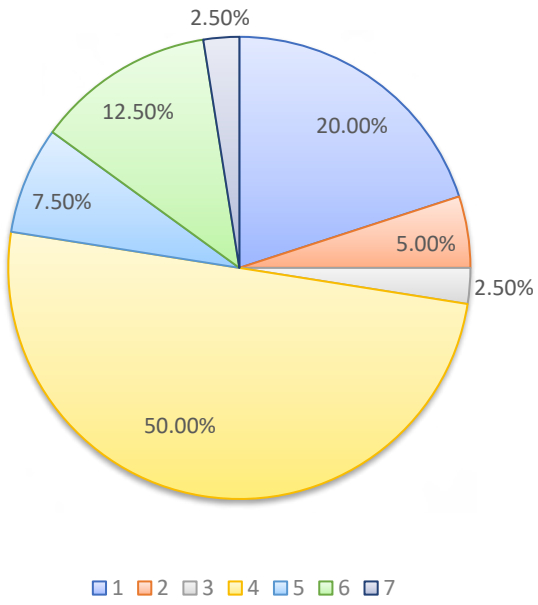
- The Government must ensure that all public officials are fully trained, resourced and supported to practically implement their legal duties under both the Human Rights Act (1998) and the Equality Act (2010).
- The Government must make it entirely clear that these non-discrimination legal duties have not changed as a result of Coronavirus, and to ensure that their actions responding to Covid-19 are not discriminatory in themselves.
- Where the Government has knowledge that discrimination has occurred (i.e. through this evidence call) this should be independently investigated, using human rights as the central framework and remedies put in place.

d) Empowerment

In order for the measures taken by the Government to address the Covid-19 pandemic to be human rights compliant*:* **Everyone should understand their rights and be fully supported to take part in developing policy and practices which affect their lives.**

What did people tell us about empowerment during Covid-19?

d.1 We asked, "Since the start of Covid-19, when a decision is being made about your care and support have decision-makers told you about your human rights? Or has the person you care about been told this information?



1. Yes- I am informed in the same way as I was before Covid-19 (20.00%)

2. Yes- I am informed but this has got worse since Covid-19 (5.00%)

3. Yes- I am informed and this has got better since Covid-19 (2.50%)

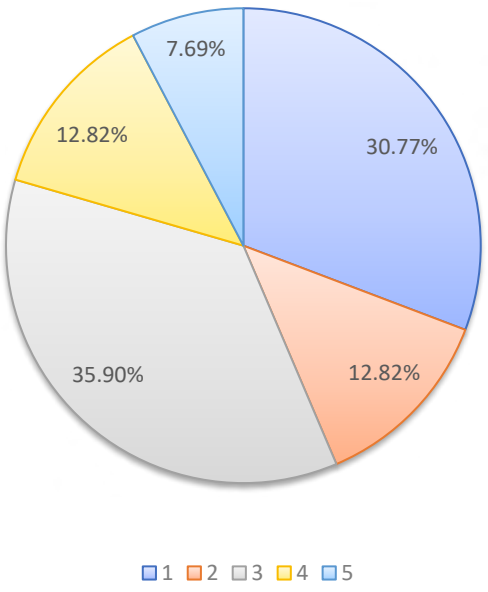
4. No- I am not informed and I wasn't informed before Covid-19 (50.00%)

5. No- I am not informed, this has only happened since Covid-19 (7.50%)

6. No decisions have been made since Covid-19 that affect my care and support (or the person's) (12.50%)

7. You can tell us more if you want to (2.50%)

d.2 We asked, "Do you feel able to talk about risks to your human rights with staff when decisions are being made about your care and support? Or can the person you care about do this?"



1. Yes- I feel confident, this hasn't been affected by Covid-19 (30.77%)

2. Yes- But I feel less confident than I did before Covid-19 (12.82%)

3. No- I don't feel able to, Covid-19 has made this worse (35.90%)

4. No- but this hasn't been affected by Covid-19 (12.82%)

5. No decisions have been made since Covid-19 that affect my care and support. Or decisions affecting the person I care about. (7.69%)

d.3 Further elaboration from people

"I have very complex language and learning needs. My human rights have not been respected before, for example my room was dirty… I was wearing other people's clothes. They wanted to restrain me to give me immunisations. My mum and dad complained and fixed these things but they are very concerning."

"Have tried and just brushed off and felt punished in other ways by trying to get my rights upheld. Either ignored or things made difficult in other areas"

"Yes - my Deputy for Property and Affairs raises any concerns."

BIHR's recommendations for ensuring empowerment:

- The Government communications about Covid-19 (and beyond) should be centred in human rights. Thus far there has been very little evidence of this, even though the main responses to the pandemic focused on rights-restricting measures.
- All public officials must be trained, resourced, and supported to embed human rights law in every interaction and to involve people in those discussions and decisions.
- People must be provided with easy to access, accessible information that enables them to understand their rights during Covid-19.
- The Government must make it clear that everyone in the UK has human rights protected in law, that these are relevant to their everyday interactions with public authorities, with clarity on which rights can be restricted (the process for doing this lawfully, legitimately and proportionately) and which can never be restricted even during a pandemic for example, the right not to be tortured or treated in an inhuman or degrading way (Article 3, HRA).

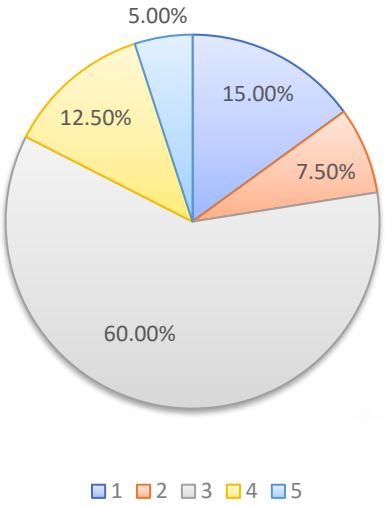
e) Legality

In order for the measures taken by the Government to address the Covid-19 pandemic to be human rights compliant**: Approaches should be grounded in the legal rights that are set out in domestic and international laws.**

Domestically we have 16 rights under the HRA. Some of these rights can be restricted in certain very specific circumstances for example, to protect the individual or the wider public from harm). Where this has been the case during Covid-19, any restrictions must be applied lawfully, for a legitimate aim and in a way that is proportionate to the risk. Other rights within the HRA, such as the right to life, can never be lawfully interfered with by the state, that remains the case during Covid-19.

What did people tell us about legality during Covid-19?

e.1 We asked, "Have you been told about which laws allow changes to your care and support during Covid-19? Or has the person you care about has been told this information?"



1. Yes, I was told which law allowed this, but I was not given details about what law (15%)

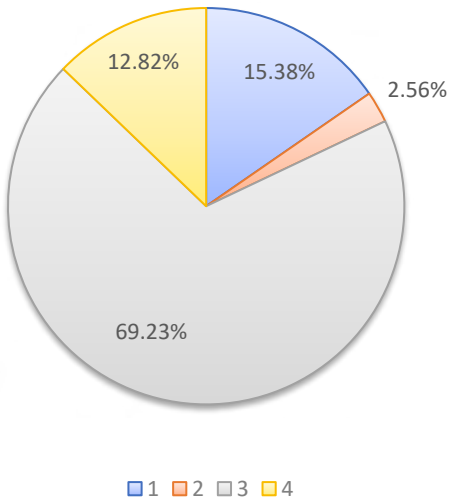
2. Yes, I was told which law allowed this and I was given details about the exact law which allowed this (7.5%)

3. No, I was not given any information about which law allowed this (60%)

4. No decisions have been made since Covid-19 that affect my care and support. Or that affect the person I care about. (12.5%)

5. Other (2.5%)

e.2 We asked, "Have workers or managers providing your care and support told you that your rights under the Human Rights Act have not changed during Covid-19. The duty of care and support providers to respect and protect human rights has also not changed. Or has the person you care about been told this information?"



1. Yes - I was provided with specific information that my human rights had not changed (15.38%)

2. Yes - I was told my human rights were the same, but not given any specific information (2.56%)

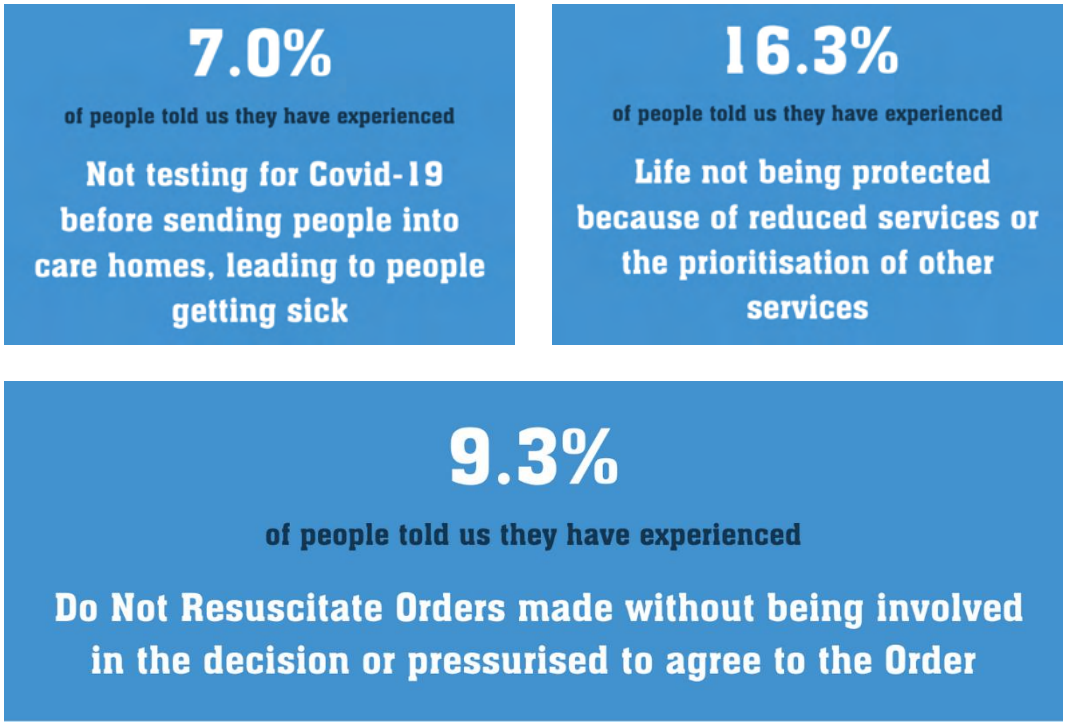
3. No - I was not provided with information about whether my human rights protections had changed in this time (69.2%)

4. No decisions have been made since Covid-19 that affect my care or support. Or that affect the person I care about. (12.82%)

e.3 Key human rights issues identified by people, their families and those who care about them during Covid-19:

People accessing (or trying to access) care and support who responded to our evidence call identified experiencing or being aware of the following rights issues during Covid-19.

Right to life (Article 2 HRA)



Right not to be tortured or treated in an inhuman or degrading way (Article 3 HRA)

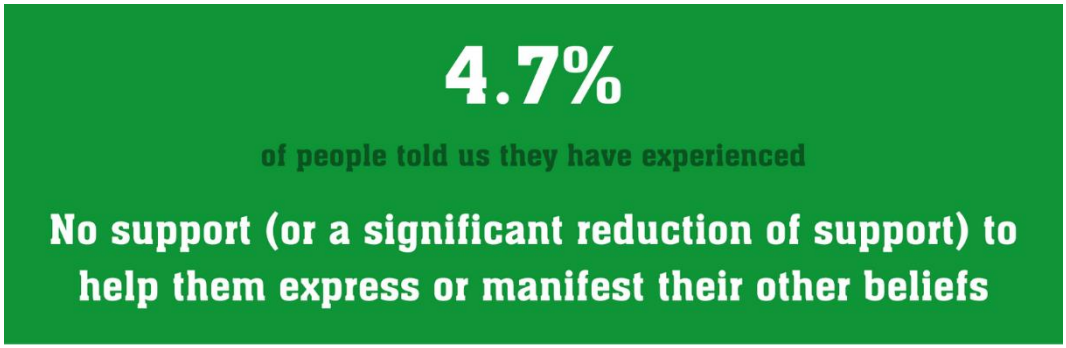
Right to liberty (Article 5 HRA)

Right to a fair trial (Article 6 HRA)

Right to respect for private & family life, home and correspondence (Article 8 HRA)

Freedom of thought, conscience & religion (Article 9 HRA)

Freedom of expression (Article 10 HRA)



Freedom of assembly and association (Article 11 HRA)

Right to non-discrimination (Article 14 HRA)*

*Article 14 is covered in more detail on under non-discrimination above.

Right to education (Article 2, protocol 2 HRA)

Peaceful enjoyment of possessions (Article 1, protocol 1 HRA)

BIHR's recommendations for ensuring legality:

- People accessing (or trying to access care and support), their families and those who care about them must be supported to know their rights and how to use them to challenge poor practice. To achieve this, accessible information on human rights and the law surrounding decisions made in health and care settings should be available in places where care and support are accessed. Access to professionals trained to support people with their rights in care and support and with challenging decisions should be available where needed.

- Frontline staff must be trained, resourced, and supported to recognise and respond to a situation in which a person's legally protected human rights are at risk. In particular, risks to rights which can never be lawfully justified, such as being left in an inhuman or degrading situation. This is necessary during Covid-19 and beyond.

- Local leadership should have oversight of these human rights risks and use this to support non-discriminatory and proportionate service-level and strategic decisions in responding to the pandemic.

- Where the use of Emergency Powers has resulted in an unlawful restriction of rights, this should be independently investigated, using human rights as the central framework and remedies put in place.

- The Government must make it clear that as a foundation law, any other pieces of new legislation or guidance must be applied compatibly with human rights law. Furthermore, the Government must ensure public officials across the UK are fully trained, resourced, and supported to meet these legal duties.

5. BIHR's Call to Action

At BIHR, we welcome the JCHR's call to evidence into the human rights implications of Covid-19. The duty to investigate where human rights may have been risked, to remedy this and to put measures in place to prevent this from happening again is crucial. However, an inquiry which exists in isolation of immediate measures to ensure rights are respected and protected is not adequate. It cannot be the case that the UK operates on the assumption that there is an acceptable level of breaching human rights as long as this is reviewed afterwards.

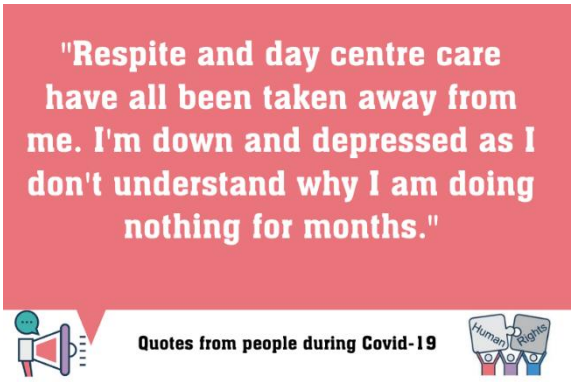
People working in health and care (and in other public services) do not want to make human rights breaching decisions. They want to be given the tools, resources, and support to uphold human rights in every single interaction with a person or their family. This is the case all the time but is even more crucial during Covid-19 when difficult decisions need to be made.

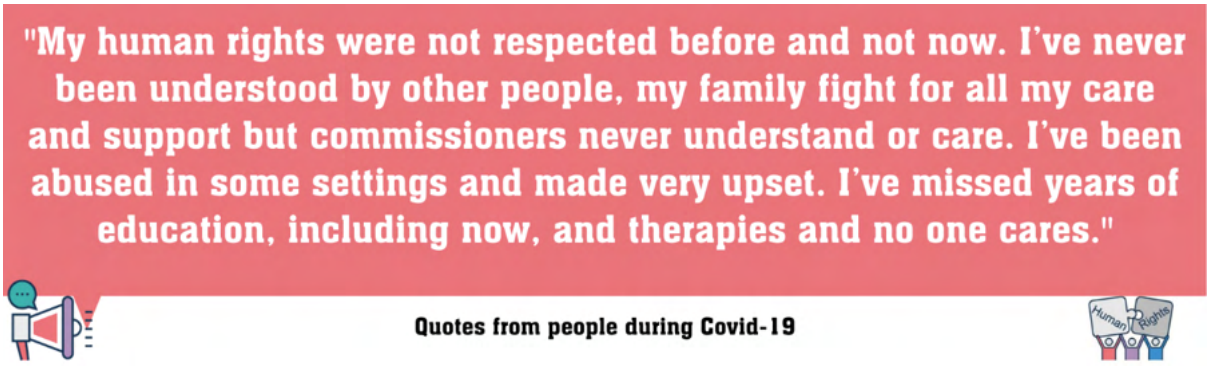
At BIHR, we know from the data gathered from people working in health and social care that, "76.92% of people working in health and care during Covid-19 were not provided with legal training or clear information about upholding human rights law." This figure correlates directly with the human rights issues raised above by people, their families and those who care about them.

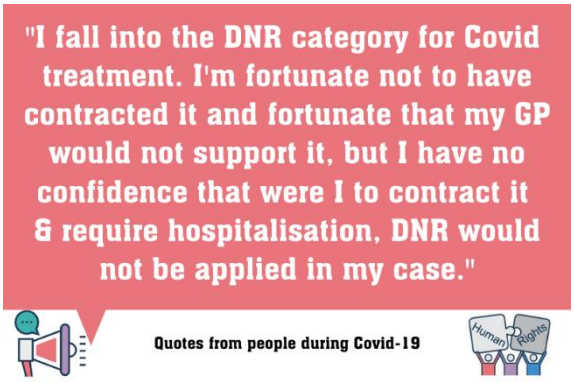
The UK's approach to making human rights real for people in the UK needs to be grounded not in inquiries or reviews but in immediate actions now to ensure that rights are upheld in every interaction a person has with a public service (or a service delivering a public function).

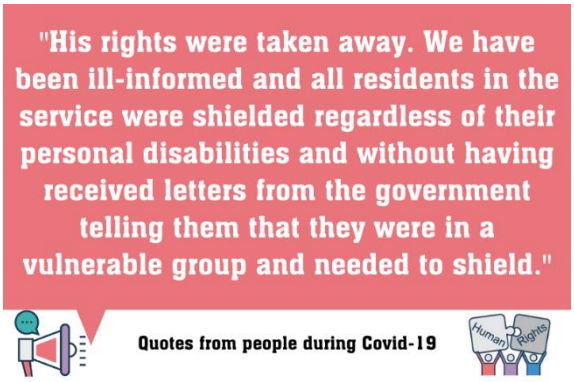
6. The voices of people

Finally, we asked people accessing (or trying to access) care and support, their families and people who care about them, "Is there anything else you would like to tell us about human rights during Covid-19?"









"It is difficult for most families to find out about about human rights for vulnerable people. Neither care providers nor social workers typically provide this information as for some, it is seen as a potential barrier to the efficient provision of care. Covid-19 has exasperated this issue."

Quotes from people during Covid-19

"The disabled, those with complex needs and their families have been completely ignored... My son hasn't had respite for 3 months saving our authority in the region of £3,000. No school provision at all for our younger autistic son who has lost 20lbs in weight and has been self harming even though my local MSP said she supported our request for some access to his special school for essential therapies such as hydrotherapy. It's shameful what has been allowed to happen. No consideration has been given to those with disabilities and even now the mandatory masks have made things worse as people criticise and condemn those who are exempt, even suggesting we shouldn't be taking our sons out of they can't wear a mask."

Quotes from people during Covid-19

"I feel they've not been taken into account. I'm scared for the future of disabled people in the UK. It feels we are an after thought and a burden."

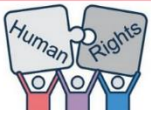
Quotes from people during Covid-19

"I think my partner felt abandoned and I found trying to access enough support very difficult."

Quotes from people during Covid-19

"My son is only 24 years old and has autism and learning disabilities, he lives with 6 other young men. He has been allowed no family visits for 17 weeks now, he has no understanding of Covid-19 or the restrictions imposed. All his activities have been stopped other than walk or in the home. He is non verbal and can not communicate by telephone and video chats would increase his anxiety. I usually see him every 2 weeks for 2 consecutive days and assist in supporting his care those days. I have always been fully involved in his care plan and decisions. Since Covid I can not see him, blanket decisions have been made and all risks relate to Covid not his individual needs or reference to his emotional or mental health or his human rights or liberty. I am not allowed to see him yet as I am considered a risk as my son will probably not comply with social distancing and cannot wear PPE due to behavioural issues. He doesn't understand and is being discriminated against because he lacks capacity. I am heartbroken and don't know when it will end."

Quotes from people during Covid-19



For more information about BIHR's support, resources and research on this issue please visit our Human Rights and Coronavirus Hub here.