Coronavirus and the Human Rights of young people who are autistic or have learning disabilities and are detained in hospitals

EasyRead version of:
Human Rights and the Government’s response to COVID-19: The detention of young people who are autistic and/or have learning disabilities.
Joint Committee on Human Rights 12 June 2020
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7. What the words mean

Some new or difficult words are in bold. We explain what they mean at the end of this paper.
The Joint Committee on Human Rights wrote this paper.

A joint committee is a group of members of Parliament and members of the House of Lords who look at what the Government does. We write down what we find out and say what we think should happen.

This paper is about a report we wrote in 2019 and how coronavirus or COVID-19 has affected the things we said should happen.

Coronavirus is a serious illness caused by a new virus. Some people call this a pandemic because it affects people in many different countries.
Our 2019 report

In November 2019 we wrote a report about children and young people who are autistic or have learning disabilities and are detained in hospitals.

Detained means people are kept in a hospital and not allowed to leave. Hospital means private or NHS hospitals that supporting people with their mental health or behaviour.

The report said many young people who are detained in hospital lose their right to:

- liberty
- family life
● be safe from abuse

● not be discriminated against.

We said the Government should act quickly to:

● change the way the CQC checks these services

● change the rules about keeping people in hospital under the Mental Health Act
• set up a special unit at the Prime Minister’s Office at 10 Downing Street to fight for the rights of young people who are autistic or have learning disabilities.

The government should have replied to the report in February this year. They told us that they have not done this because of the pandemic.
This new report

The Government made lots of new rules to try to stop the spread of coronavirus. These have changed everyone’s lives.

We started a new inquiry in March 2020 to find out how these rules affect the rights of young people who are detained.

We listened to:

- families of young people who are autistic or have learning disabilities and are detained
- the CQC
Some young people are not held in hospital under the *Mental Health Act*. This means they are free to leave. But many young people or their families are worried about asking to leave in case they are forced to stay under the *Mental Health Act*.

So when we use the word *detained*, we mean anyone in a private or NHS hospital that supports people with their mental health or with behaviour that challenges services.
1. Visits and the right to family life

What families told us

One mother said she has not been allowed to visit her son since lockdown started. This made him so scared and anxious that he tried to kill himself.

Another mother said she was only allowed to visit her daughter on her birthday. Her daughter is so upset about this that she bangs her head and hurts herself badly.

The right to family life

The European Convention on Human Rights says the right to family life includes support to stay in touch with your family. It is against the law to ban all patients from having visitors without thinking about each person’s needs.
Taking away the right to family life can also mean young people lose other rights. For example, they might be restrained or put into solitary confinement if they become upset and angry. This takes away the right to freedom from torture, inhuman and degrading treatment.

What the guidance says

Guidance is the Government’s advice to people and organisations about how to keep people safe during the pandemic.

In April this year the NHS said hospitals should not allow visitors in case they spread the virus. But one carer or family member could visit a patient with mental health issues who will be very upset if they do not see their family.
In June the NHS said that hospitals can let people visit again. But hospitals are still allowed to stop people visiting if they think it is not safe.

Hospitals must look at the risks for each patient and decide what is best for them. It is against the law to just ban visits for everyone.

Other ways of doing things

Both the mothers said it is difficult to keep in touch with their son and daughter. Things like Skype or Facetime do not work well for them.
What we think

Stopping all family visits takes away the family’s and the young person’s **human rights**. It breaks the European **Convention on Human Rights**, the rules about the **Mental Health Act** and NHS **guidance** on **coronavirus**.

The NHS should act quickly and write to all private and NHS hospitals to say families should visit unless they can show it is not safe for that person to have visitors.

If a hospital decides a visit is not safe they must write down why and give copies to the patient and to their family. They must look at the decision again, at least every 48 hours.
2. Restraint and solitary confinement

What families told us

2 mothers told us that since coronavirus their children had been:

- **restrained** more than before

- been kept away from other people more

- given more medication than usual.
They thought this was mostly due to:

- having staff they did not know when their usual staff were off sick
- things hospitals did to stop the *virus* spreading
- being upset and anxious about not seeing their families.

The right to freedom from inhuman and degrading treatment

In our 2019 report we said hospitals should tell families if their son or daughter is *restrained* or kept away from other people.
But the mothers we spoke to found out from their children. Not the hospital. This means families do not know what is happening to their children.

One mother said she has never seen her daughter so upset in the last 10 years.

Staff often do not try to calm people down in other ways before they use restraint.

**How often are people restrained**

We asked NHS England and CQC if more people had been restrained or kept in solitary confinement since lockdown started.
Neither of them had enough information to be sure about this.

NHS England did not think it was happening more. But CQC thought it was happening more in some organisations.

We urgently need good information at the time things are happening.

Last October NHS England set up a new team to make services better for children and young people who are autistic or have learning disabilities.

The Children’s Commissioner for England checks what this team is doing.
We hope this will mean we have better information about what is happening when young people are detained.

What we think

Staff should only restrain someone if they have tried all the other ways to calm them down.

They should follow rules and write down when and why they restrain someone, keep them away from other people or give them extra medication. Hospitals should send this information to the Secretary of State for Health and Social Care each week.

Hospitals must tell families each time a child or young person is restrained or kept in solitary confinement.
3. Inspections

What is happening for young people who are detained

The CQC inspects (checks) hospitals to make sure they give good, safe care.

They should protect the rights of children and young people who are detained. But they have stopped doing regular checks because of coronavirus.

Parents cannot visit the hospitals either. There is no one to check what is happening and this makes young people more at risk of abuse.
Inspections during coronavirus

In March 2020 the CQC told health and care services they would stop doing regular inspections. They would only look at services where they thought people might be at risk.

Since then, CQC have only checked 2 mental health units for children and young people and plan to visit 2 more.

They do not tell managers they are coming.

There are virtual checks to find out what life is like for people in hospital under the Mental Health Act. These video calls with staff, patients and advocates help CQC decide if they need to visit the service.
Last year a TV programme showed patients who were autistic or had learning disabilities being **abused** in Whorlton Hall hospital.

The **CQC** inspected this hospital before the TV programme.

They were worried about people’s care but could not find enough **evidence** to prove what was going on. We think it will be even harder to find out what is happening with **virtual** visits.

After the TV programme we asked an independent **inquiry** to look at why the **CQC** did not act on **abuse** at Whorlton Hall. The inquiry said they would have found out more if they had not told managers they were coming. They also suggested how **CQC** could change the way they **inspect** services.
The CQC asks patients and families to tell them about poor care or abuse. But the parents we spoke to did not believe CQC would act if they told them they were worried about their children’s care.

What we think the CQC should do

Not tell services they are going to inspect them. Especially when a young person, parent or whistle blower tells them about abuse.

Visit hospitals in person if people have been abused there, had poor care or the last inspection said services need to get much better.

Set up a telephone hotline for patients, families and staff to complain or report worries about abuse or poor care.
Check to see if services are better or worse in different parts of the country and write this down in their reports.

Check that services support young people with the right to family life and write down what they find in all their reports.

Use the ideas from the independent inquiry into Whorlton Hall to write a plan to change the way they inspect services.

The government must make sure CQC inspectors have the right personal protective equipment (PPE) to safely visit hospitals.
4. People who do not need to be in hospital

How being detained in hospital can harm young people

The law says young people who are autistic or have learning disabilities can only be detained if they need to have an assessment or hospital treatment. But our 2019 report said many young people do not get this treatment. This takes away their human rights.

One mother said her son had to stay in his room for over 7 weeks when other patients had coronavirus. He had staff he did not know when his usual staff were off sick. This meant he got very upset and harmed himself. He was given more medication, restrained and kept on his own.

Young people are more likely to catch coronavirus in hospital. The law on human rights says governments must protect people in their care. This includes people in hospital.
Leaving hospital during the pandemic

Even before coronavirus the Government’s plan to move people from hospital to live in the community was not working. Local councils and the NHS have been working on this for many years. But almost nothing has changed for young people and their families.

Now it is even more important to move people out of hospital to stop them catching the virus.

NHS England told us they were moving more people out of hospital when coronavirus started. But families said their children were going to leave hospital but this stopped because of the virus.

One of the big problems is there are still not enough workers in the community with the right skills.
What we think

Things urgently need to change so young people can move into safe homes in the community.

The Government should do all the things in our 2019 report especially:

- bring in a law to say there must be enough mental health services in the community or services to support behaviour

- change the Mental Health Act 1983 so people cannot be "detained" if they do not need hospital treatment.
5. Coronavirus infections and deaths

Getting the right information

On 7th May we wrote to Matt Hancock the Secretary of State for Health and Social Care. We asked him:

- how many people who are autistic or have learning disabilities caught coronavirus and died from it
- how many of these people were in mental health hospitals and how old they were.

NHS England started giving these numbers every week from the 16th May.
it is not always clear if the person died from coronavirus. But by the end of May about 500 people who are autistic or have learning disabilities caught coronavirus and had died from it.

Lancaster University looked at all the numbers and said people with learning disabilities are at more risk of coronavirus than other people. Especially when the pandemic is at its highest.

NHS England told us no young people under 25 have died from coronavirus in mental health hospitals. They could not tell us how many people caught the virus.

What we think

We must have clear information about how many people who are autistic or have learning disabilities catch coronavirus and die from it. This includes people who are detained.
Every week the government should say:

- how old the people were

- how many people died in mental health hospitals after they moved there from somewhere else.
6. What should happen next

Even before coronavirus young people lost their human rights when they were detained in hospital.

Now families and the CQC cannot visit, young people are at more risk of abuse, being restrained or kept in solitary confinement.

They are also more likely to become very ill with coronavirus because they have other health conditions.

This is a serious crisis. Young people and children are having many rights taken away from them:

- the right to family life
● freedom from torture, inhuman and **degrading** treatment. This includes abuse

● the right to **liberty** (freedom)

● the right to life. This includes not being at risk from the **virus**

● not be **discriminated** against.

The government must act quickly to stop this and do all the things we say should happen in this report and in our 2019 report.
Abuse - when someone hurts you or treats you badly.

Care Quality Commission (CQC) – an organisation that checks services like GPs, hospitals and care homes to make sure they give good, safe health and social care.

European Convention on Human Rights – a promise made by Governments to say they will make sure people get their rights.

Coronavirus (COVID-19) - a serious illness caused by a new virus.

Children’s Commissioner – a public organisation that protects the rights of children and young people in England.

Degrading – to treat someone in a way that makes them feel they are worthless.

Detained - kept somewhere, like a hospital, and not allowed to leave.

Discriminated - to be treated differently from other people because of who you are.

Evidence – information that proves something has happened.

Guidance - the Government’s advice to people and organisations about how to keep safe during the pandemic.

Human rights – rights and freedoms that everyone should have.
**Inspection** – look into or check services to make sure they are safe.

**Inquiry** - an organised way to ask questions and find out about something.

**Liberty** – freedom to do what you choose and go where you want.

**Mental Health Act 1983** – a law that protects the rights of people who need treatment for their mental health.

**Personal protective equipment (PPE)** - masks, aprons, gloves or overalls to protect you from a virus.

**Restrain** – to hold someone back or stop them doing something.

**Rights** - things that should happen for everyone.

**Secretary of State for Health and Social Care** – the Government minister in charge of these services and how they are run.

**Sectioned** - kept in hospital under the Mental Health Act 1983

**Solitary confinement** – to be kept alone and away from other people for 22 hours a day or more.

**Virtual** - not there in person

**Virus** - a tiny germ that gets into your body and can make you ill.

**Whistle blower** – someone who secretly reports something they feel is wrong. For example, a member of staff who is unhappy with something that is happening in their service or organisation.
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