

# Our rights, our voices

Young people's views on  
fixing the Mental Health Act  
and inpatient care

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# Executive summary

Hospital should be a safe place where everyone can get treatment for mental health problems.

But for young people the reality is often very different. They're being inappropriately put in adult wards and far from home. Being restrained, ignored and left to deal with a confusing system on their own. And when they get back to their communities, support they were promised often never materialises.

Young people told us about their experiences for this research. Most of their experiences were very poor. You can hear their voices throughout this report. They describe a system that's failing them and sometimes putting them in danger and making their mental health worse.

We also asked young people what needs to change. We've listened and recommended how the UK Government should amend the Mental Health Act 1983 to make the reforms more effective for young people and called for collective action and investment to address failings in inpatient care so young people can receive safe, therapeutic care.

Young people enter hospital at an incredibly vulnerable point in their lives. We need to do much more to make sure each one gets the care and support they deserve.

The focus of our research is Mental Health Act reform. However, young people told us about other problems – from use of cameras to concerns about agency staff. These also need urgent attention and should be part of a statutory public inquiry into failings in inpatient care.

## Definition of 'young people'

We often use the term 'young people' in this report to refer to those aged 11–25. This is based on feedback that those aged over 11 would prefer to be called 'young people' than 'children.' **In this report, we are only talking about the experiences of young people under 18.** We use 'under-16s' or 'under-18s' when there are legal or policy distinctions.

## Thank you

Thank you to all the young people who shared their time and experiences with us.

# Summary of recommendations

## **Make the reforms work for under-16s**

Many of the new rights and safeguards in the draft Mental Health Bill will apply differently depending on whether a young person is 'competent'. However, the Bill has no details on how to assess competence. This must be changed to include a requirement for a decision-making test for under-16s. This test should apply to decisions about admission and treatment in inpatient settings.

Over half of young people admitted informally when they were under 16 were admitted by parental consent, rather than their own. This means they wouldn't have had the safeguards available to detained patients. Section 131 of the Mental Health Act 1983 must be changed to make clear that 'competent' under-16s can consent to, or refuse, informal admission and that this cannot be overruled by parents.

## **Stop young people going on adult wards**

The UK Government needs to stop young people being admitted to adult wards. There should be statutory presumption against this and the Secretary of State for Health and Social Care should have to approve every case where an under-16 is put on an adult ward.

## **Have fewer out-of-area placements**

NHS bodies must be required to improve procedures when considering an out-of-area placement. New requirements could be similar to duties on local authorities under the Children Act 1989 for young people in out-of-area social care placements.

## **Support young people in the community**

The UK Government must speed up the shift to young people being looked after in their communities. To achieve this, the Mental Health Bill should include a duty on Integrated Care Boards (ICBs) to make sure the needs of under-18s can be met in their communities without admitting them as inpatients. This should include multi-agency provision for young people with complex needs currently placed in unsuitable and unregulated social care accommodation.

## **Provide greater access to advocacy for young people**

Young people told us the importance of getting independent support in hospital. The Mental Health Act should be reformed to ensure that all inpatients must get advocacy and under-18s should get an advocate without having to ask for one.

## **Less restraint on young people**

People in the ‘responsible person role’ under the Mental Health Units (Use of Force) Act 2018 should address the high rate of restraints used in young people’s mental health services. They must make sure their services provide person-centred care and reduce restraint.

## **More rights for ‘informal’ patients**

Care and treatment plans for young people treated in hospital informally should be included in the Mental Health Bill. The UK Government has committed to making care and treatment plans a requirement for informal patients – but this doesn’t appear in the Mental Health Bill. Young people we

heard from wanted informal patients to have these plans.

## **Include guiding principles in the Mental Health Act**

The Mental Health Bill should be amended to include the four guiding principles outlined in the Independent Review of the Mental Health Act. This would help raise expectations for inpatient care and provide a ‘hook’ for young people to challenge poor care.

## **Eliminate discrimination**

Young people shared experiences of racism and also discrimination due to autism. An extra equality principle must be added to the guiding principles to help eliminate discrimination and promote equity through protected characteristics.



## **Better education in hospitals**

The Department of Health and Social Care and the Department for Education should improve support for education in hospital. They should publish guidance for secondary schools on how to make sure young people who have been admitted to a mental health ward can get education and continue learning. Admission to hospital for mental health, should be an automatic trigger for an assessment or review of an Education Health and Care plan.

## **Proper planning for leaving hospital**

There's currently no statutory process to ensure multi-agency planning for young people's discharge from inpatient settings. The UK Government must make this process clear. They must particularly consider care-experienced young people who are more likely to get support from a range of services.

## **Publish more accurate information**

The Mental Health Bill must include a duty on the Secretary of State to make sure national data on young people's experiences as mental health inpatients are regularly collected and published. This should include everything from the time they wait for a hospital place to the number of young people admitted informally. NHS England should also provide greater transparency on when Mental Health Act Assessments are being overruled for under-18s.

## **Commit to wider reform of inpatient care**

Mental Health Act Reform won't solve everything. We need to see leadership and investment from the UK Government, and cultural transformation from the NHS, to address decades-long failings in inpatient care and to provide safe, therapeutic care for people with mental health problems. This includes launching a statutory public inquiry into failings in inpatient care across England.

# Language

## Advance decisions

Instructions about what medical treatment a person wants to refuse in case they lose the ability to make these decisions in the future.

As part of the UK Government's plans to reform the Mental Health Act, advance decisions to refuse treatment (mainly medication) will be given 'legal weight'. Treatment can still be given but a series of improved safeguards must be followed first.

Current proposals say only advance decisions made by over-18s will have any legal weight.

## Advocate

A person who both listens and speaks out for someone.

An Independent Mental Health Advocate (IMHA) is an advocate specially trained on rights under the Mental Health Act. They have responsibility to help and support people when they're detained.

## Capacity

The ability to understand information and make decisions. Capacity is defined in the Mental Capacity Act 2005. It only applies to people aged 16 and above.

## Care and treatment plans (CTPs)

Statutory (required) care plans for people detained under the Mental Health Act. They are not yet in force but have been suggested as part of the UK Government's plans to reform the Mental Health Act. The UK Government has said they will be extended to informal patients under 18 but this isn't included in the Bill.

## Care experienced

A young person who has been in care at some point in their life. This includes spending time in the care of the local authority (like foster care or a children's home) or being privately fostered.

## Competence

Being competent means that a young person who has sufficient understanding and intelligence to make the decision can consent (agree) to medical treatment. In this report, we talk about competence for under-16s. How to assess competence is not defined in legislation

## Education, health and care plan (EHC plan)

Statutory (required) care plans for young people up to 25. They set out the young person's educational, health and social needs and set out the additional support to meet those needs. The special educational provision set out in the plan must be provided by a local authority.



## Enhanced safeguards around treatment

New safeguards suggested by the UK Government to improve people's choice on the treatment they get in hospital. It includes:

- A new duty on doctors to take into account a person's views, wishes and feelings when deciding to give them treatment under the Act.
- Improved safeguards that must be followed before treatment (mainly medication) can be given when someone has refused it.
- A right to make legally binding advance decisions about refusing treatment (mainly medication).

## Guiding principles

The Independent Review of the Mental Health Act recommended that four guiding principles should shape the Bill. The aim is to improve experiences for patients by setting standards for services and providing clear expectations for their care and treatment.

## Independent Review of the Mental Health Act

An Independent Review of the Mental Health Act that made 154 recommendations for improving legislation.

The UK Government-commissioned independent review looked at:

- how the legislation is currently used
- its impact on service users, families and staff
- recommendations for improving the legislation and related practices.

## **Informal**

People staying in a psychiatric hospital who aren't detained under the Mental Health Act.

## **Opt-out advocacy**

When someone is automatically given an advocate unless they ask not to have one.

## **Personal adviser**

Someone who works with care leavers to make sure they have the right support when they leave care.

## **Section 117 aftercare**

Some people who have been kept in hospital under the Mental Health Act can get free help and support after they leave hospital. The law that gives this right is section 117 of the Mental Health Act. It is often called 'section 117 aftercare'.

## **Sectioned**

Being kept in hospital under the Mental Health Act. Different types of 'sections' have different rules to keep someone in hospital. How long a person can be kept in hospital depends on which section they're detained under.

## **Young people**

We often use the term 'young people' in this report to refer to those aged 11–25. This is based on feedback that those aged over 11 would prefer to be called 'young people' than 'children.'

In this report, we are only talking about the experiences of young people under 18. We use 'under-16s' or 'under-18s' when there are legal or policy distinctions.

# Part 1

## Introduction and background

More young people need support with mental health problems than ever before. In 2017, 1 in ten 17- to 19-year-olds experienced mental health problems. Now 1 in 4 do.<sup>1</sup>

Some are more affected than others. Young people living in poverty,<sup>2</sup> LGBTQ+\* young people and young people from Black and Black British communities\*\* are all more likely to experience mental health problems than their friends.

Despite this mental health crisis, many young people can't get the help they need.

Years of underinvestment in mental health services mean the NHS is often only able to see people with the most serious problems. This, and long waiting lists for services, mean young people are left to fall between gaps in support.<sup>3</sup>

In our recent survey with YoungMinds, 58% of young people who tried to get mental health support told us their mental health

got worse during their wait. Over a quarter (26%) tried to take their own life.<sup>4</sup>

Where young people need very specialised or intensive mental health care, they can be admitted to Child and Adolescent Mental Health Services (CAMHS) inpatient units. Generally this is on the basis of their (or their parent's) agreement,\*\*\* known as being an informal patient, or if they have been sectioned under the Mental Health Act 1983 – the law on detaining people in hospital for their mental health.

Before a young person can be detained in hospital, a request for a bed must be sent to the National Referral and Access Process and go through an Access Assessment to determine what type of bed is needed.

\* Young people aged 14-19 who identify as LGB are more than twice as likely (35%) to experience a mental health problem compared to young people who identify as heterosexual (13%) NHS Digital (2018) Mental Health of Young people in England, 2017. <https://digital.nhs.uk/data-and-information/publications/statistical/mental-health-of-children-and-young-people-in-england/2017/2017>

\*\* At age 11, Black boys were just as likely as White boys to have diagnosable mental health problems. However, the large racial disparities in poor mental health emerge around age 18, with adults from racialised communities many times more likely to develop both common and severe mental health problems Gutman, L. M., Joshi, H.,

Parsonage, M. and Schoon, I. (2015) Children of the new century: mental health findings from the Millennium Cohort Study. [https://www.researchgate.net/publication/308083993\\_Children\\_of\\_the\\_new\\_century\\_mental\\_health\\_findings\\_from\\_the\\_Millennium\\_Cohort\\_Study](https://www.researchgate.net/publication/308083993_Children_of_the_new_century_mental_health_findings_from_the_Millennium_Cohort_Study)

\*\*\* A 16- or 17-year-old with capacity can consent or refuse an informal admission. Their parent or someone with parental responsibility can't consent on their behalf. The position is more complex for under-16s. There's no test in legislation to assess whether they are able to consent to admission and treatment and there's a lack of legal clarity on when someone with parental responsibility can or cannot consent on their behalf.

The assessment is meant to help prevent inappropriate or unsafe admissions but Mind have heard this process is being used to overrule Mental Health Act Assessments and could mean young people are ending up in other, unsuitable, placements.

There are longstanding concerns about the Mental Health Act 1983 and the way it's used. In 2018, an Independent Review of the Mental Health Act made 154 recommendations for how it should be changed. Right now the UK Government is working on a Mental Health Bill to update the current law. The proposals include:

- new statutory care and treatment plans for people who have been sectioned
- enhanced safeguards around refusal of certain treatments (mainly medication)

- the right to make advance decisions about treatments you don't want (although currently this will only apply to people aged 18 and above)
- greater access to advocacy.

This will hugely affect young people in inpatient care but we're concerned that some of the changes won't work for them. So we decided to find out more about young people's views on reforming the Mental Health Act and what needs to change to make it a better experience.



## Failing to deliver safe, therapeutic care

Child and Adolescent Mental Health Service (CAMHS) inpatient units are failing. They should be safe places where professional can assess and help young people.

However, reports show:

- gaps in information on the number of young people using them<sup>5</sup>
- poor awareness of young people's rights<sup>6</sup>
- young people placed in adult wards inappropriately<sup>7</sup>
- lack of staff
- staff using too much restraint and medication.<sup>8</sup>

These serious failings put young people at risk. Some units are failing so badly that young people have died.<sup>9</sup>

Young people, parents, plus the Care Quality Commission (CQC) and the Coroner, have said again and again that inpatient services aren't good enough.<sup>10</sup>

The UK Government has announced a rapid review into data on mental health inpatient settings. But this doesn't go far enough to deliver the changes need to see. We're calling for:

- a full statutory public inquiry into failings in inpatient care across England
- a comprehensive fully funded government action plan to roll out better, safer, inpatient care
- long term investment in the inpatient mental health workforce and estates
- greater accountability of those involved in the provision of inpatient care at a local level
- urgent reform to the Mental Health Act, particularly for under-18s in hospital.<sup>11</sup>

## Young people on adult wards

Most under-18s are treated in CAMHS wards. Guidelines say that they must only be admitted to adult wards in exceptional circumstances.<sup>12</sup> Despite this, recent data show it's happening more often.<sup>13</sup> The CQC reports a 32% rise in the number of under-18s being admitted to adult wards between 2020/21 and 2021/22. They said the "main reason given for admitting the child to an adult ward was because there was no alternative mental health inpatient or outreach service available for young people".<sup>14</sup>

Quarterly data on the number of days under-18s stay in adult wards vary, but seem to show an increase. In the first quarter of 2017/18 the number of days was 428, rising to 727 in the first quarter of 2022/23.<sup>15</sup>

## Put in hospitals far from home

When a young person under 18 goes to hospital, they should be placed as close to home as possible.<sup>16</sup> The UK Government said they would stop under-18s being placed 'out of area' by 2020/21.<sup>17</sup> But it's still happening and there are around 300 out-of-area placements each month (Source: [Mental Health services monthly statistics](#)).

## Disproportionate sectioning of Black young people

Black and mixed-race young people make up over a third (36%) of young people in acute inpatient services, despite representing 11% of that population.<sup>18</sup>

Black young people are less likely to be admitted informally, when compared to White young people. Around 1 in 10 are admitted informally versus 1 in 3 White patients.<sup>19</sup>

## Poor education on wards

The Commons Health Committee highlighted this problem in 2014.<sup>20</sup> Mind is also concerned that young people aren't getting educational support they may be legally entitled to. Young people with special educational needs can get this support through Education Health and Care plans but we've heard that young people who appear to be eligible for a plan are being admitted without one.<sup>21</sup>

## Missing information and 'missing' young people

More than 1 in 5 young people detained in hospital are missing from official statistics, according to The Children's Commissioner for England.<sup>22</sup> NHS data on numbers of admissions also vary. In 2021/22, they reported there were 2,563 admissions (Source: [NHS Mental Health Dashboard](#)) and 2,878 admissions (Source: [Mental Health Bulletin 2021-22 Annual report](#)) of under-18s.

Published data show that the number of young people admitted seems to have dropped. In 2017/18 there were 4,611 admissions in CAMHS tier 4 wards compared to 2,563 in 2021/22 (Source: [NHS Mental Health Dashboard](#)). Data on the total number of beds available are limited but there are some reports that they have reduced and this may be driving the drop in admissions. It's also possible that data don't capture children who are detained in other settings,\* including general paediatric wards and in social care placements.<sup>23</sup>

NHS England doesn't publish data on young people admitted informally.\*\* However, available information suggests many young people are being admitted this way (31%). Without publicly available data on these young people, it's impossible to track trends or even find out why they were admitted.

\* For example, when Access Assessments are used to overrule Mental Health Act assessments so the young person cannot be admitted to a CAMHS inpatient bed and must be detained in another location, under a different legal framework.

\*\* On 31 March 2020, NHS England confirmed that there were 944 children living in inpatient care – 544 formally detained. The rest were there on either an informal basis

(296) or the legal basis for their admission was not recorded (104). These data are not published but were provided to the Children's Commissioner for England. Waldegrave, H (2020) Children's Commissioner for England "Who are they, where are they" p17 <https://www.childrenscommissioner.gov.uk/wp-content/uploads/2020/11/cco-who-are-they-where-are-they-2020.pdf>

## Our recommendations

- The UK Government must speed up the shift to young people being looked after in their communities. Professionals in some areas are working on community alternatives to inpatient admission – this must be expanded and built on across the country.
- The UK Government needs to stop young people under 18 being admitted to inappropriate placements. They must set a new deadline for eradicating the use of inappropriate out of area placements and admission to adult wards
- The Mental Health Bill should create a statutory presumption against placing young people under 18 in adult wards. The Secretary of State for Health and Social Care should have to approve every time an under-16 is put on an adult ward.
- The Mental Health Bill should include a duty on Integrated Care Boards to ensure the needs of under-18s can be met in their communities without admitting them as inpatients, where possible. This should include multi agency provision for young people with complex needs currently placed in unsuitable and unregulated social care accommodation.



- The Mental Health Bill must set out enhanced procedural requirements on NHS bodies when considering an out-of-area placement. New requirements could be similar to duties on local authorities under the Children Act 1989 for placing young people under 18 in out-of-area social care placements\*. There should also be a duty in the Mental Health Bill to tell:
  - Local authorities if a young person under 18 is placed out of area or on an adult ward
  - The Care Quality Commission (CQC) within 24 hours if a young person under 18 is placed out of area or on an adult ward. The CQC should record the reasons and suggested length of the placement.
- The Mental Health Bill must include a duty on the Secretary of State to make sure national data on young people's experiences as mental health inpatients is regularly collected and published. This should include data on the number of detained and informal patients broken down by:
  - type of unit (including places which are not mental health wards)
  - ethnicity
  - reasons for admission
  - time waiting for a hospital place
- out-of-area placements and the reasons for them
- safeguarding referrals
- serious incidents
- the number of young people under 18 getting advocacy support
- informal admission on the basis of a young person's or parent's consent
- length of time detained
- satisfaction rates
- how many young people under 18 are placed on adult wards and for how long.
- NHS England should provide greater clarity and transparency on the circumstances in which Access Assessments are being used to overrule Mental Health Act assessments for young people under 18.
- The Department of Health and Social Care and the Department for Education should improve education support and publish guidance for secondary schools on how to ensure young people who have been admitted to a mental health ward have the opportunity to access education. Admission to hospital for mental health, should be an automatic trigger for an assessment or review of an Education Health and Care plan.

\* For example, for placements outside the local authority or adjoining local authority, approval must be sought from the director of children services. Before making any out-of-area placement, a local authority must take various steps to determine if the placement is suitable. These include reviewing a children's home

statement of purpose and consulting with an independent reviewing officer, who should discuss the arrangements with the child and parents if appropriate. Once a placement has been made, the local authority must ensure the child is regularly visited and spoken to, to ensure their welfare is safeguarded and promoted.

# Part 2

## What young people told us

We listened to young people who had gone into hospital for their mental health in England and Wales before they were 18. This report focuses solely on the experiences of young people in England.

Mind carried out the research from January to September 2022. We wanted it to be shaped by young people. So we ran co-production sessions with 4 young people who had experience of going into hospital for their mental health in England and Wales. They worked with us to identify areas of reform to focus on and helped us to design an engagement plan and survey for our work.

Between April and May 2022, we opened the survey to young people aged between 14 and 25 who had been into hospital for their mental health when they were under 18. The survey was a mix of closed questions and free text responses. We heard from 403 young people with experience of going into hospital in England when they were under 18 including:

- 106 young people who had free school meals
- 65 young people who were care experienced.

The experiences of young people who identify as male and young people with Black and Black British heritage are under-represented in this survey. We have highlighted some of their experiences, but this is a limitation of our survey.

We also held 5 focus groups and 3 interviews recruiting participants via the survey. In total we heard from 21 people directly.

We ran specific focus groups and interviews for young people who:

- were care experienced or
- identified as having Black or Black British heritage or
- were under 16 or
- had experience of going into hospital in Wales.

We wanted to hear in detail from these groups of young people to understand more about their experiences of inpatient admission. Young people who are care experienced will often have multi-agency involvement and may be owed additional duties during their admission. The Mental Health Act is used disproportionately against Black people including Black young people. There are very distinct legal considerations for the admission and treatment of children under 16 (see above). Health is a devolved matter in Wales and there is a distinct legal and policy landscape for young people there.

## Young people had mainly poor experiences

We found 69% of young people disagreed or strongly disagreed that their experiences had been positive. This rose to 75% for young people who were care experienced. Only 8% of young people agreed or strongly agreed that their experiences of inpatient admission had been positive.

Half of young people disagreed or strongly disagreed that they were treated with respect during their admission.

Young people had different ideas on whether their admission had helped them get better. 30% agreed or strongly agreed that it had helped them (although 55% disagreed or strongly disagreed). This rose to 61% for care-experienced young people.

**69%**

of young people had negative experiences

**“It’s very important to take into consideration what benefits someone will get if they go into hospital. [They should] only admit someone if there is a treatment plan which can help with their mental health/recovery. Instead of it being somewhere which feels more like a holding place when people get unwell.”**

Young person (from our survey)



## Multiple admissions

Many young people who spoke to us had been in hospital many times. Nearly half (45%) had been in 5 times or more. For young people getting free school meals the number rose to 52%, and to 66% for young people who are care experienced.

Most young people (76%) had experience both of being sectioned under the Mental Health Act and being admitted as an informal patient.

## Lack of information

Young people wanted more information on their inpatient stay. This included the process of being sectioned and leaving hospital, plus being clearer about their individual rights and treatment plans.

## Young people didn't feel listened to

Fewer than 1 in 10 (9%) young people agreed or strongly agreed that their views had been listened to in hospital.

Young people from our focus groups said:  
**“Being in hospital is quite a scary thing. A lot of the time when you're in that scary place, you can be quite anxious and might lose some of your understanding around topics. Doctors should explain everything they're going to do in the most basic or advanced way.”**

**“In my treatment, I asked a lot to be involved in those meetings which discuss**

**my treatment. Sometimes you're left out of those 'higher up' meetings. You should be involved in those things.”**

Young people welcomed the UK Government's plans to reform the Mental Health Act to give greater weight to people's views but thought it should go further.

## Mental Health Act reform

The Independent Review of the Mental Health Act recommended 4 guiding principles should be included in the Mental Health Bill. These are: choice and autonomy, therapeutic benefit, least restriction and being treated as an individual.

They chose these as a way to improve patients' experiences by setting standards for services and providing people clear expectations for their care and treatment.

Young people told us how they thought inpatient admissions could be improved if the principles were followed:

### Choice and autonomy

Young people told us what would have improved their choice and autonomy in hospital. Their top 3 answers were:

- more choice about treatment
- more support to have their voice heard
- easy ways to raise concerns about their care and treatment.

**“When I was really unwell I wasn't aware of anything. I needed looking after and to be kept safe. When I began to get well being informed helped me understand what was happening.”**

Young person (survey)

**66 While I was in restraint they would all talk over me and about me while I was sat there in the room. This led to me feeling very belittled and I would shut off. I found it difficult to talk to staff. If I was treated more like a person I would have felt more enabled to speak up about my treatment and have more control over what was happening to me. Perhaps this would have led to less restrictive practice as I was on observations for a very long time. 99**

Young person (from our survey)

### Therapeutic benefit

Young people told us what would have improved the therapeutic benefit they received. Their top 3 answers were more:

- 1-to-1 time with mental health professionals
- outdoor spaces
- support when getting ready to leave hospital.

20% of young people said more support when getting ready to leave hospital, and after leaving, would have improved the therapeutic benefit they experienced.

Some young people were concerned about agency staff on wards – and how they made them feel less safe and supported. One said in our survey:

**“The policy seemed to be ‘come find a staff member if I want to talk’. At that point in my mental health I didn’t know how to express my feelings. I needed one on one time and to be actively progressed in my journey. It felt like I was just stuck in my wards just waiting to be ‘deemed less of a risk’. No progression [was] even attempted.”**

Another said: **“Using agency staff is very dangerous as they often have no mental health training. Agency nurses often had**

**no clue what they were doing and all of us patients felt very scared, unsettled and stressed/anxious. I know often having agency staff cannot be helped. But seeing so many unfamiliar, unfriendly faces at only 13 years old was petrifying and I was so scared.”**

### Restrictions and restraint

Young people told us what would have improved their experiences of restrictions and restraint. Their top 3 answers were:

- being allowed to use their phones and the internet
- fewer restrictions around visiting times
- less strict rules about using outdoor spaces.

Many young people told us they’d experienced or seen restraint, often regularly and for long periods.

Young people with autism told us they’d been particularly affected by restraint. They felt staff should have considered their autism before restraining them.

In one focus group, young people told us about cameras in bedrooms on the ward. This happened even when they were informally admitted and neither they nor their parents had agreed to using them. A young person told us that young people

on the ward weren't changing their clothes or washing because they were worried about being filmed.

### Being treated as an individual

Young people told us what would have helped them be treated as an individual. Their top answers were staff:

- having a better understanding of the impact of racism (including structural racism) on mental health
- respecting what's important to them
- understanding what sort of things can be triggering
- having a better knowledge of physical health conditions and their impact on mental health.

A young person who identified as having Black heritage told us they immediately noticed a disproportionate number of Black patients on the ward. They sometimes faced discriminatory and racist treatment but didn't feel confident calling it out.

**“[Staff should] understand all aspects of illness and not become complacent because they do it day in day out. [This means they would] realise how scary it is to be so unwell and away from family and friends.”**

Young person (from our survey)

**“I really struggled having male 1-to-1s because of trauma. But this was never taken into account and often led to incidents.”**

Young person (from our survey)



**66 Use of sectioning for young people with autism or similar learning difficulties needs to change. It did more harm than good. It kept me alive, but it wasn't an appropriate place for me to be. The alarms, the banging, the screaming and restraints are absolutely awful for anyone to go through – but especially a young person with autism. The staff need more training on autism and special needs, and the system desperately needs changing. 99**

Young person (from our survey)

## Our recommendations

- The Mental Health Bill should be amended to include the four guiding principles at the start. This would help raise expectations for inpatient care and provide a 'hook' for young people to challenge poor care. An extra equality principle must be added to the guiding principles to help eliminate discrimination and promote equity through protected characteristics.\*
- The Mental Health Bill should create a new responsible person role to oversee workforce training and policies designed to address bias and discrimination in decision-making in the operation of the Mental Health Act on the basis of protected characteristics and should report back on the impact of guiding principles in their hospital. They should also collect and monitor data on the number, cause, and duration of detentions under the MHA broken down by protected characteristics including ethnicity, gender and sexual orientation. The Secretary of State must make sure that these statistics are published at the end of each year.
- Young people told us about the trauma of restraint. People in the 'responsible person role' under the Mental Health Units (Use of Force) Act 2018\*\* should address the high rate of restraint used in young people's mental health services. They must ensure their services provide person-centred care and reduce restraint. The Secretary of State's annual report on restraint could go further than what is required in the Act and investigate how restraint is being used across the health service.

\* Protected characteristics under the Equality Act 2010: age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, and sexual orientation.

\*\* This is the person responsible for ensuring that their organisation complies with the Act. Their responsibilities include publishing a policy on the use of force and ensuring that staff receive appropriate training in the use of force.

## Care and treatment plans

Nearly half (49%) of young people said they weren't involved in agreeing the care and treatment they had in hospital, even though they wanted to be. The top three things they wanted were:

- a written care plan
- the legal right to be involved in decisions about care and treatment
- being included at meetings where their care and treatment was discussed.

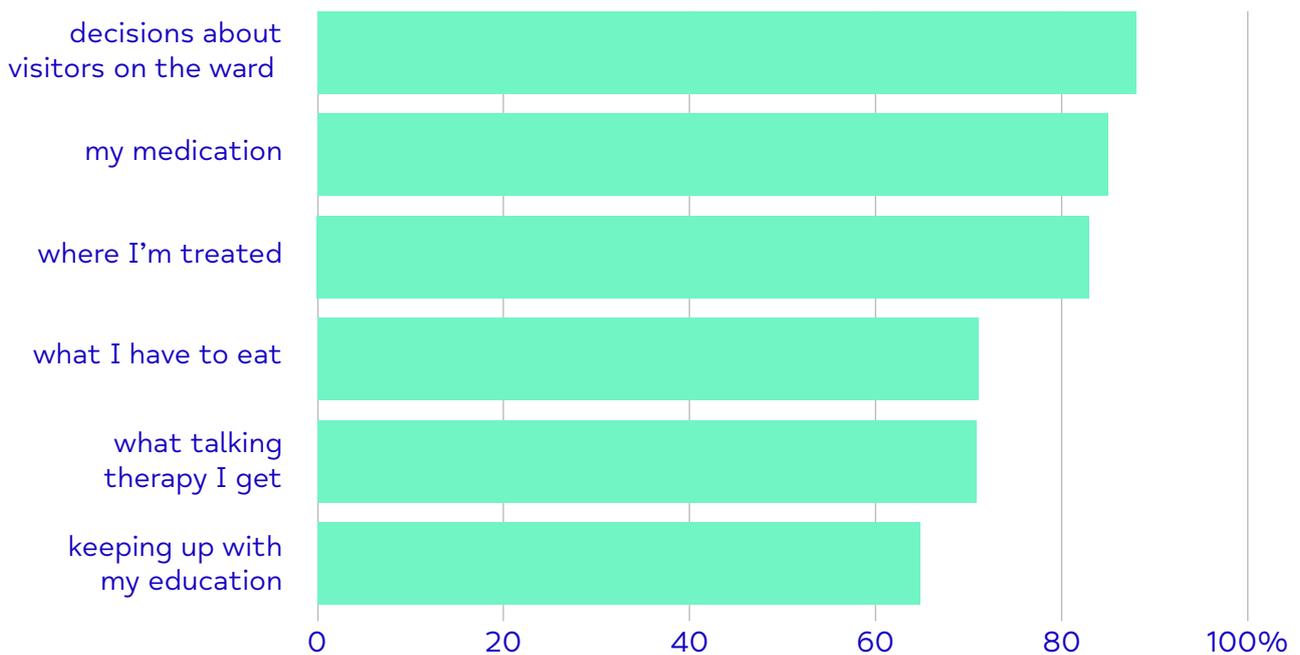
We asked young people to rate what decisions about their care and treatment it was most important they should be involved in.

Every young person was positive about the UK Government's plan to introduce care and treatment plans (CTPs) for detained

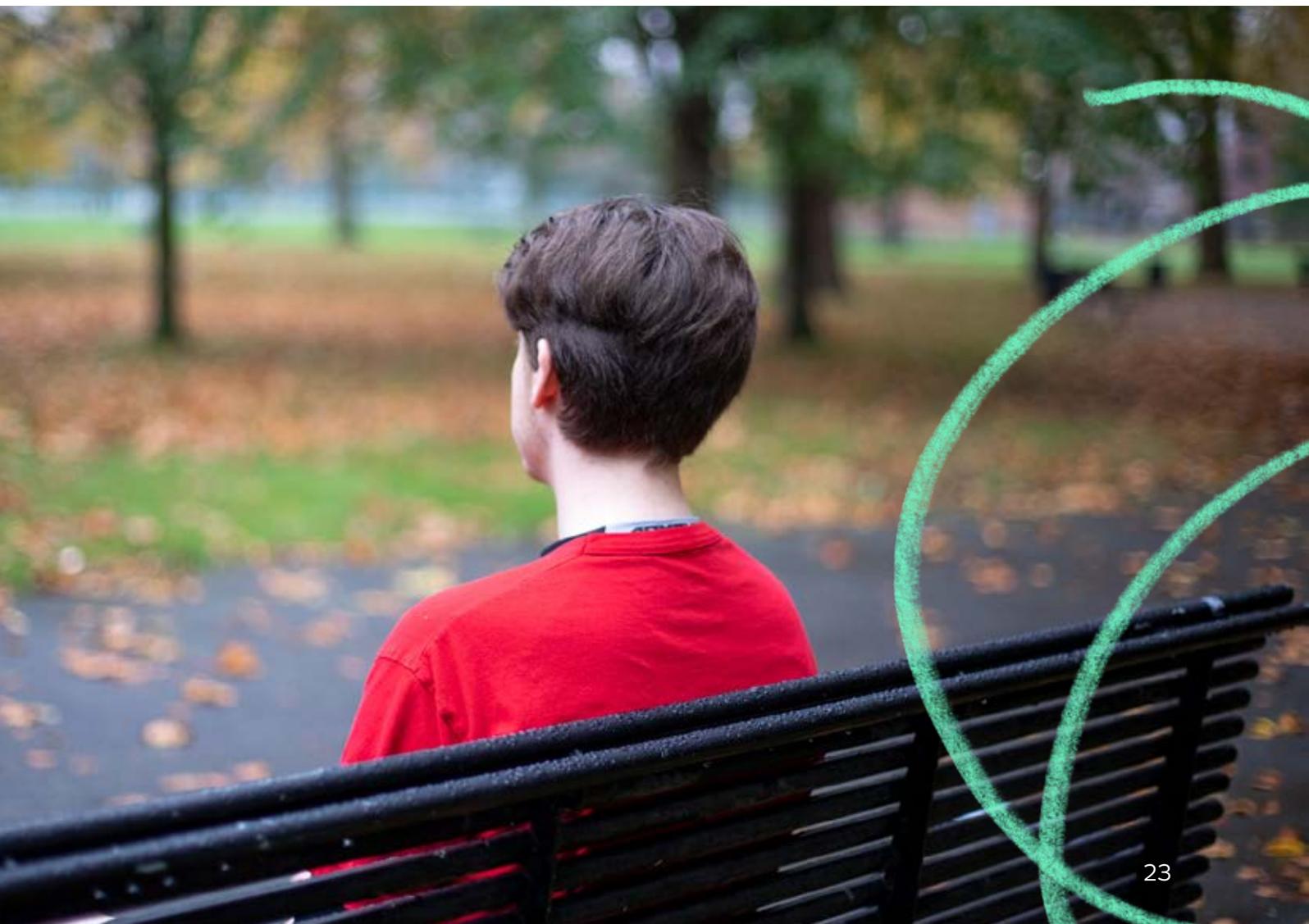
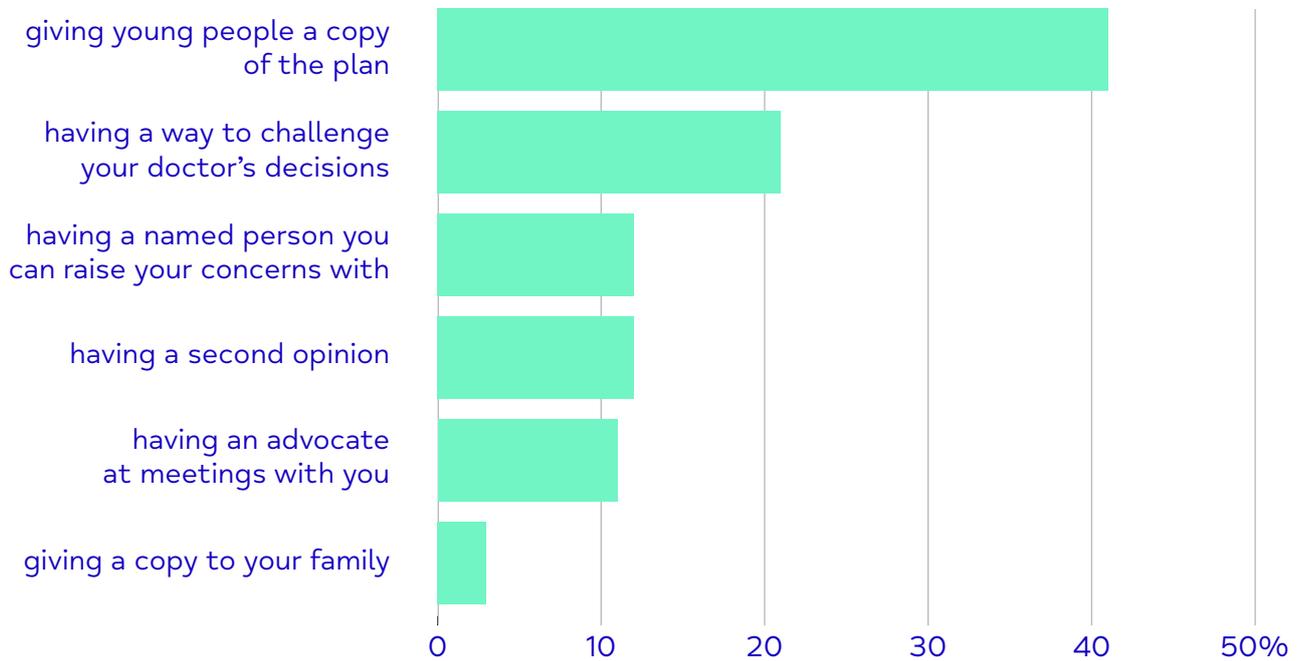
patients. They wanted these to be available to informal patients too. They told us this would give informal patients more insight and control of their treatment. One young person in our focus groups said: **“In some ways, informal patients have more of a chance to have their wishes and feelings acted on, compared to detained patients, so [it's] really important to have them written down in a care plan.”**

Over three quarters (76%) of young people thought an independent person should review the CTPs. They thought the CTPs needed to be carefully looked at in a way that worked for the young person and that it should be explained in conversation and in writing. However, young people were concerned there wouldn't be enough staff or time to complete the plan properly.

## What decisions about care and treatment should you have a say in?



## Young people suggested ways to make sure doctors followed the CTPs



“I’ve received care from the best to the worst. I have found it difficult [or] near impossible to make any formal complaint about them. I think sometimes this is additionally hard as they are agency workers so can’t be tracked as easily. This is why it’s crucial that every bit of your care is documented and recorded so everyone can be held accountable.”

Young person (from our focus groups)

### Refusing treatment

Young people had different opinions about the UK Government’s plans to introduce new safeguards on refusing medication. Many thought it was important to consider why someone was refusing medication and whether it was based on a bad experience.

Some thought the plans would delay patients getting the treatment they needed and they would be in a bad state for longer than necessary. Others thought it was really important and empowering to be able to say no to medication they knew didn’t work for them. Several young people thought it was important that the extra safeguards covered PRN (extra doses of someone’s prescribed medication) and forced nutrition (when you are given or forced to have nutrition like food and water against your will. It could also be when someone is given nutrition in a liquid through a tube into their stomach).

One focus group participant thought:  
**“If a young person doesn’t want a specific medication the doctor should listen to them. If it doesn’t work for them then don’t put them back on it. But if the young person doesn’t want to do something that’s to do with why they’re in hospital [that’s different]. You’re in hospital for a reason but that’s not an excuse [for doctors] not to listen.”**

### Advance decisions

Young people also had different opinions on the UK Government’s plans to let people over 18 make decisions in advance about certain treatments under the Mental Health Act 1983. Some were concerned that they might not make wise choices. This might make their treatment less effective, or they could ask for treatment that wouldn’t benefit them.

Others felt it would be ‘invalidating’ not to let young people make advance decisions. They thought that if adults could make decisions in advance, young people should have the same rights. They were also concerned doctors might not consider what a young person had said in advance unless there were extra rules that meant they had to.

Some young people thought they should be able to have a professional or advocate to talk them through making an advance decision. They could help young people understand the pros and cons and work together. They also thought input from family and schools could be helpful, particularly to help them return to their lives after discharge.

**“I think it’s great that you can say ‘I want this treatment and not this one’. I know myself best. And I think the ability or the knowledge of having competency or capacity is quite powerful when you should be in the position of deciding what care you receive.”**

Young person (from our focus groups)

**“It would be good to not have to tell the same thing about your wishes again and again to lots of different professionals.”**

Young person (from our focus groups)



“Neither me or my parents understood that I was an ‘informal patient’ on the first admission. We also didn’t understand what this meant once we were told. Making the hospitalisation process clear and understandable at the outset is important.”

Young person (from our survey)

### Informal admissions

Many young people thought informal patients were treated as being ‘less unwell’ than sectioned patients, even though the opposite was often true, and that their treatment wasn’t a priority, even though the opposite was often true. A young person from our focus groups said:

**“Someone might be complying because they don’t want to be sectioned or stay on the ward. It doesn’t mean they’re better.”**

Young people were concerned reforms wouldn’t cover informal patients. They thought they needed similar rights and protections to sectioned patients because they often faced the same restrictions.

**“They tell you as an informal patient that it’s your choice if you’re in hospital but none of us chose to be there. You’re told if you don’t agree you’ll be sectioned, or when in hospital you’re told if you don’t do what [you’re told] they’ll discharge you. They use both sectioning and informality in a threatening way. It doesn’t make a difference – either way you’re forced.”**

Some young people said they didn’t understand the difference between being detained and being informally admitted, particularly when they were first admitted. They said it was important to understand the difference so you could know your rights and make informed choices.

### Parents’ role in consenting to admission and treatment

Half of the young people who had been admitted as an informal patient when they were under 16 said it was their parents who agreed for them to go into hospital. Less than a quarter of those young people said they had agreed themselves and 13% said they didn’t know who had consented.

Some young people shared their confusion over whether it was they or their parent or guardian making the decision to be informally admitted. They told us this made them feel ‘bypassed’ and ‘disempowered’ in their own care and treatment. Young people wanted it to be clear when they could make their own decisions.

“A lot of the time, when I get treatment it almost needs my parents’ stamp of approval. It can get annoying.”

Young person (from our survey)

## Under-16s

87% of young people agreed or strongly agreed that under-16s should have the same rights to make choices about their care and treatment as others if they understand what's involved. This rose to 90% for young people who were under 16.

**87%**

wanted under-16s to have a say over care and treatment

Young people have mixed opinions on how to assess decision-making ability for under-16s. Some were concerned not having an assessment test for under-16s in the Mental Health Bill might make people feel less in control of their treatment and that they had fewer rights than over-16s. A young person from our focus groups said: **“When it comes to treatment, I technically know myself best. I should**

**be able to make those decisions whether I’m 14 or 18.”**

They also felt it would be unfair if the lack of a test in the Bill made it harder for under-16s to get safeguards. This could mean doctors were less accountable.

**“Sometimes, this professional says I have competence but this one doesn’t. It could be within the same hour. Competency and capacity should be decided on a case-by-case basis. There should be a set-in-stone process, where you need to tick this box or that box to assess competence.”**

Young person (from our focus groups)



**“Having an advocate helped me feel listened to, less alone and more like a human being. I only knew I could have an advocate the second time I was sectioned, and encouraged others in the ward to do the same. Many did not realise it was an option.”**

Young person (from our surveys)

### Support to have their voices heard

Just over half (52%) of young people had support from an advocate in hospital. Most of them (59%) said they were offered support without having to ask for it. Young people didn't always find it helpful. 44% found it helpful or very helpful and 37% found it neither helpful or unhelpful. Around a fifth (19%) found it unhelpful or very unhelpful.

The main things young people told us were:

- The importance of having someone independent to help you get your voice heard.
- Communication – some had positive experiences on communication and said advocates shared information in a simple-to-understand way. Others said they weren't understood – which made them upset.
- Some young people said there wasn't enough information on getting an advocate, and that it was unclear how they could help.
- Some found it difficult to get in touch with advocates and said the service wasn't always consistent.

Of the young people who didn't get help from an advocate, over a third (39%) said they were never offered advocacy and didn't know they could get it. We found 1 in 10 care-experienced young people said that even though they asked to see an advocate they didn't get to see one.



Nearly half (49%) of young people thought it would have helped them if they'd had an advocate. This rose to 57% for young people getting free school meals and 79% for care experienced young people. This suggests care-experienced people particularly value support from an independent person to help them understand the mental health system and make sure their voices are heard.

Most young people (92%) thought that every young person on a ward should be offered support from an advocate.

**“If Government have got anything right this year that [increased access to advocacy] is one of the things.”**

Young person (from our focus groups)

Young people were extremely positive about extending advocacy to informal patients. Many said it should be available to young people without them having to ask (opt out advocacy). Lots of young people said they didn't know they could have had an advocate when they were first admitted. They said it would have been very useful when they were new in hospital. Others said asking for an advocate might feel impossible for some young people. This could stop them getting advocates.

They also told us how important it was to have the role of an advocate explained and that the advocate should be there on the ward so patients could get to know them.

### Leaving hospital

Many young people said they went from having lots of support at hospital to almost nothing in their community.

Some talked about being promised community support that never happened. Some told us they left hospital with no plan at all.

Communication problems meant community teams sometimes didn't even know young people had left hospital. Several mentioned they were never told they were entitled to section 117 aftercare and thought it wasn't talked about enough. One young person said in our survey: **“It felt like the doctors in particular shared very little information, especially about discharge, with myself and my parents. My discharge was brought about so suddenly (a matter of hours) that I had to be medicated with sedatives just before leaving. This**

**wasn't made clear to my parents who then had to take me to A&E once we'd returned home and their affects had worn off.”**

A focus group participant said:

**“If you've been on section 3, you will get s117. I wasn't aware of it before the leaving hospital meeting and don't think that s117 was spoken about enough. [I] don't think lots of young people know about it as additional source of support for them.”**

Young people thought having care and treatment plans could help them leave hospital, especially if they were updated before they left and sent to the right professionals, family members and carers. They also told us how important it was to have discharge meetings with professionals they would be working with in the community. A few young people thought it was particularly important for staff from schools and colleges to attend to help them return to education.

Care-experienced young people shared just how many teams were involved in their care and how good communication was important. They told us about:

- Poor communication between teams even about big things like changes to treatment.
- Information being shared without permission and even against their wishes.
- Some personal advisors helped them to understand community mental health teams and regularly asked them to confirm what they could share with other professionals.

**👂 [It's] Important for education to be involved [in discharge planning] because although you'll go to the CAMHS school, once you're discharged you'll either go to mainstream school, PRU or take time off. 🗨️**

Young person (from our focus groups)

## Our recommendations

- The Mental Health Bill should extend care and treatment plans (CTPs) to informal patients under 18. The UK Government has committed to making CTPs a requirement for informal patients – but this doesn't appear in the Mental Health Bill. Young people we heard from wanted informal patients to have these plans.
- Over half of young people admitted informally when they were under 16 were admitted by parental consent, rather than their own. This means they wouldn't have had the safeguards available to detained patients. This includes a right of appeal to the tribunal or a nearest relative. To change this:
  - Section 131 of the Mental Health Act 1983 must be changed to make clear that 'competent' under-16s can consent to, or refuse, informal admission and this cannot be overruled by parents.
  - The UK Government should publish data on the number of young people under 18 admitted informally. This should include data on whether they have consented or if someone has consented on their behalf.
  - The Code of Practice must provide clear guidance to determine when parental consent can be relied on in care and treatment for young people under 16.
- Many of the new rights and safeguards in the draft Mental Health Bill will apply differently depending on whether a young person under 16 is 'competent'. The Bill must include a test on how to assess decision making ability for under-16s. This test should apply to decisions about admission and treatment in inpatient settings.
- Young people had mixed opinions on whether advance decisions should be extended to under-18s. We strongly believe they should – and this should be included in the Bill. There should be a duty to offer young people the chance to make advance decisions, including after they've left hospital. Young people must be able to get professional support to help them understand the implications of making an advance decision and properly funded independent support for them to do so if they choose.
- All inpatients must get advocacy, and the Mental Health Bill should extend this to young people under 18 on an opt-out basis
- The Department of Health and Social Care must work with the Department for Education to make sure that young people's needs in mental health inpatient care are reflected in updated advocacy standards.
- The CQC should immediately make sure advocacy provision is a key part of their inspections. This currently doesn't happen. Advocacy provision should also be part of the Ofsted Inspection Framework for young people with SEND and those who are care experienced.
- There's currently no statutory process to ensure multi-agency planning for young people's discharge from inpatient settings. The UK Government must put in place a clear process for this. They must particularly consider care-experienced young people who are more likely to receive multi-agency support.

# Beyond the Mental Health Act

The focus of this report is Mental Health Act reform but young people raised a number of issues outside its scope that also need to be addressed:

- Better communication about care and to build stronger relationships with staff.
- Lack of support in the run up to discharge and period after discharge.
- Lack of one-to-one time with staff.
- Concerns about use of agency staff who may not know much about the young people under their care.
- Use of cameras and recording equipment as a monitoring technique on wards.
- Not enough respect, acceptance and understanding of:
  - young people's individual needs and triggers, for example the impact of past trauma on a young person's ability to work with staff of the opposite sex
  - the impact of racism, including structural racism, on mental health
  - the needs of young people with learning disabilities and autistic young people and how they are affected by life on the ward
  - LGBTQIA+ issues. For example: respecting pronouns
  - how scary and stressful an experience inpatient admission can be for young people.
- Unwelcoming ward environments and the lack of outdoor spaces.

These issues need to be looked at and should form part of a statutory public inquiry into failings in inpatient care across England, where the voices of people with lived experience and their loved ones are heard and essential systemic changes are identified.

We need to see leadership and investment from the UK government, and cultural transformation from the NHS, to address the failings in inpatient care that have been going on for decades and to provide safe, therapeutic care for people with mental health problems. Alongside a public inquiry and reforms to the Mental Health Act, we're calling for:
- A comprehensive, fully funded action plan, based on evidence of best practice, to roll out better, safer inpatient care across England.
- Long term investment in the inpatient mental health workforce and estates so people can get safe, therapeutic and culturally appropriate care in the right environment, and to prevent the system reaching crisis point again.
- Strengthened accountability of those involved in the provision of inpatient care at a local level, through improvements to leadership, transparency and oversight.

# Conclusion

In our research most young people had poor experiences of being in hospital. Many didn't have any control over their care and treatment.

They said professionals didn't bother finding out their views. That they were confused over who could make decisions and couldn't get the right information or support to make their voices heard.

Young people thought the Mental Health Act reforms might improve the situation. But they said that lack of staff or an independent body checking they were happening could stop change in its tracks.

Others thought the reforms didn't go far enough. They felt it was vital that informal patients were able to get safeguards like advocates and care and treatment plans, the same as other patients.

The vast majority told us under-16s should have the same rights to make choices about their care and treatment as others if they understand what's involved.

## We need urgent change

We believe reforming the Mental Health Act will only work if all young people get the new rights and safeguards. It's essential that urgent changes to the law come with urgent changes to the mental health care system. These changes need to be shaped by the views of people who've actually used the system.

This includes making sure the care people get isn't determined by who they are. It's about making sure everyone can get support before they have to enter hospital .

We need safe, specialist care across the country, and better ward conditions and culture. The UK Government, the NHS, Integrated Care Boards and individual providers must take immediate action to deliver this change. This means coordinated leadership and investment to meet the full cost of the Mental Health Act reforms and changing the system.

Young people have warned us there's still a very long way to go to deliver the kind of mental health services they need and deserve. We must not let them down.

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