

YOUNG Mi MINDS

MENTAL HEALTH ACT

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1.0 Executive Summary

This report outlines the key findings and themes from workshops and calls facilitated with 19 young people with lived experience* of the Mental Health Act.

The key theme that emerged throughout the research was that young people did not feel listened to or able to engage meaningfully in their care and treatment.

- Young people expressed that the care they received felt more like detention, and that instead of being person-centred and tailored to individual needs, staff tend to adopt a **one size fits all approach** to the care and support provided.
- Young people are **assumed to be difficult** and often **feel like a burden** when trying to engage in their treatment. The young people we spoke with shared experiences of how professionals defined their efforts to engage either through asking questions, challenging decisions, expressing preferences or making notes as challenging behaviours or symptoms of their diagnoses.
- Young people want to be meaningfully involved in decisions made about them and staff are often seen as the main barrier to this, with informal patients being threatened with section if they are seen to be 'challenging' their treatment and care.
- Young people want staff to take the time to talk to them, clearly explain their rights, listen to their thoughts and concerns, and offer **individualised treatment and intervention**, as well as medication, to provide a more well-rounded approach to their care and support.

Having supportive staff and access to an advocate throughout the process of being detained and during their time spent in hospital, made a huge difference to young people's experience of the care and treatment they received. However, accessing advocacy is problematic. Many young people cited out of date information, lack of staff knowledge about advocacy and the lack of availability of advocates outside of 'office hours' as reasons why they were unable to receive this support.

"The nurse took the advocate round to each patient then asked each person if they needed an advocate. This was really good and I think this is something which should happen more often."

*The charity Mind defines 'lived experience influence and participation' as: "The development and promotion of opportunities in order that a diverse range of people, with lived experience of mental health problems, influence and participate in our work. This recognises that people want to take part in a variety of different ways and there is not a 'one size fits all' approach."

1.1 Background

In 2017 the government asked for an independent review of the Mental Health Act 1983 (MHA), to look at how it's used and to suggest ways to improve it. The review's final report said that the MHA does not always work as well as it should for patients, their families and their carers, and a wide range of changes have been proposed.

A public consultation about the proposed changes was open between January and April 2021 and the YoungMinds Service Design Team was asked by the charity Rethink Mental Illness to facilitate engagement with young people whose lives have been impacted by the Mental Health Act to find out what they think about the proposed changes.

The questions we posed to the young people were based on the questions devised by Rethink Mental Illness. Not all questions were relevant or applicable to the young people we worked with, and therefore were not included in our research.

We enabled room within the sessions and calls to raise important issues that had not been highlighted as part of the review. These are outlined in more detail in the subcontracted theme section of this report.

1.2 Who was involved?

Rethink Mental Illness are a charity aiming to improve the lives of people severely affected by mental illness through our network of local groups and services, expert information and successful campaigning. Our goal is to make sure everyone affected by severe mental illness has a good quality of life.

The **Department for Health and Social Care (DHSE)** is a department in the UK government which is responsible for government policy on health and adult social care matters in England. They help support ministers in ensuring that people live more independent and healthier lives for longer.

YoungMinds is leading the fight for a future where all young minds are supported and empowered, whatever the challenges. We're here to make sure they get the best possible mental health support and have the resilience to overcome life's difficulties.

1.3 Participants

YoungMinds conducted two workshops and a series of 1-1 calls with young people. In addition, all young people completed a pre-workshop task ahead of their engagement, outlining a journey of being detained under the Mental Health Act. All young people were compensated for their participation in this research.

All workshops and calls were delivered digitally through Zoom. We received positive feedback about how the online space was set up, as well as the support provided to young people. Facilitating the workshop in a remote space enabled young people to take time out from the workshop if and when they needed to, without drawing attention to themselves. It also allowed us to speak to young people currently in inpatient care, as well as young people based throughout the UK.

The young people we worked with had a mix of direct experience of the Mental Health Act, through entering under section or voluntarily, as well as young people with indirect experience through close family members or friends.

The young people we spoke with represented a mix of genders and ethnicities.

Workshop 1

Workshop 1 participants were 6 Activists between the ages of 19-24. Activists are volunteers recruited by YoungMinds. They are young people who have experience of mental health difficulties and use their lived experiences to make improvements and suggestions to projects and services based on their experiences.

Workshop 2

Workshop 2 participants were 8 externally recruited young people between the ages of 16-25.

1-1 calls

3 Activists between the ages 22-24.

2 external young people between the ages of 16-18.

1.4 Subcontracted theme: Children and young people: Main findings and analysis from subcontracted work by Young Minds with Children and Young People

Ultimately, the key theme running throughout the feedback we received is that professionals should truly listen to young people and work *with* them to plan and deliver their treatment and care. Young people are experts in what they need by way of their experiences and their thoughts, feelings, wants and needs. It is their right to have their voices carry real weight in their individual care and treatment plans.

In addition to the above, and to the key themes and experiences outlined in this report, we want to highlight the following:

- **Young people entering services as voluntary patients reported experiences of being threatened with section for disagreeing with or challenging their treatment and care.** This uncertainty about their rights disempowers young people further when they can already feel unsafe and as though their wishes are not considered to have the same weight as those of the parents, carers and professionals involved in their care.
- **Young people expressed that sometimes detention can feel like the best thing at a point of crisis, despite stigma and previous negative experiences.** Although many highlighted significant areas for improvement, some young people shared concerns that always following the guideline of 'Least Restriction' could lead to young people missing out on the right support i.e. inpatient care. This aligns with their concerns about the standard and quality of community based care, with many young people we spoke with expressing that there needs to be considerable investment and improvement for it to be a genuine alternative to inpatient provision.
- **Young people highlighted that professionals need to have a better understanding of racism and issues impacting on trans and non-binary young people.** We heard examples of young people having difficulties accessing choices of Halal food and the importance of professionals understanding the social and cultural issues that can contribute to young people's mental ill health e.g. cultural stigma about mental health and family members not believing in mental health difficulties. Consideration also needs to be given to the difficult and potential traumatic experiences that may be caused by placing trans and non-binary young people on single gender wards. These experiences further highlight the importance of the principle of 'Treating the person as an individual'.

1.5 Theme 2: Reasons for being detained

What would therapeutic benefit mean to you?

- Young people highlighted the importance of having access to regular therapy and a variety of interventions from mental health professionals. Young people want a more holistic approach to their care, based on a mix of therapy and medication, rather than a reliance on medication alone. Feedback demonstrates that CAMHS units are better at providing this than AMHS units with provision of education, art therapy, groups and occupational therapy.
- Young people found that staff at CAMHS focus more on the future than staff at AMHS, which felt more beneficial overall.

“The ward I was on offered a variety of therapies like art therapy, body image therapy, and occupational therapy activities. Staff worked with me to recognise that sectioning me made me give up, and coming off a section might give me hope.”

“The unit where we had group therapy twice a day with actual psychologists who were interested in helping you. In another unit, the activities coordinator (an Occupational Therapist) who made sure we had things to do and advocated for us getting off the ward for regular walks. The sensory room in one hospital was also really helpful, especially if there was a nice staff member on to sit with you and talk you through some relaxation techniques.”

“I've been on one CAMHS ward and that was really good. It was a really therapeutic ward. At the AMHS ward it's more medical based. One of the biggest differences is that at CAMHS they have to have a school at the ward. I think this gives the care more structure and there's more interaction and support. At CAMHS they look more at what happens after.”

- Consistency of therapeutic interventions is really important. There is a lack of consistency across different CAMHS services with young people using the term 'postcode lottery'. For example, some young people were offered therapy and others weren't depending on which unit they stayed on.
- Young people felt that having supportive staff made such a difference to their experience of being detained. They expressed that having the opportunity to speak with their consultants and other medical professionals at least once a week would be helpful, with time taken to explain and explore treatment options in ways that young people understand. It was also highlighted that particular care should be taken when communicating with young people with neurodiversity because often sectioning, care and treatment is explained in a neurotypical way and this can, amongst other things, lead to incorrect assessment of risk.
- Young people felt that inpatient units are places where young people get better, but only up until a certain point due to limited therapy and intervention. One young person noted that staff are often trying to keep young people alive for as long as possible, but are not focussed on the quality of their lives. Short term stays were considered helpful by some because they allow the young person to take some 'time out' and rest but remaining an inpatient in the

longer term can mean it becomes a part of the young person's identity and can leave them disengaged with life outside of the unit.

"We've normalised inpatient units to be detrimental rather than to be helpful. Things tend to get worse and this is usually due to not providing any further intervention. You wouldn't tell someone who needed a heart transplant that they can't go into hospital because they're getting worse, so why is this the case for mental illness?"

"[If you have an eating disorder] you meet a lot of other young people with EDs and come out with a lot of ideas and behaviours."

"They're focused on the quantity of your life (how long you live for) but not as much on the quality of your life."

Something we particularly wanted to highlight was the frequency of incidences of young people entering services voluntarily and then being threatened with sectioning. Most of the young people we spoke with shared experiences of being threatened with being put on section if they disagreed with or tried to challenge their care and treatment options or questioned decisions. They also shared examples of times when ward rules seemed to conflict directly with their individual rights, and therefore staff did not allow them to do things like go on walks or visit shops despite the fact that they were by right entitled to do this as voluntary patients.

The need for clearer communication of young people's rights as voluntary patients evidences the importance of advocacy for this cohort.

"You're silenced for being a 'difficult patient' or 'a trouble-maker' but you're not being difficult you're just asking questions."

"They say that you're informal but if you don't go then you'll be sectioned. You shouldn't be threatened with a section, this needs to be clearer."

"Staff see it as a burden if you ask for something else or want to speak out. The environment is always not as safe as you would expect."

What would you like or expect staff to tell you when you are being sectioned?

- Feedback from conversations with young people shows that often a leaflet about young people's rights is handed to them when they are in the process of being detained, and possibly very unwell, without explanation or discussion. When a young person is detained, staff should always take the time to have a supportive conversation with the young person to discuss their rights and recognise that each young person may need their rights explained to them in different ways and at different times, depending on how unwell they are. For example, staff may need to regularly revisit the discussion about rights with a young person during care and treatment reviews, particularly if the young person's rights change due to moving from informal patient to sectioned patient or after moving from CAMHS (children adolescent mental health services) to AMHS (adult mental health services). Providing information sheets would be helpful in addition to, not instead of, conversations.

- Staff must speak in a clear way, using simple language and avoiding the use of jargon. As mentioned before, consideration must always be given as to whether a young person is neurodiverse and this must be taken into account when rights are explained.

"There's a lot of jargon which is difficult to read through and understand."

- It is incredibly important that young people are made aware that they have the right to an advocate, how they can access an advocate and how they can be involved in their treatment and care. Young people we spoke with advised that this didn't always happen and some didn't know what advocacy is.

"A lot of people are given their rights but nothing is really properly explained to young people. I've spoken to a lot of people about this too. If you're in hospital and really poorly, you're not going to have the brain power to properly understand this information. Therefore people end up being really compliant when they don't really know what's going on. You're told your rights like someone is when they're arrested. It's not a calm and supportive chat."

"I wasn't told about advocacy which is a big issue as this was one of my rights."

"I wasn't aware that I could challenge or have involvement in my care and treatment."

1.6 Theme 3: Care and treatment in hospital

If you thought that you might be detained again in the future, what would you want people involved in your care to know?

- Young people expressed how important it is for them to be consulted about treatment options and medication and be supported to meaningfully input into their care and treatment plans.
- We heard that young people wanted to be asked questions such as 'What support do you want from us?' Young people wanted to know that professionals are there to support them. We also heard it is important to respect that young people might not be able to give an answer straight away.
- It is often assumed that doctors and psychiatrists are always right but young people explained that they knew what they wanted and needed from their care, and wanted their input to be taken seriously, so when staff are patient, supportive and believe in patient participation, it makes a big difference.
- Young people are also very wary of how and when diagnoses are made. Some of the young people we spoke with said that staff turnover can create inconsistency in diagnosis as well as treatment and care. They gave examples of clinicians who have been practising for a long time but are not always aware of up to date thinking and research and can use out of date terminology.

"I was prescribed medication but I was so unwell so the barrier was my illness as I couldn't understand that the medication could help me. But because I was so unwell I couldn't advocate for myself and couldn't ask the questions I would have wanted to ask. I was glad I had taken the medication but I would have liked to have a choice in what medication I could take."

"A nurse I spoke to recently said that some of their colleagues just don't understand some diagnoses. I was able to get a diagnosis that I really needed recently just from one really good nurse."

"Is it right to diagnose a young person with emerging personality disorder when they are 14, very distressed and they have only been known by clinicians for 2 weeks?"

- As with any other Mental Health service, the transition between CAMHS and AMHS is a difficult time. CAMHS provides education and supports young people to plan for their futures. The support provided at AMHS is very different and young people are not supported to prepare for a life beyond discharge.
- Young people also advised that transitioning to AMHS meant being on wards with people who are much older and being expected to suddenly take more responsibility for their own care and understand things that would not have been expected in CAMHS, all of which adds more difficulties to an already stressful time.

"The day you turn 18 you don't just become an adult. You're expected to be treated differently when you turn 18 but you don't change that much. Being in a ward with 80-90 year olds is not therapeutic at all"

when you're only 18. You can be 17 and know what you need but you can also be 18 and not know what you need."

What would you like included in an advance choice document?

An advance choice document is an agreement where young people are encouraged to input their views and wishes about any future inpatient care they may receive. During our research we asked young people what they would want included in their advance choice document.

- Young people want their medication to be included in their advance choice document; this should include which medication they want and what dosage, as well as what PRN medication they would prefer in case of restraint.
- Young people want all their preferences and information included in these documents and want staff to have conversations with them about this.
- Information about what to do if a young person changes their mind at a time when they are unwell should also be included.

"Staff should say to the young person 'what do you want us to do if you change your mind? Do you want us to consult someone else? Do you want us to consult your nominated person?'"

What if your advanced choices aren't the same as when you are in a crisis? Should they still be followed? What are the 'lines'/limits to that?

- It all comes back to truly individualised care and support. Young people want staff to review each situation based on their knowledge of the young person, to consider how unwell they are and in turn, make well informed decisions.
- It's important for other friends/family members to be involved in this process too if they know the young person better than their parents.

"Depends. If I'm in a crisis and on a lot of drugs then maybe they shouldn't follow my advice. However if I'm asking for a small adjustment then they should follow what I want at the time."

"Two sides: one half makes me think if I was asking for something reasonable I would want it to be listened to. However I would also want my previous choices to be listened to. It would be really helpful to be able to revisit and review these so they are kept up to date."

"Ask a friend that might know better than a parent. It might not necessarily be a parent but would be someone who knows you really well. They could tell the doctor that your behaviour isn't normal (if that's the case)."

How often should they be reviewed or updated?

- Young people want advanced choice documents to be reviewed on a regular basis.

"(Advance choice documents) Should be reviewed on a case by case basis. They should also be regularly reviewed as things change."

"It would be good if it were reviewed by a third party anonymously. It comes down to unconscious bias in people who know the young person."

1.7 Theme 4: People who support you in hospital

Sub-theme: Carers

Do you agree or disagree that someone under the age of 16 should be able to choose a nominated person?

- All young people agreed with the proposal for under 16s to be allowed to choose a nominated person where they have the ability to understand the decision.
- Young people want to be able to nominate a person that might not necessarily be a parent. Young people highlighted they would like to nominate an advocate or a member of staff at their school or another family member who they may have a better relationship with.

"Yes. When I was sectioned they asked my family member but they have a lot of stigma about mental health. My school would be good."

Who is the best person to involve in your care?

- It can be helpful to have education involved to an extent but it should be based on how the young person feels about this. Some young people found the support invaluable but others found that school involvement could be intrusive and lead to teachers knowing about their personal situations when they didn't need to.
- Young people want those involved in their care to be assessed on an individual basis including the level of parent/carer involvement.
- If a young person is insistent that they don't want their parents involved, clinicians should listen and explore why. Their involvement or the threat of their involvement can lead to young people not sharing the full story with clinicians which can increase risk. Parents and carers should be informed of high risk 'A&E' situations.

"I wish my school had been a bit more involved. When I was at university they got more involved which I didn't want. I think it needs to be reviewed on an individual basis and discussed with the individual."

"Family e.g. older brothers and sisters, as there might be different and closer relationships."

Have they been able to be involved?

- Some young people had other family members (such as brothers or sisters) and friends (instead of family members) involved in their care.
- Some young people had schools or universities involved with mixed feelings about this.

"My brother could explain better why I didn't want my mum involved."

Are there any challenges around naming them as the best person to be involved in the future?

- One young person noted that the person they would choose as their nominated person, might not always be the best person for staff to contact. Having a social worker review their nominated list and having a discussion with them could help with this.

"I would know who I would want to tell everything to and who I don't. Sometimes I have picked someone who might not have actually been a good person for me. I once had to make a list of everyone I wanted to talk to and my social worker looked through the list and rang each person to check it with them. I would rather them go through the extra hassle to do this than them just to call a parent."

Sub-theme: Advocacy

What has your experience been with an advocate in hospital?

- Young people agreed that advocacy should be available to all children and young people in hospital, not just those detained under the Mental Health Act.
- Several young people highlighted that notices about advocates on their wards were out of date. Professionals at the hospitals often were not aware of who the local advocates were.
- Young people noted that staff at the hospitals rarely explain or notify them about options for advocacy.
- Some young people shared positive experiences of advocacy and cited that having supportive staff on the wards who knew and understood about advocacy helped enable access.

"The actual hospital doesn't explain what advocacy is. They had a very outdated poster which wasn't very helpful."

"When I was in hospital, I was informal so didn't have access to an advocate which was really scary. Even when you're informal, it doesn't mean you're free."

"I could email the advocate and she came into the hospital which was really good. She came in and sat with me and with the staff. It's important to have someone who is unbiased. Someone who gives you information but doesn't tell you what to do. Someone who can listen and sympathise."

What else could they have done?

- Young people want advocates to be sensitive, caring and supportive and understand systems and social issues as well as mental health. Advocates should be available and accessible, including out of 'working hours' (9 to 5) and should work in a trauma informed way. This means advocates should be sensitive to the wider context of the young person's life, and should understand how this might influence them and the type of support they might need. They should support young people to understand how important it is for them to be at the centre of their care and help them use their voices.

- Young people want advocates to have a good understanding of social and systemic issues such as racism.

“Understanding of systems and social issues that run through all of this. You can have a great advocate but if they don't understand your experience of racism they aren't going to be able to help you in the way you need them to. During my care I only met one person of colour...I felt unsafe due to the racism in the system.”

“Young people need someone independent who can help them understand the complicated environment they have found themselves in at a pace they understand. They need to feel confident that they have someone available who can work with them, and help them understand their rights and how to challenge decisions to improve their care. They need to know that advocacy is a right and not a privilege to be earned or a burden on the healthcare provider.”

1.8 Conclusions and recommendations

Advocacy

- An advocate should be offered to all young people detained under the Mental Health Act, including voluntary inpatients.
- Young people should be made aware of what an advocate is, and that they have a right to have one.
- Information about advocates should be clearly communicated to young people at the beginning of their care.
- Up to date and relevant information should be advertised on the wards to ensure young people can access an advocate if and when they choose to.

Autonomy

- Young people should always be involved in decisions around the care and treatment they receive.
- Staff should always discuss decisions that are made about a young person with the individual.
- Even when young people are particularly unwell, they should still have a say in the direction of their care, and this should be listened to.

Individualised

- Every young person should receive care, intervention and treatment based on their own individual needs.
- Staff must understand that young people's care should be completely personalised and individualised or else risk adding additional trauma to their experience.

Communication

- Staff should always clearly communicate information to young people.
- It's particularly important for staff to ensure that young people are aware of their rights. This might mean communicating this information more than once, and in different formats.
- Staff should always communicate information to young people using straightforward language and without the use of jargon.

Neurodiversity

- Awareness around supporting neurodiverse young people needs to be improved.
- Staff must be able to better understand neurodiversity ensure that the care and support they receive and all communication is tailored to their specific needs.

Consistency

- Where possible, ensuring the consistency of staff who support young people is vital to their recovery.
- Staff turnover can create inconsistencies in the diagnoses young people receive. In addition, consistency of the therapeutic interventions which are offered to young people is really important.

Compassion

- Throughout the research, young people felt the most important aspect to their recovery was having staff who understood them and offered them the support and care that they needed at that time.
- When young people had positive relationships with mental health professionals, they said it made a significant difference.

Therapeutic benefit

- It's important for young people to be offered a range of different therapies, as well as medications, to ensure that each individual receives the interventions and support that is right for them.
- Once again, care and treatment should be personal, individual, participatory and holistic.

Nominated person by under 16s

- Young people don't always have good relationships with their direct family members.
- It's important for staff to understand these relationships and offer a flexible approach in terms of who the young person wants involved in their care.

Transitions

- There is a big difference between the type and amount of support young people receive at CAMHS compared to AMHS.

- Staff from the two services need to collaborate and ensure young people receive a smooth transition between services.
- Staff at AMHS should have conversations with young people about their futures and help them prepare and plan for a life beyond inpatient care.

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