DISCHARGE PLANNING AND AFTERCARE FROM CAMHS TIER 4 CARE

Young People's Experiences and Recommendations

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Contents

Executive Summary

Barnardo's set out to learn from the experiences of young people who have been discharged from Tier 4 units. The aim was to enable young people's voices to influence emerging and ongoing service developments in local authorities and Integrated Care Systems areas particularly in England, where we had observed of growing demand for services for young people being discharged from Tier 4 units through contact with commissioners and partner agencies.

We carried out and analysed semi-structed interviews with six young people and equivalent questionnaire responses from one young person. All seven young people had recent experiences of leaving a Tier 4 unit. Our analysis led to four key findings as follows:

1. Young people asked for discharge planning to start as soon as possible after their admission to a Tier 4 unit and for the process to be transparent, so that they are involved in and understand all discharge planning and decisions. Unfortunately, most of the discharges experienced by this group of young people were lacking in these areas and young people reported much increased anxiety, fear and a sense of a lack of care, as a direct result.

2. Young people wanted discharge planning to include identifying trusted adults to create support networks for when they leave the unit. Their support networks might include family, caregivers and professionals with whom they have built a strong relationship, and these people could also act as advocates. Young people reported that their personal contacts in their support networks need emotional and practical support, advice and guidance to play a positive role in their recovery after leaving the unit.

3. For the most part, young people did not feel listened to when they tried to communicate what aftercare services and support would help them. Young people told us that the crisis, community and aftercare services offered were inadequate and unavailable at key times, creating a sudden drop-off immediately after discharge, often leaving young people feeling isolated and unsupported when they were most concerned about their mental health. Young people want access to aftercare services which are more individualised with professionals they know and trust and this should include access to mental health specialists which meet their specific needs.

4. Young people found the experience of Tier 4 to be traumatic and wanted to be able to look forward to positive futures whilst on the unit. Young people, their families and care givers need help with recovering from that trauma and moving on, including support with the impact on family relationships, the loss of peer and social networks, reengaging in activities, jobs and/or education and feeling able to talk about what they have been through. Young people's recovery benefited from opportunities and support to reclaim their voice and sense of autonomy.

Our recommendations aim to identify areas for improvements in discharge planning and aftercare services based on our findings and the analysis of the themes that informed those findings. These can be found on page 28 of this report.

Glossary

Aftercare	Health and social care help and support after young people leave Tier 4 units.
AWP	Avon and Wiltshire Mental Health Partnership NHS Trust.
BNSSG	Bristol, North Somerset and South Gloucestershire.
CAMHS	Child and Adolescent Mental Health Services.
DBT	Dialectical behaviour therapy (DBT) is a type of talking therapy.
Discharge planning	A plan developed to make sure a move from hospital to home is as smooth as possible. It is the link between the treatment in hospital and the care needed in the community.
Edge of care	Where there is a risk that a child or young person could be taken into care by a local authority.
HYPE	A Barnardo's service in the Bristol area that empowers young people to use their voice and experience to create positive change in local health services.
In care	Being 'in care' means that for some reason a child or young person cannot live with their own family and are being cared for by a local authority.
ICS (Integrated Care System)	ICS are made up of health and care organisations who share plans and joined-up services. They are formed by NHS organisations and local authorities in that area and also include the voluntary sector, social care providers and other partners with a role in improving local health and wellbeing.
Key Worker	NHS autism and learning disability keyworkers support children, young people and families to help avoid unnecessary admissions to mental health hospitals.
Leaving care	Transitioning out of local authority care, for a young person who may be 16 years old or older.
Sectioning	Being sectioned means that you are kept in hospital under the Mental Health Act 1983.
Section 17 Leave	A provision under the Mental Health Act 1983 in the UK, which allows patients detained in a hospital for mental health treatment to be granted leave of absence. This leave can be for a specific purpose and duration, and is considered an important part of the patient's treatment plan.
Tier 4 CAMHS	Specialised inpatient units, where young people with more severe mental health problems can be assessed and treated.

Introduction

Between April 2022 and June 2024, the multidisciplinary Care Pathways programme team at Barnardo's worked across the UK to identify and respond to gaps and inadequacies in the care system. Our team consisted of professionals with backgrounds in therapy, research, service design, property, business development, operations, quality assurance, human resources, and learning and development. They worked closely with colleagues, partners and commissioners across the UK with the aim of improving support and services for young people in care, leaving care, and on the edge of care.

Through Care Pathways' contact with commissioners, we observed a growing demand for various support options for young people who were being discharged from Tier 4 CAMHS. We saw Key Worker services opening in some areas and local authorities looking to commission residential care homes to bridge a gap in services post discharge.

We believed that the design of any future solutions for young people would benefit from the voice and experiences of young people with lived experience. This led us to decide to design and implement the research project detailed in this report. The research team was led by the Care Pathways Research Officer and other team members, working in close partnership with AWP Research and Development colleagues and Barnardo's HYPE team who deliver a service that empowers young people to use their voice and experience to create positive change in local health services.

We wanted to understand the experiences of young people who have been discharged from Tier 4 CAMHS units following an admission for a mental health crisis or escalation. Our aim was to inform and influence the design of planning and provision post-Tier 4, referred to in this report as aftercare.

Methodology

An evidence review was completed prior to this project (January 2023), allowing us to get an initial sense of the evidence landscape and what the gaps were. Whilst there was limited evidence available, what did exist suggested several things:

- Children and young people may find the predictability of the unit reassuring, making discharge unsettling and scary[1]
- Too often discharges are not well planned and do not include the wishes of young people[2]
- Services are not well connected which leads to gaps in care[3]
- Parents and carers are often not getting the support they need[4]

None of the evidence reviewed, included the views of children and young people. We therefore sought to fill a clear gap through this project. We adopted a qualitative approach, as this would both add to the evidence base and improve understanding of young people's experiences at this particular point on their care pathway. We wanted to look beyond the numbers and data in the evidence review, and hear the experiences as described by young people.

We designed a set of questions which would encourage young people to reflect on:

- how discharge was discussed and planned with them while they were on the unit
- how those plans and their overall support were managed and adhered to during and after transition from the unit to their lives outside
- how the professional and personal relationships in their life affected their experience of discharge, transition, and recovery.

The questions were co-designed with two young people with experience of Tier 4 in-patient settings.

We also allowed some space for a wider reflection on their discharge process as a whole, and how they might make suggestions for change if they were in a position of authority.

We offered and provided several ways to respond to our questions, given that we wanted to acknowledge that in-person or virtual semi structured interviews might not be suitable for everyone. Participants were offered the opportunity to attend an interview, write their responses to our questions, send in voice notes, or suggest their own creative ways of responding. Of the seven people we spoke to, six attended either in-person or virtual interviews and one decided to write their answers.

Following these discussions, we undertook a process of thematic analysis. Bringing the various conversations together in a research software tool called Dovetail, we were able to draw out several common themes. These led to the creation of the four key findings which linked to the three key original research questions.

The report is structured under the four key findings below, which emerged through our thematic analysis as the cornerstones of a supportive discharge process from Tier 4 units. Each finding chapter is titled in the collective voice of the young people:

1. Clear and transparent discharge planning would help us with recovery.
2. We want to choose our post-discharge support networks and the people in them need support services.
3. We want to have a say in what our professional post discharge support will looks like.
4. We need help to process, understand and be able to talk about what we have been through in order to find positive ways to move forward after leaving the unit.

For confidentiality reasons, all young people's names have been changed and pseudonyms have been used throughout this report.

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1   cco-childrens-experiences-in-mental-health-wards.pdf (childrenscommissioner.gov.uk) 2020
2   Supporting document – children and young people mental health inpatient competence framework.pdf (hee.nhs.uk) (2021)
3   Young people say what they need from mental health services | Healthwatch Cambridgeshire (2021)
4   Supporting document – children and young people mental health inpatient competence framework.pdf (hee.nhs.uk) (2021)

Who did we speak to?

During the planning and initial stages of this project, we identified that services in the Bristol, North Somerset, and South Gloucestershire (BNSSG) area were currently active in plans to improve Tier 4 discharge planning and were keen to participate in work that involved the voice of young people in this area.

We also identified a participation group through Barnardo's HYPE service within the BNSSG area which consisted of young people who had themselves experienced discharge from Tier 4 units. Through the invaluable support of HYPE team who facilitated this group, we were able to speak to seven young people about their experiences.

Several young people had attended the same Tier 4 CAMHS unit, although in total there were four different units mentioned across these conversations. While the young people all live in the same geographical area, and had a unit available nearby, there were times when no beds were available in their local area, meaning they had to travel further for their care.

As the young people we spoke to, were already involved with participation work, and were based in one geographical area, this offered both benefits and limitations. Their involvement in participation may mean that they found it easier than other young people to speak about their experiences, which ultimately led to the gathering of rich and informative qualitative data. However, we recognise that this means the views gathered for this project represent a sample of the wider population with lived experience.

We also recognise that Tier 4 units may approach discharge differently in other local areas. But we hope that, despite this limitation, our report shows what is important to young people when leaving Tier 4 care. We are confident that these findings, themes and final recommendations are also consistent with our wider evidence review.

As this project considered the views of young people, a suggestion for future work is to also consider the views of professionals working in this area.

We, and the young people, do recognise that any service-related shortcomings discussed in this report, come at a time when services are under great stress, when funding is limited, and when staff numbers are not always as they need to be. While it's important to recognise this, we want to reflect on the impact on young people and we believe therefore that the shortcomings they discuss need to be considered and addressed.

All young people had experienced a discharge from a Tier 4 CAMHS unit in the last three years. They were aged between 16 and 18 years and two of the young people were in the care of local authorities whilst receiving CAMHS service. The group identified as follows:

Gender: five females and two males
Ethnicity: five White British, one British Bangladeshi, one Black African/White British
Sexuality: four heterosexuals/straight, one bisexual, two 'none given'
Religion: three Christian, one Muslim and three 'none given'
Age: one 16, four 17 and two 18 year-olds (at time of interview/questionnaire)

This project was submitted for review and approval by the Health Research Authority who reviewed the study structure and materials including granting ethical approval for the work undertaken in this paper.

Key Findings

Key Finding One

1. Clear and transparent discharge planning would help us with recovery.

> **"There's a huge power imbalance and, the thing is, there's always going to be stuff that they don't tell a patient. But you do need to tell me what's going on. I really wish they would tell you what's happening. Yeah. And tell you why it's happening, too."**
>
> Samreen, aged 17

We began the research expecting findings based on discharge plans made with young people before they left Tier 4 units. We anticipated hearing about the quality of those plans, the meetings in which they were created, the amount of say that the young people had in what went into them, and how that plan matched up to the support they received when leaving the unit and when back in the community.

However, many of our questions around the discharge planning process received limited responses. This was because six out of the seven young people felt they had very little involvement or say in their discharge plans. In the case of *Katie (aged 18)*, she was *'so frustrated'* by the *'lack of say'* that she decided to *'discharge myself before I was ready to leave.'*

Katie left the unit with no clear or transparent plan in place. While this can, in part, be attributed to her self-discharge, CAMHS policy states that discharge planning should begin with patients as soon as they are admitted to the unit and our understanding is the self-discharge is not uncommon, making it even more important that discharge planning is started on admission where possible. None of the young people believed that their discharge plans were initiated when they arrived on the unit.

One of the earliest and clearest findings to emerge from our interviews was that young people felt that discharge plans were unclear or *'translucent'* and as result they often did not know or understand what was going to happen before and after their departure from the unit.

The three themes that led us to this conclusion are discussed in more detail below:

1.1 A lack of clarity around discharge plans can lead to increased anxiety about our life after the unit.

> **"So I really wasn't sure who I'd go to after I left the unit if I needed help. I kind of thought I'd have to wait for another meeting, but I wasn't too sure. That was probably quite scary when I came out."**
>
> Will, aged 16

The young people felt fear and anxiety around leaving the unit, which was greatly increased if they were not clear on what aftercare would be available for them. Not knowing who would be on their care team or who to contact if they felt like things were getting more difficult or what mental health interventions were going to be offered to them, were all destabilising factors.

When we asked Samreen how she had felt about leaving after a six month stay, she told us *'I was very, very worried. I was very scared. I tried to show that I was ready as it had been six months – if you are not ready after six months, when are you going to be?'* Earlier in our interview, Samreen had said that *'I really wish they would tell you what's happening. Yeah. And tell you why it's happening, too.'*

Will described it as a *'scary'* time as he approached leaving the unit, because he *'wasn't really sure'* who he could go to for support. He believed there might be a delay in his next scheduled appointment and wanted at least *'a bit of a plan'* as it felt for him as if his discharge had come 'out of nowhere' and he was not ready.

For *Katie*, it felt like there was no guarantee of appropriate support or an understanding of what aftercare was being offered at all. She said *'it would be nice if they could kind of almost guarantee you that there will be support, even if they can't tell you what exactly what it will be.'* She discharged herself from the unit feeling like she had no understanding of what support to expect and only knowing *'one person who was going to be on my care team.'*

Throughout these interviews, it was clear that a lack of explanation and discussion around discharge planning had led to increased anxiety when it was time to leave.

1.2 When we do not feel ready to leave, or do not understand why we are seen as fit for discharge, we feel scared and uncared for.

> ### "I wasn't really sure what had changed. I kind of felt the same."
>
> Will

Will was told he was better and ready to leave but he did not feel better as this did not reflect what he was experiencing in his own mind: *'it all came out of nowhere to me. It was really strange. It kind of felt very haphazard and like I was just being pushed out of the unit.'*

Olivia (age 17) told us *'I was very happy to be leaving, to be going home. But I was really scared. It felt like a big jump to go from so much support to almost none, and I wasn't sure I was ready.'*

Frances (aged 18) and *Katie* felt not only unprepared and scared to go home, but also that the move might be dangerous for them:

'I had an independent review and they said that I wasn't ready to leave, that it wasn't a safe discharge. But the psychiatrist decided to discharge me anyway.' – Frances

'I flagged up that I was learning to understand myself and I didn't feel safe, but you're telling me to go home anyway. But I'd told them that if I do go home, this bad thing is going to happen or that I don't feel safe and they are just sending me anyway. That kind of reinforced in my head that 'well, you can just do the thing you've told

them you are going to do or that this awful thing is going to happen.' If they're going to discharge me, why do I still feel like this?' – Katie

Throughout the interviews, young people clearly and consistently did not feel they had been told why they were being discharged and why they were seen as ready to leave.

Young people acknowledged that there are often decisions that need to be made about their care, and that they may not always agree with those decisions. Nevertheless, when these decisions were not clearly explained to them in a transparent way, they were not able to understand them. As a result, young people were not reassured about their safety and recovery post discharge.

1.3 Lack of quality discharge planning leads to missed opportunities for robust aftercare and community care.

> ### "I don't want to keep going on about it, but maybe they shouldn't have discharged me on a Bank Holiday."
>
> Olivia

We found evidence that the lack of quality discharge planning led to missed opportunities in both the short and longer-term. *Olivia* found herself being discharged in the run up to a Bank Holiday weekend, meaning she had four days in which she and her family were unable to access even the most basic support, such as a check-in call or a follow-up meeting from a community CAMHS service. She felt *'unsupported and stressed'* and acknowledged that this decision also left her parents with similar feelings, as they were *'basically in charge of keeping me safe for five days'* immediately after a month on a unit.

Olivia believed that had she been offered an appointment the day after she left the unit, this would have reduced her and her family's anxiety and acted as a *'bridge'* between life on the unit and her return home, helping her to settle. When asked if she could only make one change to her whole experience, she chose not to be discharged at a time when she could not access support.

The longer-term impact of the quality of discharge planning was experienced by *Katie, Olivia* and *Frances*. Three of the seven young people felt that they left the unit with limited clarity on the discharge plan in place.

Katie had been receiving Dialectical Behaviour Therapy (DBT) while on the unit. She had felt that she could 'get so much out' of this therapy, and that it was *'really good for me',* but knew she was likely to be leaving the unit before the full 12-week programme was over.

So, in a discharge planning meeting, she asked to continue accessing DBT after discharge, but initially did not get a clear answer. Later, she was told that having just turned seventeen with the waiting list for DBT with community CAMHS over a year long, there would be no point putting her on the list as she would be too old to access DBT through CAMHS by the time she reached the top of the list.

During our interview, *Katie* reflected on her feelings about this process: *'If they knew it was definite that they couldn't put me on the waiting list, I would have appreciated them looking into different ways that I could access something similar, but they didn't.'* She is now with Adult Services, receiving DBT, and finding it extremely helpful but feels that this has taken too long.

Katie had identified an intervention that was helpful, asked to continue to access it, but actually experienced the planning process as a barrier to access, rather than an enabler.

Olivia described her plan as *'somewhat'* clear, as she was told the name of service but informed that the service might not have capacity for her. She was not told what that service offered or how they would work with her. *Olivia* believed that this was because staff were trying to prepare her for disappointment, in case the service was not offered to her.

Frances' first discharge had not felt planned or clear at all but had benefited from a much clearer plan in place on her second discharge from a different unit where she felt supported to have a say in her discharge plans, knew where she was going, what support would be in place and the steps of the process were clear to her throughout.

Frances reported that on this second in-patient stay, she immediately knew who her *'assigned people'* at the hospital were and that they *'did a lot of work with me about what I wanted and then went into my meetings and advocated for me.'* Coupled with this, she knew that when she was discharged, she would be going to stay in a residential care home.

Staff from the home were involved in *Frances'* discharge plans, visited her on the unit and told her about where she was going, helping her to envision what her near future would look like. She knew that she would always have *'at least three members of staff available',* that there would be an *'on-site therapist',* and she also knew when and how she would be seeing her CAMHS worker and her psychiatrist.

The discharge planning for *Frances,* took the voice of the young person into consideration, was clear and transparent, was relational, and it was adhered to. Our analysis of the young people's experiences would strongly suggest that these should be the cornerstones of good discharge planning.

Key Finding Two

2. We want to choose our post-discharge support networks and the people in them need support services.

> "One thing I would have liked is if my family got an overview of the weekly meetings. I wish they were made aware of things like my discharge date changing, but they didn't know until my planning meeting. I didn't tell them because I assumed they'd know, but they didn't know."
>
> Katie

Six out of the seven young people identified and described individuals that had helped them to transition out of the unit and back into their lives. The young people who had a robust and reliable support network reported a more positive experience of recovery both on the unit and after they left.

Young people wanted to play a role in identifying their support network post discharge and this went beyond professional support. Young people reported that resilient, well-informed people from their personal support network, made the most impact.

Young people demonstrated the benefits of both identifying their own aftercare support networks, alongside ensuring that those people are enabled to take a supportive role in the young people's recoveries.

During this chapter, we will look at the three themes that led us to this finding:

2.1 Consistent, well-informed and trusted adults with whom we had a secure relationship often played a defining role in our recovery after leaving the unit.

> "She [Mum] would always push for what was right for my care, although she never wanted me in there and she wanted me home as much as possible, she knew keeping me there was the right decision. So just having someone that made sure everything was good and everything was being done properly – that helped a lot."
>
> Daisy, aged 17

We asked young people who had been helpful when they had transitioned out of a unit and what they had done to be helpful. In six out of seven cases, those who had played the strongest roles in recovery were the adults who already had a long-standing and secure relationship with the young person. These were either professionals that had already been in the young person's life before they were admitted to the unit, or family members or caregivers.

Daisy spoke at length about the role her mother had played in supporting her recovery. Her mother had advocated for better care for her while on the unit. She had also attended discharge planning meetings, gaining a clear understanding of what would be happening for her daughter next and was able to *'push for what was right for my care.' Daisy's* mother had challenged the decision when they [the unit] *'tried to kick me out halfway through my stay',* believing that it was not the right time for her daughter to leave.

When discharged, her mother encouraged *Daisy* to find work in order to re-establish some normality in her life: *'my mum was like 'you can't come home to nothing and just live in your room, you need something to get out of bed for.' Daisy* believed that her mother's approach fundamentally supported her recovery.

Olivia shared a similar experience with her mother; *'my mum was so supportive and accommodating. Even though she felt unprepared, she took into account what the doctors had said about how to take care of me. And when I was out, she kept me distracted and busy, which was what I needed.'*

For the two young people above, it was the continuous advocacy and support from a parent that really made a positive difference in transition and recovery, but it was not a parent or carer for all young people.

Frances describes how her social worker, who began supporting her partway through her first admission, was a constant before, during, and after the second admission. Her social worker came to see *Frances* every week on the unit *'to account'* and *'escalated concerns'.* She felt that it was hugely important to have this trusted individual involved in her plans for discharge and that, because they were there throughout, they were well able to support her to progress with those plans after she left.

Katie was effusive in her praise for her Community CAMHS Worker, who she was supported by before, during, and after her time on the unit:

'If I could frame a picture of my Community CAMHS worker and write 'this woman is a legend', I would. Because she just made herself as accessible as possible all the time. If I needed anything she'd call me that evening or she would tell me a time she could see me the next day. And even if we weren't doing anything specific, just having someone that I trusted made me feel a lot safer.'

Katie's experience demonstrates how the trust in her worker acted as a protective factor. *Katie* told us that because she knew she had a trusted worker with her every step of the way, she felt able to challenge any decisions or plans she did not agree with and to try new activities that might help with her recovery.

Three other young people told us that having a trusted worker helped them to open up, *'alleviate some of the burden from my shoulders',* and to understand that setting small goals can be a great way to progress in recovery.

It was encouraging to hear that these relationships, both professional and personal, were key in transition and recovery. Young people told us that such connections need to be supported, nurtured, and encouraged.

2.2 We know who we trust and feel supported by, and these people should play a role in our discharge planning and post discharge care packages.

> **"I don't understand why the contact was cut. They wanted to do it, the school had allowed them to do it, and I found it really helpful. But then the unit just stopped it and I didn't know why."**
>
> Katie

Whilst parents and social workers are often expected to be play a major role in post discharge recovery, one theme revolved around the identification of people who might not be as obvious but can be integral.

Young people particularly valued those who were able to bring some normality to their lives. As *Olivia* told us, *'I think people just acting normal around me was a big help. I felt so not normal, so it was weird to see friends or family or anyone again, but them just acting normal made me feel more normal.'*

Katie was really pleased when *'two members of staff from my secondary school'* were given permission to visit her. When they visited, *Katie* told us they would *'just be really chill'* and *'play cards'* and this gave *Katie* something to look forward to every week. *Katie* acknowledged that this also took some pressure off her parents, because they knew *Katie* had other trusted, responsible adults in her life.

Unfortunately, *Katie* reported that these visits were stopped by the unit. *Katie* was never given an explanation as to why, leaving her feeling unsupported, ignored, and confused, contributing to her eventual decision to discharge herself.

Will talked about visits from his wider family and close friends of the family. *Will* felt he could just talk to them, be honest with them, and in the case of one family friend who worked in the NHS, he could share his concerns about things he was seeing on the unit and get help with understanding what should be happening and how.

Will also highlighted the importance of a cousin who *'was just good to have a laugh with and make stuff less serious.'*

These examples show how important it is to be maintaining and re-establishing some normality in their relationships for young people's recovery. Young people described how admission to a unit had been extremely destabilising for young people's lives and relationships and therefore sought to reach for stable figures, who could reconnect them to their normal life in their discharge planning phases. It was these connections that young people held close and valued, especially when they felt distanced and uninvolved in their discharge planning. Young people told us they need to be able to include in their discharge planning the people who already make them feel heard and understood.

2.3 Our families and care givers need emotional and practical support, advice and guidance to play a positive role post discharge.

> **"People get tired of fighting, as well. It's a big thing. Families are fighting for their children and it isn't going anywhere. I've seen people who just couldn't fight any longer and then their child is lost to the system and it's just really sad. There shouldn't be such a big fight for something that is just basic human kindness."**
>
> Frances

We have reflected on how important it is to have families, care givers and/or trusted adults as an integral part of discharge and recovery. However, young people shared that these individuals are not always adequately informed and supported to play this supporting role.

Katie and *Olivia* provided examples where parents, with the very best intentions, had acted on the advice of the Tier 4 unit in ways that young people believed to be counterproductive to their recovery.

Katie told us that her parents were advised to not *'shut any doors'* when she returned home, as they would need to be able to see her at all times. She believed it was suggested that she should be *'watched when I'm having a shower and going to the toilet', and that even when she went to school she couldn't 'have any privacy. I had locker checks and bag checks and I just felt like I was in prison.'* Even though she had spent a considerable amount of time recovering on a unit, the advice that her parent followed, left *Katie* feeling they still could not trust her.

Katie interpreted this as her parents saying *'We don't know what to do. We want to support you, but we can't force you or hold you down.'*

Olivia shared that when she was discharged her doctor told her mum *'This is all on you now'.* Her mum had felt *'unprepared'* and *'stressed'* at the thought of her daughter going from 24-hour care to nothing, particularly given that she was released just prior to a Bank Holiday weekend.

Frances' family were not helped to support her post-discharge and had also lost vital family support that was helping them to *'jointly function'* when *Frances* was admitted to the unit: *'I don't think the impact hospital admissions have on family is talked about a lot. When I was removed from home, all the support my sister and my mum got was cut there and then.'* *Frances* would go on to live in a residential care home after she was discharged, but she wondered if she would have been able to return home if the support for her family had been continued.

Will also believed that *'more could have been done'* because his mum *'was struggling and it was just hard.'* He felt that the professionals involved in his discharge plan and aftercare were *'dismissive'* of his mum and *'didn't really value her opinion that much.'*

A more nuanced approach to involving families and caregivers in transition and recovery is what these young people told us they needed. Young people clearly identify benefits to their recovery in having the support of a trusted adults and by contrast, disadvantages where family members were struggling or unable to provide them with support.

The themes drawn out under this finding demonstrate the effects trusted individuals can have on young people's recovery if they are able or enabled to act effectively as advocates for young people.

It was often assumed that people who are already in the young person's life will know how to help a young person, when in fact, they need support, advice and guidance to play that new role. This does not negate the need identified by young people for trained professionals and services to come in and make positive impacts towards recovery.

However, young people suggest that by not making the most of already available support, by not encouraging wider networks to play a role, and by not paying attention to who the young people want to be helped by, a disservice is being done to their recovery potential.

Key Finding Three

3. We want to have a say in what our professional support post discharge looks like.

> "I found it a bit prescriptive. It was just like 'let's tick these boxes'. And when they made it a bit less like that, that was nice."
>
> Olivia

In this chapter we focus on what young people were telling us about the professional support they either received or wanted to receive, as part of any discharge planning and once they had left the unit.

As outlined in our first key finding, young people reported not being sure what support they were likely to receive and not feeling included in their discharge and post-discharge plans. However, young people had their own ideas about how they wanted to be supported, what professional help they wanted or needed, tried to communicate this, but did always feel supported towards these goals.

In our third finding we demonstrate the impact on young people of feeling that their opinions on their care were not being taken into account, the impact of not receiving support and services due to the lack of available care, before looking at what support young people received and finally what young people believe would have worked for them.

3.1 When our attempts to communicate our needs are not taken into account, we are likely to have negative experiences of Tier 4 aftercare.

> "I just needed 10 minutes to calm down and be okay, not to have the police called or my parents lock and barricade the door. They weren't doing it to be horrible, that's what they'd been told to do. But now I'm trapped and this is ten times worse."
>
> Katie

Katie described being extremely vocal and clear in outlining the interventions and activities she felt would help her to recover, both before and after she left the unit. DBT had been beneficial while on the unit, and she asked to continue receiving this support once she left. When home, she knew that when she felt *'worse'* taking some time to walk outside or speaking to her CAMHS worker were beneficial. She also recognised that while she had improved in respect of the eating disorder for which she had been admitted, her improvement in her relationship with food had left her facing the *'underlying issues'* in a new way.

Katie reported that she represented all of this clearly, and was left asking *'why are you not helping me?'* She discharged herself from the unit because she believed the message she was being given was *'there's nothing we can do for you.'*

While *Katie* understood that her decision to discharge herself may have affected her discharge plans, she did not believe there was ever a clear plan in place or that her own views on her future care were considered. *Katie* asked about discharge planning on arrival at the unit, did not receive a clear response, and was aware of no discharge plan that followed her departure. Leaving without access to DBT, without a clear plan in place, and with only crisis numbers to call in distress or when her CAMHS worker was not available, Katie told us she felt unsupported and anxious.

Katie knew that her parents were only ever acting with her best intentions in mind and were following advice given by staff from the unit. However, *Katie's* anxiety levels were increased by her parents not allowing her to close doors, feeling she was *'being watched when having a shower and going to the toilet'* and *'locker checks and bag checks'* at school. At home, *Katie* tried to communicate her need to be allowed space or to go out for some fresh air when she needed to calm down, but instead, her bedroom door was *'locked'* and *'barricaded.'*

For *Katie*, the advice of the staff on the unit left her asking *'why aren't you trying to trust me?'* She said *'you're supposed to trust me until I show you that you can't, not not trust me until I prove that you can. That's not how it works.'*

Katie also reiterated many times in her interview that she felt she had identified the correct treatment for herself when beginning a course of DBT whilst at the unit but was not supported to access DBT outside the unit and not placed on the waiting list due to her age. *Katie* believed that continued access to DBT, at the right time, may have prevented some of the challenges she has faced since discharge.

Samreen tried to communicate *'that I wanted to go back into care [by which she meant foster care]'* after discharge and that she believed her professional support network should have *'talked me through it'* or at least *'definitely talked about different options'*. *Samreen* also felt that she would have benefitted from some *'individual work'* when both preparing to leave the unit and after discharge, but that instead she was offered family therapy. She told us *'there was too much family therapy going on and not enough individual work. I was feeling very lost in the middle of it.'*

For *Samreen*, while *'the whole family needed to have their say, I wasn't having a space for me to talk.'* *Samreen* described a *'pushed narrative'* throughout the family therapy she received pre and post discharge which was *'really hard'* and silenced her, leaving her feeling like her attempts to communicate her needs were being ignored.

After a few weeks, *Samreen* told staff that she did not want to continue family therapy as it felt *'redundant.'* She says that they *'thought about it'* and then told her *'it's just really important that this goes on.'* *Samreen* eventually received individual psychotherapy which she says is *'what she always needed',* having raised concerns about the family therapy both as part of her discharge planning and after discharge.

Frances talked us through her experience of discharge from the first of two units she stayed in, sharing *'I found the transition out of hospital really difficult because I was going back to a place where I told them I didn't feel safe, and no one listened to me that I didn't feel safe there.'* *Frances* was told she was no longer at risk because a person who was considered a risk to her no longer lived at the property, but for her *'it hadn't stopped'* due to her complex post-traumatic stress disorder associated with the property.

Frances describes being *'in a place that was triggering me like over ten times a day and I was having flashbacks.'* Despite raising concerns, *Frances* felt her requests and warnings on the associated risks were ignored. And she would soon be admitted back to a different Tier 4 CAMHS unit.

3.2 Aftercare services are less available to us at times of the day/week when our personal support is also less available to us, and these services are inadequate. This leaves us feeling isolated and vulnerable at times.

> **"I think that's a big misconception that you come out the other end and you're just fine. And I think that's why a lot of people don't get the support they need."**
> Will

One of the most ubiquitous findings from our research, was that the sudden decrease in available care when leaving a unit is a huge challenge. Six of the seven young people we spoke to specifically mentioned the experience and impact of going from 24-hour care to professional support only being available during working hours of 9-5 Monday to Friday. For young people, this was one of their biggest challenges post-discharge.

Daisy put it this way, *'Especially, night times are the worst when you go from 24-hour care, someone always there – if you need something, someone's awake. To a quiet house that's all dark. It's scary.'*

Olivia told us that *'night-time has always been more challenging for me because during the days you can have appointments and support. But at night you're on your own with no professionals. It felt a lot more difficult than the unit where you could just come out of your room and there's loads of people to help you.'*

For *Will*, it was the weekends that stood out: *'you have a lot of support in the week when you have your sessions, but then over the weekend you don't know who to go to... That was probably quite scary when I first came out.'*

Katie told us that *'I felt very alone. My CAMHS worker is not going to pick up the phone at two o'clock in the morning and it's not her job to do so...So I found that really difficult, because I was like 'there's no one else I can talk to. There's no one else that I know. There's no one else on my team that's available.'*

Five of the young people referenced multiple times in their interviews the impact of the sudden absence of care, pointing to a clear gap in the discharge planning process and aftercare services. Young people believe an 'out of normal hours' professional support service would make major improvements to the discharge experience and the early stages of recovery after leaving the unit.

Again, six of the seven young people felt strongly that out of hours support should be more readily available to them from CAMHS professionals. Young people found being given telephone numbers to crisis lines to be inadequate, frustrating, pointless, and felt like a tick box exercise. *Samreen* said *'They just gave me the number for the CAMHS crisis line and that was it. It wasn't helpful, I was just talking to a random person.'*

Katie said *'Talking to strangers when you're in a crisis is terrifying. I don't want to explain my whole life story, but I don't want to just say I'm having a bad day because that isn't giving an accurate picture of how I feel right now. If I was calling or messaging crisis lines, I never felt particularly heard.'*

Olivia told us *'They always talk about the crisis line, but I'm not the biggest fan. It's not been the most helpful in the past.'*

Daisy said: *'I don't think I would ever call a crisis line for my mental health. My mental health is impulsive, and if I'm in a crisis, I'm not gonna get myself out of it that way.'*

Frances shared that *'crisis management has never worked and it never will because it won't get anyone better. It just patches them up until the next crisis happens. You wouldn't put a plaster from Sainsbury's on a massive wound where you're bleeding out, would you? It just makes no sense.'*

The young people described these interactions with crisis lines as inadequate because advice such as *'put some lavender in your room'* or *'take a bath'*, or *'repetitive'* and *'prescriptive'* safety planning felt impersonal and generalised. This leads us to the next theme on the types of support that young people found more effective.

3.3 Collaborative personalised approaches to discharge planning and aftercare with consistent and trusted professionals increases our inclination to engage in services.

> "I think when people started to see me as a person, and a whole person, and there were people really advocating for me and pushing for me, saying that I'm actually a human being at the end of the day, that I'm not just a 'complex case' who is 'treatment resistant' – when that dialogue changed I started to open up more and that really helped my transition."
>
> **Frances**

Young people found it easier to engage with the support offered and find support that met their needs, when it was discussed with them and those discussions took their opinion into account, allowed them to make choices and suggestions and evidenced that their own personal hopes and goals were valued. On occasions, it was as simple as having a person who listened – a listening ear gave them the confidence and ability to open up, and this led to a better experience of the support or service.

Will told us that a community mental health worker that he started engaging with after his time on the unit helped by *'literally just listening, really. Listening and asking*

questions and validating my view by saying things like 'yeah, that sounds really hard for you'...A lot of the time I felt like I shouldn't feel how I did, but they would say 'you've been through this thing and this has happened so it's ok to feel the way you do. I hadn't really had that before, so it was really helpful...And they were probably one of the reasons I managed to get a lot better and be a lot more independent...I started off sceptical but then I opened up because I had this one person who I felt I can trust and who understands me.'

Samreen suggested that too much of her clinical care had felt cold and that she often felt the way discharge, care, and support were discussed with her was impersonal and just 'kept the dog on a tighter leash.' She could clearly remember occasions when the interactions felt more human and these moments stood out. She mentioned for example, a worker who did try to see things on a 'person by person' basis and listened to her when she did not want certain information shared with her family. This left Samreen feeling respected and meant she engaged well with this worker.

We have touched on Katie's relationship with her CAMHS worker before, but it is worth revisiting to consider the elements of this support that were relational, collaborative, and personal and how these increased Katie's desire to engage.

Katie shared that her worker would make suggestions for interventions that might help, but always be clear that 'if it doesn't work, it's okay, we can find something different.' She encouraged Katie to try new treatment options and to report back, working with her to make changes and find a better solution. They did art therapy together, and while Katie said she felt 'stupid' at first she enjoyed how her worker would 'teach me how to do things' and 'help me to see things differently.'

This collaborative, relational way of working 'gave me something to look forward to' because 'I loved seeing her on a Tuesday.' Her worker would tell her 'if I had a magic wand, I would take it away. But I don't. So what can I do for you right now?' Katie genuinely looked forward to both seeing her and working with her to improve her mental and emotional health.

Frances perhaps gave us the clearest indications of how crucial this kind of relational, personalised support can be. She reported that, during her first stay on a unit and the first part of her second stay, her meetings and clinical conversations had 'felt so cold, like they were trying to control an animal in a zoo.' She felt that 'no one cared' and this 'kind of confirmed what I thought; that people were bad and can't be trusted. This made me hide my anxiety.' Over time, through a series of workers and situations, Frances began to see things differently.

At her second unit there was a worker who would simply 'sit next to me and ask if I wanted a cold bottle of water' and then start conversations which would lead to discussing potential places Frances could live when she left the unit. Frances' social worker would also challenge her, pointing out that if she wanted to get out of the unit she needed to work on certain behaviours – 'they were very real with me, which I probably didn't like at the time. In the long term, it really helped.'

As Frances was approaching discharge, it seemed likely she would be going to stay in a residential care home rather than back with family. While this was a scary prospect at first, she reports the positive impact of the staff from the home coming to see her on the unit, telling her about the beach near the new home, and showing her pictures of the dog she would be living with. 'No one was talking medical jargon, no one telling me everything I'm doing wrong. No one telling me I'm ill over and over again. They were saying 'we want to help you, we'll find you a school, you can have meals when you want and get food from the cupboard when you want.'

Frances shared that this continued, consistent, caring and relational approach enabled her to talk about her hopes and dreams, so she asked for support with applying for university.

Throughout this theme, young people provided evidence that when professionals supporting them with discharge planning or post discharge support relate to them, make them feel seen and heard, they are more willing to engage in the support they need. This, in turn, increases the likelihood that they make better progress in their recovery journey after leaving the unit.

As part of their personalised support, young people told us they need services and professionals to ensure that they treat the whole person and not just their diagnosis.

Katie reported that when she was 'not underweight' anymore, it seemed as though her support on the unit did not treat the 'underlying' needs that emerged.

Samreen felt that when she asked for support, the response often came from staff *'reading my diagnosis and going off that'* even if she was saying *'that is not what I'm struggling with right now.'*

And for *Frances,* until she was assigned an autism specialist worker, it felt like *'everybody was either focused on the fact that I was autistic or the fact of my mental health diagnosis, but no one looked at the full picture.'*

This theme suggests that successful support often relies on personalised, collaborative, and relational approaches which look at the whole person.

3.4 Timely access to specialists can play a decisive role in positive outcomes for us after discharge.

> **"That's really when the rapid progress started to happen."**
>
> **Frances**

Whilst a personalised relational approach to care is needed across the board with young people experiencing discharge from Tier 4 units, the analysis of young people's interview responses also showed the value of specialist support in positive patient outcomes.

Frances saw the biggest uplift in her recovery journey when she was assigned an autism Key Worker. *Frances* *'finally felt listened to'* with someone who acted as an advocate and could explain the impact of her autism, whilst also ensuring professionals did not regard everything *Frances* experienced as being part of her autism. *Frances* described how this worker *'understood and helped other professionals around me understand that some things I struggle with aren't going to change because they're part of my autism.'* This meant that those around her were able to focus on the areas they could change, meaning *Frances* felt supported and was able to thrive.

Katie reported a lack of understanding in relation to her eating disorder at times, with staff suggesting that she was fine once she was no longer underweight when in fact she *'actually struggled more when I wasn't underweight.'* It was the art therapy and DBT, once accessed through adult services, which sat outside of her weight treatment that *Katie* felt made the crucial difference in her recovery.

Discharge Planning and Aftercare from CAMHS Tier 4 Care

Key Finding Four

4. We need help to process, understand and be able to talk about what we've been through in order to find positive ways to move forward after leaving the unit.

> "Letting people know really helped me, because I felt less like an alien and I felt less alone. I could try and live like a normal person because people know now, and they're not looking at me like I am some kind of monster."
>
> Katie

In our fourth and final finding, the focus is on the importance of supporting young people who have been discharged from Tier 4 units, to understand and be able to explain what they have been through and find positive ways to move forward and integrate back in the community. The aim is to share what young people have told us that either was helpful or could have been helpful to move forward after their time in a Tier 4 unit.

The themes that emerged from our analysis related to time and space to process their experiences in the unit, planning and engaging in a new future, relationships with family and carers, the impact of admission on young people's social networks, being able to talk about what they have been through and regaining their voice and autonomy.

The young people who participated in this research were involved in a participation service or a group made up of young people who have been through Tier 4 units. The group continued to work together to use their experiences to support change in the system. It was clear that the power of their collective experiences and the relationships they held with both each other and the Barnardo's project workers who run the group, had provided opportunities to understand and reflect on their experiences with people who could understand them and support them.

The following themes led us to the fourth finding. Below are examples and further detail from our interviews with young people.

4.1 We may need time and support to recover from the experience of being on a Tier 4 unit, which can be traumatising.

> "I realised there was no way that I would be able to leave a unit and then go back into school. I really needed that two months of being at home because I think being in the unit was – well, I hadn't realised just how stressful or emotionally draining it was."
>
> Samreen

Frances and *Will* highlighted the *'misconception'* that, when leaving the unit, you are fully recovered and able to immediately *'move on with your life.'* As *Frances* put it, *'people think that when you leave hospital, you're better. No, you're not. You're just hopefully at a point where someone can work with you in the community. If that's not done right, then people can get poorly again, and then people get trapped in a circle.'*

What young people told us they needed at this point was varied, but three young people shared that the *'trauma'* of being on a unit left them needing considerable time to slow down and do very little, reflecting on what they had been through and thinking about what came next.

Samreen reflected how, while on the unit, it had been traumatising to see *'other people that were quite similar to me in terms of being unwell'. Samreen* was grateful that she was discharged when school was closed for the long summer holiday. *'Being at the unit was so stressful that I really needed that...a vacation from a vacation. The best way I can describe it is downtime.'*

After a six month stay in the unit, *Samreen* felt there was too much to process to begin immediately reintegrating into normal life. Young people felt that *'so much has changed'* in their personal lives and networks since their admission that they needed to both understand and adjust to these changes.

Will, told us that our interview led him to reflect that *'the unit in itself is a trauma',* and he also felt that time to adjust and rest was a necessity; *'it was a really weird time. I can't think what helped other than time, really.'* Will says that he needed to rest and at that point, talking would not have helped – *'it was just time going out for walks and just sleeping. Honestly, I was just sleeping a lot.'*

Space and time were essential for *Will* and *Samreen,* while others, as we see in our next theme, benefited from planning, looking forward to and then getting involved in new activities; a timely reminder of the importance of recognising there is no one size fits all plan or approach.

4.2 Supporting us to plan for our futures and access meaningful, enjoyable, and varied activities of our own choosing is important for transition and recovery.

> **"Literally anything from giving me books to read or going to the shops or going to see a movie or going on a dog walk. Just usual things like that, nothing crazy. Just normality."**
>
> Olivia

Young people wanted to be able to look forward to and then access activities and they required support to do this.

In *Daisy's* interview, we learnt that she had been supported to access a range of meaningful and enjoyable activities after transition. These contributed towards her recovery and helped her to avoid 'returning to' negative contacts and situations that were associated with her mental ill health and her admission.

Daisy says that her mum did everything she could to keep her busy in those initial weeks after leaving, taking her on holiday, getting her *'back into the gym',* and making sure she did not just *'live in her room 24/7.'*

Most importantly though, *Daisy* found that being supported to find a job during the weeks leading up to discharge was most impactful. *Daisy* states that her *'job was always something that I loved'* and that having work was *'one of the things that kept me alive and kept me*

going.' There were several factors that made this job so powerful for *Daisy,* leaving her feeling *'a lot happier.'* She was forced to be sociable through it, it felt like *'normality'*, and she had *'some sort of responsibility again after having nothing.'*

Other young people talked about seemingly simple activities that made a huge difference to them. *Declan* (aged 17) repeatedly mentioned a non-mainstream school which allowed him to feel active, included, and *'normal'.*

Frances found discussions about going onto university were a key part of her recovery, alongside looking forward to and planning simple things like being allowed outside, having a dog to play with in her new residential home, and having the freedom to choose what she wanted to do with her day, were all equally impactful.

For *Olivia,* it was her mum supporting her to go for walks, attend the cinema, or read a book which helped in that initial settling in period post discharge.

For *Will,* something as simple as *'being able to listen to music'* that really helped him to settle. He told us *'Literally anything [would help] from giving me books to read or going to the shops or going to see a movie or going on a dog walk. Just usual things like that, nothing crazy. Just normality.'*

Katie felt so *'trapped'* when first leaving the unit by the levels of control and observation that she compared her life to a *'prison.'* This was a recurring theme for those young people who felt that professionals and trusted adults were too preoccupied with keeping them safe and not focused enough on their progress towards recovery.

For *Katie,* though, despite these comparisons to *'prison'*, there were clear examples of activities that helped her to start to feel like she was recovering well. It was particularly encouraging to hear her talk about her experience of art therapy, which she felt allowed her to work with someone who understood her and enabled her to express herself in new ways. She reflected that as she initially felt *'stupid'* and *'can't draw',* and *'I don't like mess'*, this was her *'worst moment.'* But as her therapist gave her permission to be creative, to make mistakes, and to *'learn new things'* she began to see things differently.

Through this activity, her therapist was able to support her to understand the emotions she was expressing and this, in turn, made her feel seen and heard. This way of

working *'was really helpful and was a way of looking into things I never would have thought of...because it's not something that I'm good at'*. Working with her therapist also led to a relationship which made *'navigating a normal life a lot easier',* because *Katie* felt she had someone who she could trust to understand her.

Katie said that being able to attend a new school, which she had to fight for, was equally powerful. When asked what one key change she would make around the time of discharge, she simply said *'let me outside, let me move.'* *Katie* identified different activities as integral to her recovery, that she believed could have made the transition out of the unit easier.

These examples show that the young people's recovery during this transitional period benefited from basic, everyday activities, many of which felt very out of reach for them during their time in the unit. Being able to look forward to *'normal activities'* was healing. It seems apparent that what young people need, and when they need it, will vary from person to person. However young people also told us how important it is on the road to recovery pre and post discharge to support young to think about, work towards, and take part in meaningful activity and plan for their futures.

4.3 We and our families and care givers may need some support with navigating the impact of Tier 4 admission and discharge on our relationships post discharge.

> **"It felt a bit strange between me and my parents sometimes, because I knew they wanted the best for me. But, a lot of the time, if they asked me how I was feeling or something, I wouldn't want to tell them because I didn't want to make them upset."**
>
> **Will**

Will felt *'guilty'* about what happened because *'everything's going on and Mum hasn't been able to be in work.'* He felt like he was *'holding someone back'* and that he was *'the reason they're feeling this way, which really wasn't nice.'*

All seven of the young people talked about the roles of family and caregivers when it came to transition from the unit and recovery once discharged. As we have seen in previous findings, these roles, and the experience and impact of them, were varied and changeable.

Five of the young people expressed complex feelings around approaching their families or caregivers for support and being honest about their emotions. These young people mentioned guilt and frustration in their relationships with family members and caregivers. The felt like they had upended their families' lives and that family members were having to play roles that they were not prepared for. At the same time, young people told us that it was sometimes frustrating when families and caregivers made them feel *'watched'* and *'constantly being asked how I was feeling.'*

For *Daisy,* the complications came because she *'hated mum being my carer'*. While her mum was a strong advocate for her, *Daisy* would find herself *'not wanting to speak'* because she felt like she was burdening her.

Declan was very aware of the effect of his admission to a Tier 4 unit on his mum and wished that someone had been able to support her with these feelings, as he felt unable to be the one to discuss it with her or help her.

Olivia recognised that her mum gave her the most important support for her following discharge, and that her recovery *'wouldn't have gone so well if I didn't have that',* but like *Will* also felt guilty about her mum taking on support *'that she wasn't prepared for'* and it taking up so much of her mum's time. *Olivia's* sense of guilt made it hard to approach her mum at times when professional support was not available, such as during the night.

Katie's relationship with her parents was affected by feeling overly observed, who she believed were following the advice of professionals but not listening to what *Katie* said she needed.

We noted a disconnect between young people and their families/caregivers. Guilt and frustration on the part of the young people seemed to be coming up against the parents and caregivers' anxiety, worry, trauma and desire to do the right thing – but often, there seemed to be no meeting in the middle and no support with how young people and their families could be working together more constructively.

Young people told us that they held back their real feelings so as not to distress their families but recognised that their families would want to know the truth. Young people wanted to support to help them and their families navigate painful and complex feelings before and after discharge, giving all parties a chance to consider how they create a better environment for recovery after leaving the unit.

4.4 We are at risk of isolation when we leave the unit and may need help prior to discharge to prepare for potential changes in our social networks.

> **"It was a weird time. Like, I didn't have anyone in my life at that time. School wasn't going on and it was just me and my mum."**
>
> Daisy

Throughout this report, we have reflected on ways in which young people did not feel fully prepared for their discharge from Tier 4 CAMHS units. Young people wanted an opportunity to consider and understand what life might be like for them when they leave the unit, particularly in reference to how their previous social groups and friendships may have changed and moved on.

Will wished he had been more prepared for the experience of leaving the unit and what might have changed. He left the unit with a sense of who his friends were on the outside and who he would be spending time with, but since being out he says, *'I haven't heard from them.'* This unexpected change in his friendships *'felt like a barrier to getting better'* because it led *Will* to believe that people *'aren't going to like the avenue'* he was going down or *'understand'* his decisions.

After six months on a unit, *Samreen* told us she would have benefited from *'extended leave'* from the unit prior to discharge to give her chance to slowly adjust. Instead, she felt it was *'full time in a unit and then suddenly let out into the real world'* and that *'things had properly changed'* and she was unsure how to reintegrate into a new life after all she had been through. *Samreen* found it difficult to adjust when realising that after *'6-7 months of life being on pause'*, *'everyone else had moved on – my friends had moved on, my sisters had moved on.'*

Both *Katie* and *Daisy* also reported similar feelings, with *Daisy* stating that as *'my life stopped...everything else had moved on'* and the *'readjustment...was a lot more difficult than you expect.' Katie* felt like *'I had no friends'* not because her friends had distanced themselves, but *'because I disappeared and didn't tell anyone what was going on.'*

Each of these young people reported that their social life and relationships had shifted in dramatic ways when they were discharged. The commonality of this experience led us to determine that some work could be done with young people once they are admitted to a unit, looking at their current social group and connections, how to maintain these where appropriate, to consider how friendships and social contacts may be impacted and to prepare young people for coping with potential changes in these relationships once they leave the unit.

Frances demonstrated how envisioning the support, contacts and environment after discharge, in her case to a residential care setting, can improve the process of discharge immeasurably. Perhaps the same is possible if we can help young people to anticipate and prepare for how their friendships and social life might have changed whilst they have been in hospital.

4.5 We need support to be able to share our experiences in safe and authentic ways.

> **"Letting people know really helped me because I felt less like an alien and less alone."**
>
> Katie

We also learnt that it can be important to support young people to share their stories safely, authentically, and appropriately within their various social networks. Young people expressed difficulty in knowing how to tell people what they had been through, but those who were able to do so found it powerful and believed it played a key role in recovery.

Katie had always found it hard to share her story or be honest about her mental health before being on the unit. After being discharged though, she shared some information about her experiences on social media. The

response was a surprise, leaving her feeling seen, heard, and uplifted.

Once *Katie* had shared some context around her condition and experiences, she found that other people shared similar stories with her. She then felt she could speak to certain people about her mental health and that she *'could try and live like a normal person'* because while a lot more people now knew about her mental health admission and history, *'they're not looking at me like I'm some kind of monster.'* Once this information was 'out there' and *Katie* felt comfortable with it, *Katie* told us *'I had some kind of support system, and I met people who had gone through similar things...and now I have people who I trust with everything because I'm like, ok, you get it.'*

Daisy shared her story at her new job where she had *'been able to tell a few people about my past and they know about my mental health and my struggles.'* *Daisy* experienced this as freeing, giving her more confidence to share her story *'selectively'*. *Daisy* *'picks and chooses'* who she tells and then benefits from these relationships as she now has a small number of people who can be there for her when she needs them to be.

Unfortunately, others still experience a barrier to sharing their story and potentially finding similar networks of support to *Daisy* and *Katie*. *Will* still struggles with *'the perception of others'* and with knowing that people know he was in hospital, but perhaps makes *'assumptions'* about why.

Alongside supporting young people to picture a life outside the unit, young people want help with finding ways to share their story in a way that feels right to them. This might not be publicly and it might only be with one person, but through this research we have seen the power that sharing your story can have, and believe that giving every young person the opportunity to prepare to do this in some way, if they want to, would be a positive step in their aftercare journey.

Furthermore, after we stopped recording our semi-structured interviews, five of the young people said that it had felt really positive for them to answer our questions, reflect on their experiences with new people, and look back on the progress they had made since admission and/or discharge.

We were able to see the power of sharing your story in action, and we believe it should be a central tenet of recovery.

4.6 We need support and opportunities to reclaim our voice and autonomy.

> **"I think that was really affecting me, I was very restricted. I was under section which meant I couldn't leave without Section 17 leave, and the only person that could write that leave was my consultant. But if she feels, for some reason, that it's not appropriate at the time, it could mean I don't leave the unit for days or weeks."**
>
> **Samreen**

The final theme covers young people's loss of autonomy and voice following a Tier 4 admission. An admission usually comes when it is deemed that someone cannot keep themselves safe and needs daily intervention, so it is to be expected that some decision-making, planning, and day-to-day choices are taken out of their hands and young people understood this. While young people acknowledged that *'there's always going to be stuff you don't tell a patient'* and when *'working with young people, sometimes you are going to have to override their opinions',* five of the seven young people reported experiences that left them with what they characterised as a dehumanising lack of power with their autonomy stripped away in ways that felt excessive.

Katie, Samreen, Frances, and *Will* highlighted their lack of involvement in decision making and planning when we asked about discharge planning. We heard that staff would *'dictate'* rather than listen, that discharge meetings felt like *'they all had a conversation about me but I didn't get to have a say'. Katie* gave the example of when she had wanted to change a plan she had previously agreed to, but *'there was never an option to change it.'* This perceived lack of flexibility and inclusion in key decisions left young people feeling that their voice and autonomy was denied beyond what was necessary.

We also learnt that if young people can reclaim their autonomy and begin to use their voices again, that this could be another integral element of their recovery.

Katie's self-discharge brought potential pitfalls, but it was the decision to discharge herself that gave her a sense of power and ability to fight for her rights and pursue personal goals. *Katie* decided to leave the unit as she no longer felt she was getting the support she needed. As a result, *Katie* felt empowered to ask for the help she needed to attend a new school, to continue asking for access to DBT, and to approach her art therapy and other support with a renewed enthusiasm. Her discharge decision and what followed, left her feeling that *'if I push harder, maybe people will listen.'*

Katie told us she was *'so bored of being made to feel like this was my fault when I didn't ask for any of this.'* It was *'purely out of frustration'* that *Katie* was able *'to find my voice to say, you need to do something because this is not working for me.'* Katie suggests that this reclaiming of her voice and identity led to her gaining the strength she needed to engage with recovery.

Frances' recounted it as *'night and day'* in comparing how she was allowed to exercise her voice and autonomy during her two discharge experiences. On her first unit, she was discharged to a home where she did not feel safe and had said she did not want to return to, and within weeks of her return she became ill again and was admitted to another unit.

At the second unit, not only was *Frances* listened to when she said that she wanted to live in a residential care home when discharged, but she was supported to find one outside the city, near a beach, and with a dog – all of which were things she had asked for. Being listened to, gave *Frances* the confidence to discuss and aim for longer term goals such as going to university.

Will felt his voice, self-expression and autonomy were too restricted. He was not able to listen to music, he did not feel comfortable sharing his experiences with friends, and he did not feel able to be honest with family about how he was feeling due to his guilt at what he believed he had put them through. It was his community mental health practitioner with whom he was eventually able to be honest, who would listen to his concerns and tell *Will* it was okay for him to feel that way and was *'the reason that I managed to get a lot better and be more independent.'*

Daisy felt that having a strong voice in meetings in the form of her mum, meant that she did at times have someone fighting to keep her autonomy in place. *Daisy* told us that the unit had tried to *'kick me out'* when she didn't feel *'safe to leave'* and had shared these concerns with her mum who had fought for her to stay. When *Daisy* was able to *'pick and choose'* who she discussed her mental health with after discharge, rather than having conversations go on around her, but without her input, she really started to feel she was recovering.

We asked each young person what advice they would give to a new worker supporting young people as they are being discharged from a Tier 4 unit. *Olivia* told us she would say *'Just give the young person a lot of space to speak. I feel that's really important, that they get to speak about how they're feeling and what support they think they need. Even if they just want to rant about their discharge, let them speak and listen.'*

Olivia's advice encapsulates this final chapter and finding. Allowing young people to speak, listening to their voice, and granting them autonomy where possible, can be powerful tools in their recovery.

Themes and Findings on a Page

Key Findings	Themes
1. Clear and transparent planning would help with young people's recovery.	1.1 A lack of clarity around discharge plans can lead to increased anxiety about life after the unit. 1.2 When young people do not feel ready to leave, or do not understand why they are seen as fit for discharge, they feel scared and uncared for. 1.3 Lack of quality discharge planning leads to missed opportunities for robust aftercare and community care.
2. Young people want to choose their support networks and the people in their support networks need support services.	2.1 A consistent, well-informed and trusted adult with whom young people had a secure relationship, often played a defining role in recovery after leaving the unit. 2.2 Young people know who they trust and feel supported by, and these people should play a role in young people's discharge planning and post-discharge care packages. 2.3 Families and care givers need emotional and practical support, advice and guidance to play a positive role post discharge.
3. Young people want to have a say in what their professional support post-discharge looks like.	3.1 When young people's attempts to communicate their needs are not taken into account, they are likely to have negative experiences of Tier 4 aftercare. 3.2 Aftercare services are less available to young people at times of the day/week when their personal support is also less available to them, and these services are inadequate. This leaves young people feeling isolated and vulnerable at times. 3.3 Collaborative personalised approaches to discharge planning and aftercare with consistent and trusted professionals, increases young people's inclination to engage in services. 3.4 Timely access to specialists can play a decisive role in positive outcomes for young people post discharge.
4. Young people need help to process, understand and be able to talk about what they have been through in order to find positive ways to move forward after leaving the unit.	4.1 Young people may need time and support to recover from the experience of being on a Tier 4 unit, which can be traumatising. 4.2 Supporting young people to plan for their futures and access meaningful, enjoyable, and varied activities of their own choosing, was important for transition and recovery. 4.3 Young people, their families and care givers may need some support with navigating the impact of Tier 4 admission and discharge on their relationships post discharge. 4.4 Young People are at risk of isolation when they leave the unit and may need help prior to discharge to prepare for potential changes in their social networks. 4.5 Young people need support to be able to share their experiences in safe and authentic ways. 4.6 Young people need support and opportunities to reclaim their voice and autonomy.

Recommendations

Throughout this research, the young people we spoke to were both explicitly and implicitly pointing to areas where discharge from Tier 4 CAMHS units could be improved.

Our goal was to listen to the views and experiences of young people and draw out the standout recommendations for improvements for local authorities, CAMHS providers, commissioners, decision makers and key stakeholder organisations to consider:

1. **Discharge planning should start at admission and be clear, transparent and personalised in approach, taking the voice of the young person into consideration.**

2. **Young people need to identify their post-discharge support networks and families and caregivers need some emotional and practical support so that they can support young people after they leave the unit.**

3. **Involve young people's trusted adults and support networks in discharge planning from as early as possible, so that they can advocate for young people.**

4. **Young people should be supported to reflect and prepare for engaging with meaningful activities (work, sport, art, education etc) that can lead to a positive futures and wider benefits post discharge.**

5. **Young people should be prepared for managing changes to their social groups after their admission to a Tier 4 unit.**

6. **Young people should be supported to consider how, and with who, they may want to share their story and experience around their Tier 4 admission and how to do this safely, as this can be key in recovery.**

7. **Young people, their families and caregivers need help with navigating the impact on their relationships of admission to Tier 4 units and the aftercare.**

8. **Aftercare and Community CAMHS services should meet the needs of young people who are still recovering after their discharge and be young person centred, collaborative and personalised, considering the whole person not just their diagnosis.**

9. **Aftercare and Community CAMHS services for young people being discharged from a Tier 4 unit, need to operate outside of normal working hours (particularly overnight and at weekends), as young people find crisis lines to be frustrating and inadequate as a primary avenue for out of hours support.**

10. **Young people should be given the opportunity post-discharge to use their voice and reclaim their autonomy. An example of this could be participation work being offered to all young people who are discharged from Tier 4.**

Conclusion

We want to begin by saying how grateful we are for the time, honesty, and reflection that each of the young people brought to this research project. We would not have been able to do any of this without them. Whilst we had anticipated young people sharing information about how their discharge plans were created and implemented, the richness of the insights and experiences they have shared has meant that this project went way beyond that.

Their accounts of and views on how discharge plans were created, implemented and could be improved, are integral to the themes, findings, and recommendations we put forward in this report. By describing in such detail what helped and how, what they needed and when, and what was missing and how that might have helped, young people have enabled us to paint a broader picture than we anticipated of what young people believe would better meet their needs in planning for discharge, at the point of discharge and then through aftercare.

It is important to repeat at this point that we understand and appreciate that young people are describing experiences that have taken place during a time when services are stretched, when funding is limited and staff numbers are insufficient.

The research intended to 'engage with young people who have experience of discharge from Tier 4 CAMHS units to understand experiences of current planning and pathways'. We were aware of service developments happening in various local areas across both health and social care stakeholder organisations to find potential solutions and services to improve the discharge process. We hoped to be able to make sure young people's voices were influential in any such changes.

The young people want this insightful picture to be impactful and lead to change, as key stakeholders in health and social care continue to consider how young people's experience of discharge from Tier 4 CAMHS units and aftercare can be improved in the future, thereby contributing to better longer-term outcomes for young people leaving Tier 4 units.

We are now hopeful that, from the strength of the material that the participants in this research gave us, we have been able to put together a set of themes, findings, and recommendations that can be used to make sure that the voice of young people, who have lived experience of Tier 4 discharge, is at the centre of future developments.

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