

Away from hospital and into the community

A research report into alternative options for young people's mental health crisis care

January 2023



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Acknowledgements

We would like to thank the members of the advisory group for their contribution in the production of this report. The members of the group are: Chris Hampson (Chair), Rosa Napolitano, Lynn Gradwell, Angelina Morgan, Tim Wates, Felicity Mallam, Dr Des Holden, Stephen Firn, Maria Zazovskaya and Paula Lavis.

Foreword

Chris Hampson, Chief Executive, Look Ahead

Mental health support for young people in the UK has arguably reached crisis point. The psychological impact of the pandemic on young people combined with workforce and funding challenges have created a perfect storm. The figures are stark: over 1,000 young people aged under 18 were detained under the Mental Health Act in 2021/22, with this figure expected to rise year on year.

What these figures don't tell us, however, is the experiences of those young people themselves; what happens to them, what helps, what doesn't? And critically, about the experience of those that are sent home – deemed not unwell enough, not high-risk enough to be detained or provided in-patient support?

As a specialist supported housing provider for both people with mental health needs and young people, we have become increasingly aware over recent years of a gap in provision for young people in mental health crisis. A gap through which too many of the young people we support were starting to fall. This is why we commissioned Care Research UK, with the support of the Wates Family Enterprise Trust, to help us understand the bigger picture and the multiple, often competing, factors at play.

What we found sometimes makes uncomfortable reading. But it is our hope that by highlighting these issues, that policymakers, clinicians, health and social care commissioners and providers like us can come together to develop new models of specialist community-based services that provide a real alternative to the current provision. I know I am not alone in my belief that if this collective challenge is not met now, there is no doubt that we will see the consequences within our adult mental health pathways and hospital wards in the years to come.

To end, I would like to say a personal thank you to the Wates Family Enterprise Trust for their support, the health care professionals, and to the young people and their families and carers who shared their stories, insights, and often deeply personal experiences with us. We cannot begin to make the much-needed improvements to how our health and social care systems support young people experiencing crisis without understanding the difficult, often very painful, realities on the ground. It is our sincere hope that research like this will take us further along this path.

Chris Hampson

Chief Executive, Look Ahead

Tim Wates, Lead Trustee for Housing, Wates Family Enterprise Trust (WFET)

The Wates family has been involved in housing and the broader built environment for 125 years and continues to be committed to this sector in the long-term. Our aim for our Housing Research is that each piece of work the Trust funds moves forward a collective knowledge to better achieve a provision of accessible and quality housing for all.

We believe that good housing is essential to enable and support life opportunities from cradle to grave. Whilst this belief is widely shared, a great deal of work remains to be done in achieving real progress towards quality housing for all, in part, because of the complexity of the challenge and the tendency for initiatives to be piecemeal.

This research has gathered interviews from professionals, young people, their families and carers, in order to shed light on the challenges in the current system. It is encouraging to see that the report calls for these same groups to be involved in the development of alternatives ensuring future response in care and support remain relevant and appropriate.

We join Look Ahead in their commitment to better provide for young people in crisis. The evidence gathered in this report suggests there is a greater reliance on police services in tackling young people's mental health issues and, as such, there is a significant increase in the use of short-term orders. Interviews and data suggest that A&E departments are becoming a main port of call for young people in highly vulnerable states, despite the fact they are rarely equipped to offer such specialist services.

We hope that the WFET support of Look Ahead, to undertake this research, will provide evidence to start conversations across the NHS, housing, social care and local authorities about appropriate alternatives for young people's accommodation and support as they experience mental health crisis.

We look forward to being involved as the conversation grows and solutions emerge.

Tim Wates

Lead Trustee for Housing, Wates Family Enterprise Trust

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A research report into alternative options for young people's mental health crisis care.



Executive summary

Introduction and context

The need for children and young people's mental health (CYPMH) services is currently extremely high. Data for England shows that there are increasing rates of mental health detentions and hospital admissions for under 18s (NHS Digital, 2021; NHS Digital, 2022).

A recent NHS Confederation report stated that “the number of children and young people contacting mental health services rose by nearly a third from 2020 to 2021.”

Both the NHS and the government has a desire to respond effectively to this increased need and demand. The NHS Long Term Plan (2019) promised to grow mental health funding at a greater rate than overall NHS funding, with an extra £2.3bn a year alongside a maximum waiting time target of four weeks and a commitment to age appropriate crisis services. However, the funding increase and revised targets come at a time when the NHS is facing bed capacity and workforce challenges across all its services.

It is within this context that Look Ahead, in partnership with the Wates Family Enterprise Trust, commissioned Care Research to undertake research to better understand the experiences of young people in mental health crisis, the services currently available to them, how these services could be improved and new services that could be developed. By carrying out desk-based research and conducting a series of semi-structured interviews with young people, their families and carers, and mental health professionals, the research aims to:

1. Gauge the experiences and views of young people, their families and carers, and mental health professionals about the current system for children and young people (CYP) experiencing a mental health crisis.
2. Develop a research informed, community-based service for children and young people in mental health crisis/or who have complex mental health needs.
3. Raise awareness and influence national debate around the current challenges facing CYPMH crisis services and the impacts these have upon young people, their families and carers, and staff.

Through our research, the following themes emerged and were analysed in more detail:

Demand for and access to mental health crisis care for young people

There are a number of biological and social factors that lead to a young person facing a mental health crisis, all of which are contributing to escalating demand on services. Some of these factors, such as trauma and loss, economic hardship and experiences of abuse are not new but others, such as the impact of Covid-19, are. It is likely a combination of these factors has led Child and Adolescent Mental Health Services (CAMHS) to the aforementioned 'tipping point', with 1,134 under 18s detained under the Mental Health Act in 2020/21, with the problem especially acute for 16-18-year-olds.

Within our research, we found that obtaining appropriate support at a time of crisis for young people can be particularly challenging. The interviewees highlighted the following factors as being of particular concern when it came to accessing support:

- A&E was unintentionally playing a front door role for accessing mental health services for many parents and young people, something it is not set up to do
- Parents and young people found the high thresholds for support in a time of crisis particularly challenging. Professionals, however, had a more nuanced view, stating that the thresholds were important for managing demand
- The challenge of access put particular strain on parents, some of whom themselves struggled with their mental health whilst trying to get access to services for their children.

The challenges of service delivery of crisis care for young people

“ *It's not good for her here (in the general paediatric ward), we haven't got beds for her, we need her out of here.*

Parent, recounting mental health nurse

Our interviewees spoke of a range of different challenges in supporting young people in a crisis. Both professionals and people with lived experience expressed concern at a lack of capacity within acute settings for young people. Both groups spoke with empathy regarding the challenges the NHS and wider health system faced with workforce challenges and increased demand, but they wanted more to be done.

The challenge of moving through the health system was repeatedly highlighted by those interviewed, with the transitioning of services from young person to adult as being especially traumatic. One person said “...my biggest fear before I turned 18, was that they will stop caring because I'm not a child anymore”, a CAMHS nurse agreed, stating that “18 is very young. Then, they'll go to an adult psychiatric ward, which is just different. They're not going to get the hand holding, the hugs”. Whilst we did find that some progress has been made in the NHS Long Term Plan's aim for better transitions for those aged 18-25, this was not always the experience of the people we interviewed.

Our research also found that many areas of the NHS were investing in alternatives to inpatient admission for young people but, these were not well known about or used, especially by people with lived experience that we interviewed.

Many professionals and some young people highlighted the role that early intervention teams can play in preventing hospital admission, with one parent stating that assertive outreach by the CAMHS team “was the difference between going to hospital or not”.

Potential solutions to the challenges outlined

As part of this research, we requested feedback on an alternative style of mental health crisis provision. This was succinctly explained within the interview as a residential, community-based crisis service that could be used as:

- An intervention for young people who did not meet the threshold for inpatient admission
- An alternative to inpatient admission
- A potential step-down service for young people who are being discharged from hospital, but who do not feel able to return to their own homes immediately.

Feedback from the interviews was overwhelmingly positive about such a service. Based on conversations with young people and staff, it was felt the service should have the following features:

Feature	Young people	Parents	Mental health professionals
Homely, non-clinical environment	✓	✓	✓
Access to a wide range of specialists across disciplines (including clinical input)	✓	✓	✓
A place where young people will want to be		✓	✓
Opportunity for family involvement		✓	✓
A safe environment		✓	✓
Easy access to 'people who understand' for spontaneous chats	✓		
Close to home		✓	✓
A degree of privacy/space	✓	✓	
Subtle surveillance	✓		
Activities/ outings	✓	✓	
Acceptance of diversity	✓		
Staff who can 'cope with chaos'		✓	

The research found that such services do exist, but they are not mainstreamed. Anecdotal evidence suggests that, where they do exist, they are well used. The report did not seek to conduct a large-scale economic analysis on the savings such a service might bring to the public purse, but did offer general comparisons, which are shown in the table below.

Type of service	Weekly cost	% cost of community-based alternative @ £2,000 per week
General admission (CAMHS)	£4,200	47.6%
Secure unit (CAMHS)	£4,567	43.8%
Unregulated mental health placement	£9,650	20.7%
Semi-independent high needs placement (average weekly cost across 5 placements)	£4,550	44%

Report Recommendations

The principal recommendation of this report is the commissioning of new accommodation-based or community in-reach services that support young people at a time of mental health crisis. Such services would be, amongst other factors:

- Delivered by a collaboration of the NHS, supported housing and local authorities
- Funded jointly using new integrated care structures
- Located in a geography that works for the young people, their families and carers
- Sensitive to the age a young person would need to leave, ideally up to the age of 25.

In addition, the report makes the following recommendations concerning day-to-day crisis care for young people:

- Wherever possible, the wider system supports the NHS in its aim to deliver 0-25-year-old services, thereby making the transition from CYP to adult services as flexible as possible
- The NHS and wider partners enhance their capacity to keep young people away from A&E when they are experiencing crisis. Where this is unavoidable, we recommend:
 - Provision of a dedicated national crisis support line for young people as recommended in the NHS long term plan
 - More training for medical staff in supporting CYP with mental health issues, their families and carers
 - Dedicated space/teams for young people experiencing a mental health crisis in A&E. These could be attached to the psychiatric liaison teams for adults in many acute hospitals.

Introduction and context

Look Ahead, in partnership with the Wates Family Enterprise Trust, commissioned Care Research to undertake original research to better understand the experiences of young people in mental health crisis, the services currently available to them, how these services could be improved and new services that could be developed. The research examines the perspectives of young people, their families, carers, and the staff who work in the child and adolescent mental health space.

Data for England shows that there are increasing rates of mental health detentions and hospital admissions for under 18s (NHS Digital, 2021; NHS Digital, 2022). A recent NHS Confederation report stated that children and young people’s mental health (CYPMH) services were at a ‘tipping point’, and identified how demand for CYPMH services has grown significantly since, and possibly as a result of, the pandemic. It stated that: “the number of children and young people contacting mental health services rose by nearly a third from 2020 to 2021.”

There is a will within the NHS and government to respond to this increased demand. In response to the Health & Social Care Committee’s report on children and young people’s mental health, the Department of Health & Social Care (2022) stated: “Over the coming decade the goal, subject to resources, is to ensure that 100% of children and young people who need specialist care can access it.” Before the pandemic, the NHS Long Term Plan (2019) promised to increase mental health funding at a greater rate than overall NHS funding, with a promised increase of £2.3bn a year alongside a maximum waiting time target of four weeks and a commitment to age appropriate crisis services.

However, the NHS is trying to cope with this increased demand in the context of a reduction in the total number of young people’s inpatient beds and workforce challenges. As a result, the wider health system has been funding private providers for several years to give care to CYP in mental health crisis. Estimates from Laing Buisson (2019) showed that a majority of inpatient mental health care for under-18s is now privately provided, with independent operators looking after 55% of all the children and young people who are hospitalised. Their research also showed that non-NHS providers earned around £316m a year for treating children and young people with mental health issues.

In addition to increased demand, the availability of hospital beds for young people with mental health problems has reduced steeply in the past five years. This is as a result primarily of reductions in capacity in the independent market, driven by staffing challenges, providers’ ability to deliver high quality care and a perception of the acute broader reputational damage that would result from a negative CQC rating (Financial Times, 2022).

It is within this political and financial context that this research was commissioned with the following aims:

1. To acknowledge what works, what doesn’t work and where the gaps are in the current landscape of CYPMH crisis services in England.
2. To gauge the experiences and views of young people, their families and carers, and mental health professionals about the current CYPMH crisis system.

3. To develop a research informed, community-based service for children and young people in mental health crisis/or who have complex mental health needs.
4. To raise awareness and influence national debate around the current challenges facing CYPMH crisis services and the impacts these have upon young people, their families and carers, and staff.

Research Approach

To achieve the above aims, the research has been organised across four distinct phases:

1. Initial desk-based research to identify current services available, where the gaps are and what local approaches exist across England.
2. Interviews and discussions with mental health professionals and other professionals connected with children and young people mental health crisis services.
3. Interviews with children and young people, families and carers who have experienced mental health crisis and the current mental health crisis services available.
4. An economic cost-benefit analysis of an alternative children and young people mental health crisis service.

To gain a clearer understanding of the current approaches within CYP's mental health crisis care, we spoke with professionals directly involved in providing mental health crisis support, and those connected with relevant services. The aim of the interviews was to better understand the processes and experiences that staff, young people, their families and carers face when moving through the CYPMH system, and to better understand the strengths and challenges within the current system.

Twenty two participants were interviewed from within the NHS and health and social care sector across 21 interviews (one interview included a pair of participants). Many of the participants worked in multiple roles and drew on many layers of knowledge and experience. To maintain anonymity, precise roles and employers have been removed, though the list in Appendix 1 gives an indication of the breadth of professional experience represented in this cohort of interviewees.

To better understand the lived experience of those that have engaged with young people's mental health services at a time of crisis, we interviewed four service users and six parents. These young people, the children of the parents that we interviewed, had experienced a wide range of mental health issues, including depression, anxiety, self-harm, suicidal ideation and attempts at suicide, postnatal depression, eating disorders, addiction and psychosis. In line with the principles agreed in our independent ethics review, only young people aged 18 or over were recruited to the research.

Alongside this, Care Research undertook desk research, which had four aims:

- Analyse relevant NHS data around the current use and need for CYPMH crisis services
- Gain a clearer understanding of some of the root causes of mental health crisis in young people
- Explore recent and current governmental and NHS plans around children and young people's mental health support, in particular community-based support
- Identify what community-based mental health crisis services are currently available in England for CYP experiencing a mental health crisis.

The findings from this work are integrated throughout the report.

Conditions of interview

All interviews took place via Zoom and lasted up to 40 minutes. A semi-structured interview approach enabled us to focus the interviews on our research questions, whilst also allowing the interviewees to expand on issues of particular significance to them. We utilised interview schedules to loosely structure the interviews and these can be found in Appendix 2.

All participants were offered a £25 Amazon voucher, with this having no bearing on the answers or responses given during the interviews. Participants were informed that if, at a later point, they wished to withdraw their contributions, they would not be required to forfeit or return the voucher.

The interviews were transcribed and subsequently analysed to identify key themes using research analysis software NVivo. Due to the volume of recorded content and the scope of the project, a broadly deductive approach to analysis was taken whereby, in discussions with Look Ahead and its partners, several thematic areas were identified as research priorities. NVivo then enabled the research team to identify and group together anything that was said from each interview that was relevant to those themes. We also independently identified several other themes considered pertinent to this work but not in the original themes identified with Look Ahead. This approach enabled us to better understand the presence of each theme and the issues raised within each theme across the whole interview corpus to gain clearer insights of the central ideas, arguments and issues raised by the interviewees.

Ethical considerations and limitations

Ethics

All information regarding ethical approval for our research and steps taken to protect our participants' personal information can be found in Appendix 3a.

Limitations

It is important to note that there were some methodological limitations to this study. Firstly, all of the participants were self-selecting, i.e. they made an independent choice to respond to and participate in the research, as would be common in any form of interview-based research. However, this does risk self-selection bias. Self-selection bias means when individuals choose to participate, the research will likely attract people that have a substantive link with the topic (Olson, 2011). This may bias the content and may mean the interviews are not representative of everyone's experiences. Another limitation to raise here is that, for ethical reasons, we decided to only interview young people aged 18 or over. This means the current experiences of those under 18 could not be directly represented in our interview data.

Look Ahead's role in the research

Look Ahead is a specialist housing provider, which supports thousands of people with mental health needs, learning disabilities and autism, young people and those who have experienced homelessness across London and the South East with a diverse range of needs. It helps individuals to make choices, achieve goals and take control of their own lives by providing tailor-made support, care and accommodation services. Look Ahead appointed Care Research UK to design the scope for the research via a grant from the Wates Family Enterprise Trust. In the third section of this report, we propose models of care to support young people that are akin to those Look Ahead deliver.

Summary of findings

Each interviewee offered a range of valuable views and experiences around the current state of CYPMH crisis services. To meet our research aims, we arranged the themes that emerged from the interviews with all stakeholders into the following areas:



Area 1 Demand and access

Escalating demand
Lack of crisis options/
high thresholds



Area 2 Challenges of service delivery

Capacity, staff and
waiting times
Moving through the system
Alternative community
options



Area 3 Possible solutions

New innovations, including
residential community

The following sections will address each of the three areas separately, outlining the key themes and drawing on illustrative quotations from across all interviews.

Findings



Findings



Area 1: Demand and access

The first key theme identified through our research was the demand for CYPMH services and how to access them. In this section, we summarise these findings as follows:

Factors leading to a crisis – we summarise the literature on reasons why a young person enters a crisis.

Prevalence data – this demonstrates an ongoing and rising demand for residential placements for CYP experiencing mental health crisis.

Crisis options – A&E is often the main option for young people in crisis, with thresholds for inpatient care accepted as extremely high and widely thought to be available only after a serious self harming/suicide attempt.

Growing number of factors leading to mental health crisis in young people

A wealth of literature identifies a range of sociological and biological factors that contribute to young people experiencing mental health crisis. These factors include (but are not limited to):

Trauma/loss/grief

Losing a loved one is considered one of the most common and traumatic events a child or adolescent can experience (Revet et al., 2020). If a young person loses a parent, they are susceptible to a range of complex biopsychosocial outcomes (Kentor & Kaplow, 2020). Boelen, Olf & Smid (2019) highlight how traumatic loss where an individual is bereaved in traumatising circumstance can lead to prolonged grief disorder, post-traumatic stress disorder (PTSD) and persistent complex bereavement disorder, with a need for highly specialised treatment for children experiencing these issues.

Economic hardship

Golberstein, Gonzales & Meara (2019) demonstrate that the effects of economic conditions on children's mental health are 'clinically and economically meaningful; children's mental health outcomes worsen as the economy weakens' (p.955). Research by Kinge et al (2021) shows children with low-income parents have a higher risk of mental disorders. However, De France et al (2022) state that the negative relationship between poverty and mental health, though well documented, is not definitive as it will depend upon how individual children and young people manage the physiological and psychological stresses created by poverty.

Social factors such as loneliness

Hards et al (2021) state that loneliness is often associated with depression and anxiety in children and that this relationship may be bi-directional. Calati et al (2019) state that feelings of social isolation are also strongly correlated with suicidal outcomes. Christiansen et al (2021) found that, in adolescents and young adults, loneliness and social isolation were associated with poor mental health. Finally, Healy et al (2022) found that bullying victimisation represented a significant risk factor for mental health problems in children and adolescents.

The social impact of COVID-19

Samji et al (2022) described the COVID-19 pandemic as an ‘unprecedented threat to global mental health’ (p. 173) with children and adolescents more susceptible to the mental health impacts of the pandemic. Their meta-analysis showed that a high prevalence of COVID-19-related fear was noted among children and adolescents, as well as more depressive and anxious symptoms compared with pre-pandemic estimates (ibid, 2022). Knowles et al (2022) state that the variation in mental distress pre and mid-pandemic were more specifically tied to the negative circumstances individuals, their families and carers faced during the pandemic, such as issues around housing, financial support, social support and disrupted daily routines.

Experiences of abuse

Childhood physical and sexual abuse victims are at increased risk of developing depression, anxiety, and PTSD in adulthood (Adams et al, 2018). Alongside this, those experiencing psychological maltreatment can also be at a significant risk of experiencing PTSD and related mental health challenges (Hodgon et al, 2018).

Current data around the prevalence of mental health crisis in young people

Public health data for England (NHS Digital, 2021) shows that in 2020/21 the total number of under 18s detained under the 1983 Mental Health Act was 1,134. This number has remained reasonably constant with the total number of under 18s detained under the Act in 2018/19 totalling 1,118 (NHS Digital, 2019). This shows that between 2018/19 and 2020/21 there was a small increase of 1.4% in the number of under 18s detained under the Mental Health Act 1983.

The table below demonstrates the rates of detention under the 1983 Mental Health Act for children and young people (2020/21) by age and detention type next to the same figures for 2021/22.

2020/21*			
Age	Rate of detentions per 100,000	Rate of Short Term Orders (Section 136) per 1,000,000	Rate of Community Treatment Order (CTO) per 100,000
15 and under	3.0	1.9	0.2
16-17 year olds	64.9	40.4	5.0
2021/22**			
15 and under	3.4	7.7	0.3
16-17 year olds	48.3	118.4	4.0

*Figures sourced from NHS Digital, 2021

** Figures sourced from NHS Digital, 2022

The data shows an increase in the rates of detention across each detention type for those aged 15 and under. They also show the overall rate of detentions for 16-17-year-olds and community treatment orders has reduced, but there has been a significant increase in the use of short term orders. This suggests a greater reliance on police services tackling young people’s mental health issues.

These comparisons of available data clearly demonstrate a continued and growing demand for mental health crisis provision. The most recent data (NHS Digital, 2022) testifies to an increased need for those aged 15 and under as well as a greater reliance on police services to deliver mental health support for those aged 16-17.

Lack of crisis options and high thresholds for admittance

“ I’ve got parents who are sobbing at me saying “What does my child have to do? They’ve already taken a significant overdose. What does my child have to do before you will help me?” I’ve got no answer. I’m sick of saying, “I don’t know what to say to you. I’m so sorry.”
CAMHS nurse

At the time of a mental health crisis, it is imperative that young people, their families and carers have somewhere to turn to access timely and effective support and treatment. However, our research indicated that accessing prompt, appropriate support can be extremely challenging, and that this can result in distress and adverse trajectories for service users, their families and carers. Our interviews with mental health services indicated that, theoretically, young people might initially present in crisis at a range of services:

- Speaking to a GP
- Calling NHS 111/999 (ambulance or police)
- Presenting at Accident and Emergency (A&E)
- Contacting CAMHS (if already working with CAMHS).

However, according to our interviews with all stakeholders, the ultimate destination for care in a crisis is often hospital A&E departments. At this point, CAMHS teams are called to assess the young person and to decide whether and where they will be admitted or how they will otherwise be supported. This referral process is illustrated in figure 1 below.

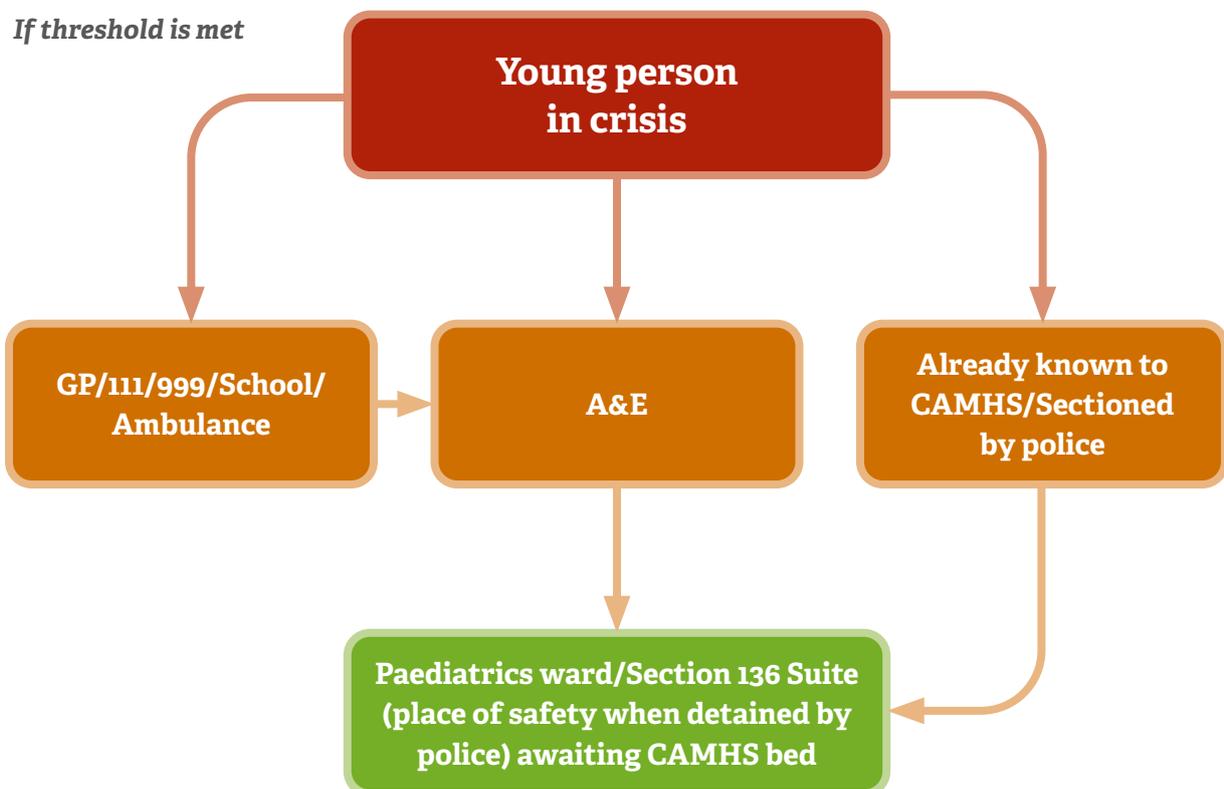


Figure 1: The usual referral process for young people in crisis

Our interviewees, many of whom had first-hand experience of crisis presentations at A&E (either as health professionals or as service users/family members), raised serious concerns about this approach to crisis care. These are addressed below.

A&E poorly positioned as the front door into CYPMH pathway

The principal concern of our interviewees was that A&E departments are equipped to deal with physical health emergencies. They are not perceived by young people, families and carers or healthcare professionals as appropriately equipped, staffed, or resourced to manage and treat young people experiencing mental health crisis. Our interviews indicated that where physical health is the primary concern, i.e. overdose or serious physical self-harm, this can result in young people being placed in general paediatric (and sometimes adult) wards for ongoing monitoring, if beds are available, whilst waiting for on-call mental health teams. In some cases they may wait for days or weeks for a bed following their initial presentation.

The issue is that neither the A&E departments nor the general wards can offer the specialist treatment required to support CYP experiencing a mental health crisis. They are predominantly set up to meet physical health needs, yet are increasingly attempting to perform an emergency triaging function for young people in crisis.

“ Additionally a lot of hospitals don't have separate children's A&E. They're lumped then with adults and, obviously, the experiences that they see in main A&E, with various people with drug problems, alcohol problems, it can be quite scary for young people, really. Some of the services are certainly not appropriate, and the pathways as well.

Children's social worker & CAMHS team member

Our interviews with service users, their families and carers indicated that on-call crisis teams are often under-staffed and there can be long delays before they arrive to assess a young person. At times, especially if the A&E department was busy, this resulted in young people in crisis sitting for extended periods in a waiting room while they waited for crisis support to arrive. One parent recalled waiting for five hours through the night for the only CAMHS crisis team member in the (large) county to arrive to see the child. Another parent, however, had an excellent experience of their child receiving good support when presenting at A&E, where there were 'floating CAMHS workers'. The experience meant that her son didn't have to wait in a busy emergency service but was transferred to a calm and relaxed CAMHS environment very near the hospital.

“ The speed at which he was seen and removed from the A&E setting was amazing.

Parent

A high threshold for inpatient admittance

The high threshold for admittance into a hospital ward or a specialist mental health facility was widely recognised across all stakeholder interviews. Some mental health professionals accepted, and supported, this high threshold as they felt that admission to a unit was not necessarily the best option for many people presenting in A&E. Accordingly, for others, upholding the threshold was part of their organisation's culture and provided a necessary framework within which they worked.

“ The aim of the crisis teams is to keep them out of hospital as much as possible.

CAMHS team member

Whilst the benefits of a high threshold for inpatient admittance are acknowledged, they do cause anxiety for parents and young people.

Many professionals and most service users, their families and carers shared an understanding that you had to have attempted suicide multiple times to be offered inpatient support. For many mental health professionals this threshold level was deeply frustrating. For parents and service users it provoked strong emotional responses; they reported feeling angry and abandoned.

“ *It was very clear from what the doctor had written that he has suicidal intentions and was planning for it. It kind of felt that at that time CAMHS were only interested if he attempted it, which obviously we didn't want him to do.*

Parent of service user

Parents and mental health professionals also expressed concern that the high threshold resulted in a range of negative implications: worsening mental health for the young person, worry for exhausted parents, and costs to other emergency services such as police and paramedics. Indeed, several interviewees and parents reported feeling caught in a ‘roundabout’ system of call outs, referrals, discharge, call outs, referrals etc with no treatment plan or intervention to start to address the problems. Some parents were very keen to point out that they had had some good experiences of CAMHS, once their children had met the threshold. One parent stated it felt like they now had ‘an open door’ to CAMHS for one child.

“ *They can't do enough for my son, they have never given up on him, even when he gave up on himself...I just wish I could get the same for my daughter.*

Parent of service user

Impact on parents and families

It was very clear from our interviews across all stakeholders, that parents and, to a lesser extent families, are subject to significant amounts of responsibility and stress whilst supporting their children during a mental health crisis. Because of the challenges of service delivery detailed above, parents reported that they were almost always required to support the child in the family home. In their opinion, this not only meant that their child was not being appropriately treated and kept safe but that considerable and damaging strain would be placed on themselves, their families and carers, which in-turn risked worsening mental health for everyone. This was one of the most strongly evidenced themes in the interviews.

“ *The parents were like, “What do you mean? What do you mean I'm taking her home?” ...It was quite difficult for them, which I get because the parents were coming to us crying for help. We were like, “Can you take them home?”*

CAMHS Clinical Nurse Specialist

Parents reported significant levels of stress as the responsibility for their young person's health and wellbeing fell on them whilst they tried to hold down jobs and care for other children within the family unit. Parents spoke about the challenge of keeping their children safe and enabling recovery during not only their challenging mental health conditions but also because the child was ‘a typical teenager’ and often not willing to listen to, share with or even engage with their parents. Several parents reported the serious negative impact of this on their own health and wellbeing.

Several service users also reported feelings of guilt and responsibility for the impact their illness was having on their parents and siblings. Many health professionals had also witnessed and empathised with the desperation of families and carers for inpatient care and were aware of the negative implication of the high thresholds on them.

“ *Once a week therapy...and then come home for the rest of the week and carry on as normal? She's not able to do that. She needs intensive input and if she doesn't, because she's not getting it, she's craving it from emergency services, I suppose, because to get someone to listen to her.*

Parent of service user

Demand and access – recommendations

The experiences of the interviewees indicate that A&E has become, in some instances, an accidental hub or front door for children and young people experiencing a mental health crisis.

It is clear from our research that young people, their families and carers would like to see the NHS and wider partners enhance their capacity to keep young people away from A&E when they are experiencing crisis.

Where this is unavoidable, they would like to see new approaches engaged to improve the experience, many of which align with the NHS's existing aspirations for the development of CYP crisis care.

This report recommends the mainstreaming across England of the following initiatives:

- As recommended in the NHS long term plan, the provision of a dedicated national crisis support line and website (separate to the 111 service), which must be appropriately staffed and not a place to leave a message, and which can give real time bespoke advice to parents and carers or young people aged over 18 at the time of a mental health crisis
- More and specialist training for physical health medical staff based in A&E in supporting CYP with mental health issues, their families and carers
- Dedicated space/teams for CYP experiencing a mental health crisis in A&E. These could be attached to the psychiatric liaison teams for adults, which are now embedded in many hospitals.

Whilst many of these do exist in pockets, there is more that could be done to mainstream such approaches.



Area 2: Challenges of service delivery

Another key theme identified through our research was the challenges associated with delivering mental health crisis services for children and young people. In this section, we summarise these findings.

Capacity, staff and waiting times – issues raised by professional, CYP and family interviews on challenges with current capacity and staffing levels and the impact this has on waiting times.

Moving through the system – issues raised around young people's journeys through the current system once they have been deemed to have reached the 'threshold' for support.

Existing alternative community options – current alternative existing community options available and the perceptions of professionals, CYP, families and carers on the efficacy of these services.

Capacity, staff and waiting times

“ I think with children's services, there was no crisis support. It would literally be you would phone the out of hours and ask to speak to someone, you can get a call two days later. Parent of service user

The issues of limited capacity, staffing and wait times emerged from all our interviews. Our interviewees were clear that these challenges of service delivery are real, exasperating and extremely damaging. Health professionals reported on their frustration around their awareness of capacity issues, whilst for the service users, their families and carers this same issue translated into prolonged desperation, distress and, for many, worsening mental health.

Almost every one of the family members or service users that we interviewed described low capacity in crisis care. Some parents described desperate situations when they did not know where to turn to help their child whilst waiting for crisis care to kick in. In the quotation below, a parent recalls what she was told by a hospital where her child (who had attempted suicide) had been temporarily placed.

“ It's not good for her here (in the general paediatric ward), we haven't got beds for her, we need her out of here.”...I think the alternative was in the end while she's going into a bedsit in (a distant town), she won't be able to access her support network because she'd be too far away, and basically you're putting her in a situation where she's probably just going to do something stupid because she's got nothing left. That was all they could provide. Parent of service user

Two interviewees amongst the families, carers and the service users that we interviewed had been successful in gaining some kind of residential, community-based support. One of these was in the case of an eating disorder and another after several chaotic years of suicide attempts, addiction and psychosis. For others, the existence of residential 'placements' was something they were vaguely aware of but which, in their minds, were so 'unavailable' that they were not considered a viable option for them at the time of crisis. Indeed, most families, carers and service users described the crisis as a time of preoccupation with accessing timely and appropriate community care or securing basic hospital inpatient care. The possibility of specialised residential care was not offered and did not feature in their decision making.

Moving through the system

It was evident from our interviews that treatment needs and recovery trajectories vary across mental health conditions according to the profiles and personalities of the young people. Interviewees reflected that the system to support and treat young people needs to be nimble, flexible and offer a range of diverse pathways, and that responses need to be timely and accessible, requiring minimal effort from young people to engage. Our interviews demonstrated a consensus that services were struggling to operate in this way. The way service users move through the system may be explained by a lack of capacity within many of the organisations that young service users encounter. Other barriers to ease of movement were reported, including complex paperwork and approval channels before service users could be referred onward to other services, and some services where referrals were harder to make and slower to be actioned, particularly at weekends and bank holidays.

“*If you do decide that you do need to bring this child into hospital, you have to go through a process. You have to apply through NHS England...especially if it's crisis, Saturday, Sunday, bank holiday, Christmas, invariably it's on a Friday afternoon, you're probably going to be waiting for the agreement. There's a piece of paperwork that you've got to fill in electronically, and it's horrific to fill in. There's nothing easy about it.*

Crisis Team Nurse

Several parents and service users described a difficult journey through the system, reporting limited service capacity, communication and patient co-ordination and a perception that staff lacked the specialist training to work with young people in crisis.

Our interviews indicated that the immediate transition from child to adult services at age 18 adversely effects perceptions of care and can place young people in frightening and inappropriate situations. Although we identified that, for our sample, most young people experienced difficulty in finding suitable care under the age of 18, they were within a system that is supposed to work with parents and schools to provide a team of people around them. There was a perception across interviewees who had experienced or witnessed the child-adult transition, that the sense of being 'surrounded' drops away after the 18th birthday as parents are no longer legally required to be involved and responsibility for care transfers to the young person. This leaves what is perceived as a deficit of care. Additionally, some professionals reported situations where 18-year-olds were admitted to adult psychiatric units and had found this terrifying and traumatic. The quotations below illustrate the experiences of changing care across the transition from child to adult services from the perspectives of a service user and a mental health professional.

“*Eighteen is very young. Then, they'll either go to an adult psychiatric ward, which it's just different. They're not going to get the hand holding, the hugs, "Let's go and play a game together." It's not that sort of support. It's very different. We always worry about the young people.*

CAMHS Liaison Clinical Nurse Specialist

“*That was my biggest fear before I turned 18, was that they will stop caring because I'm not a child anymore. It's not like they need to look after me. It will be, "You're on your own now, you've got this," and that is literally how it ended up.*

Service user

The challenges presented by the transition from child to adult are acknowledged in the NHS Long Term Plan (NHS, 2019), which committed to a new approach for young people aged 18-25. The detail of this is a planned extension of the current service model for under 18s and provision of a service which integrates health, social care, education, and the voluntary sector. For example, the plan purports that the integrated 'i-Thrive' model of system change (iThrive, n.d.) could be extended from its current parameters of 0-18 to include those up to age 25.

Three years into the plan progress has been made, some examples of which are shared in section three of this report. However, not many of our interviewees had encountered or experienced the benefits of a new approach, though many shared the view that a transition service catering for a young adult population such as 16-21 or 18-25 could bridge the gap between children's and adult services.

We do know, however, that many parts of the NHS are implementing this element of the long-term plan. For example, East London NHS Foundation Trust has developed City and Hackney CAMHS to extend their provision to young people aged 18 to 25. The extended service works primarily with young people who do not currently meet the criteria for Adult Mental Health Services (AMHS) in Hackney but who are considered to require a mental health service. Some parents pointed to real life examples of flexibility in care for their children, with one son being offered additional wellbeing and mental health support on his first day at university because he had previously been under CAMHS. The parent described the transition in this instance as 'seamless' and extremely 'reassuring'.

“ *That the university and the local service had already spoken to each other without any input from me made me feel reassured – I knew the support was there for him if he needed it.*
Parent

Existing alternative community options

A range of alternative community options exist that offer support for young people living with poor mental health. In practice, however, these did not appear to always meet the needs of parents and service users in our sample: those with higher levels of need and histories of acute mental ill health and crisis. The mental health professionals in our research demonstrated an awareness of a range of face-to-face, phone and online initiatives that had been established locally, nationally, and internationally to try to enhance community offers. These included an early intervention (pre-CAMHS) support line, a walk-in 'one stop shop' for young people, a variety of crisis apps and helplines and online Cognitive Behavioural Therapy services. Parents and service users did not have the same awareness of this range of community services, and few had engaged with any services within this sector. However, some users specifically reflected that crisis line support had been useful at a time of less intense illness. We also heard successful examples of young people being diverted away from A&E and having a better experience as a result. One interviewee recounted how they were able to link a young person into mental health services during their first psychotic episode thanks to the NHS Early Intervention Team doing outreach work to their home. The Early Intervention Team had a dedicated phone number in the London borough they lived in and the parent called the number and arranged for a home visit. A mental health assessment was carried out and the young person was prescribed medication. The parent felt this likely meant a visit to A&E was avoided.

“ *Them coming to us was the difference between going to hospital or not.*
Parent

Other concerns about community services were related to inaccessibility, including not meeting the initial threshold to be seen by CAMHS. This left service users, families and carers with nowhere to turn and long waiting lists, at a time when any wait could have a significant impact. Parents and service users also reported instances of feeling that the professionals they had encountered in community care did not seem to care about them/their child or take any ownership for their treatment.

Across the 10 interviews, we collected more than 50 quotes expressing anger, sadness and disbelief about the community care they or their family members had experienced. The quotation below illustrates that on occasion even intensive community treatment is not enough for some young people and can result in risk to life and significant stress for the parents.

“ So, they...contact her every day and that's their alternative to her being in a unit, but ultimately, she's still at home, under my supervision, and I'm still responsible for her. It is still me that gets up every morning and has to go to her room and open the door cautiously and hope she's alive because I don't know what I'm going to find.

Parent of service user

In summary, the mental health professional interviewees reported on a range of initiatives to support young people who either have started to become aware of mental health challenges or who have not reached the threshold for admission to a ward or unit. Challenges around the efficacy of remote approaches (such as phone lines and apps) were raised by some of the people we interviewed, alongside the potential to be over-reliant on such approaches when people require more intensive potentially clinical support. The small sample of parents and service users that we interviewed had largely negative experiences of community care, reporting that the range of services currently available, in their opinions, are either inaccessible, inappropriate or ineffective.

Looking forward, the mental health professionals were a valuable source of suggestions for how community care could be improved, and it is vital that they are consulted in the development of future services. Their suggestions included: in-person community approaches, such as drop-in centres, youth programmes and in-school support (particularly to support children at a younger age and hopefully avoid a later crisis).

Challenges of service delivery – recommendations

As outlined in its Long Term Plan, the NHS has an aspiration to move towards 0-25 mental health services. There are some excellent examples of good practice in this area both within the NHS and the voluntary sector, including:

- Minding the Gap partnership in Camden – a partnership of providers led by the Brandon Centre, Catch 22 and Camden and Islington NHS Foundation Trust to deliver an 0-25 inclusive service. The multi disciplinary team provides a range of mental health support to local young people
- London Borough of Lambeth and South London and Maudsley NHS Foundation Trust that addresses:
 - The small number of young people eventually transitioning to Adult Mental Health Services,
 - The fact that in certain circumstances CAMHS need to continue support for a young person after the age of 18, possibly up to the age of 21
 - The multiplicity of pathways people can transition to, which can be confusing for them.

Whilst some progress has been made within the health system in this area, throughout the research, we found young people, their families and carers struggling with the transition from children's to adult mental health services.

As such our principle recommendation for this section of the report is that:

- Wherever possible, the wider system supports the NHS in its aim on delivering 0-25 services, thereby making the transition from children's to adult services as flexible as possible.

Other recommendations regarding the challenges of service delivery are:

- Better support for the parents of young people experiencing a mental health crisis is required, e.g. leaflets, dedicated helplines, opportunities for online support and learning
- The continued expansion of community options for young people facing crisis. More on this recommendation is covered in the following section of the report.



Area 3: Possible solutions

The final key theme examined possible solutions to the concerns raised around demand, access, and the challenges of service delivery. Our findings are summarised in these three areas.

New innovations – here we discuss the feedback from professionals, young people, families and carers when we proposed a new form of community-based residential support for young people in mental health crisis, including discussions around important features to make such a venture effective and successful.

Examples of residential services – in this section, we explore two services in England that provide community-based residential support for young people experiencing mental health crisis.

Indicative costings of an alternative service – here we explore the costings around the proposed new form of service and how this compares to the current costs of supporting young people experiencing mental health crisis.

New innovations

As part of this research, we requested feedback on an alternative style of mental health crisis provision. This was succinctly explained within the interview as a residential, community-based crisis service that could be used as:

- An intervention for people who did not meet the threshold for inpatient admission but who were in mental health crisis
- An alternative to inpatient admission
- A potential step-down service for people who are being discharged from hospital, but who do not feel able to return to the family home immediately.

This idea was positively received across both sets of interviews. Mental health professionals were able to offer invaluable insight into how such a service might fit within the current provision framework.

“ *These services are desperately needed to prevent lengthy hospital admissions or to get somebody out of hospital and when they're not quite ready for full community. Absolutely, there'd be a massive need for that.*

CAMHS Nursing Lead

Some interviewees (in both professional and service user/parents' groups) were aware of services, but which they knew were scarce and limited to certain geographies, so they were only accessible to a few. Two interviewees from the service user/parents' group had managed to access similar facilities. For the others, it had not been considered an option.

Interviewees suggested several ways in which alternative residential support could be beneficial. Professionals saw the value of the service providing short-term 'in the moment' support, particularly in a climate where other short-term support has disappeared from the system.

“ *I know that when I worked on the adolescent unit, occasionally, but not often, it was quite rare. Someone would be in crisis, and we will admit them. That crisis could last a weekend, a few days...I always thought that that was a really good use of resources because it's needed at that time, is short-term, and it maintains the young person's safety for that very risky time.*

CEO of independent children's mental health service

Finally, parents recognised the value of such a service as being a place of safety for their child, which would not only allow them to gain a little independence but also provide much needed respite for overwhelmed parents, families and carers.

Features of the service

“ It would be somewhere that has that ability to be cosy and homely, making it so you don't feel like you're trapped in a place for a long period of time because you're being monitored, even though you are.

Service user

The mental health professionals that we interviewed were invariably experienced and sensitive to service users' needs and it was therefore no surprise to note that the 'ideal features' of such a provision often echoed those identified by the service users themselves, their families and carers.

Table 1 below details all suggestions and the interviewee group or groups that these suggestions came from. The most frequently mentioned features are at the top of the table. We have also included a selection of the quotations collected to give a sense of stakeholders' responses.

Feature	Young people	Parents	Mental health professionals
Homely, non-clinical environment	✓	✓	✓
Access to a wide range of specialists across disciplines (including clinical input)	✓	✓	✓
A place where young people will want to be		✓	✓
Opportunity for family involvement		✓	✓
A safe environment		✓	✓
Easy access to 'people who understand' for spontaneous chats	✓		
Close to home		✓	✓
A degree of privacy/space	✓	✓	
Subtle surveillance	✓		
Activities/outings	✓	✓	
Acceptance of diversity	✓		
Staff who can 'cope with chaos'		✓	

Table 1: Features for community provision

The selected quotations below highlight how the various stakeholders expressed their views about the design of the service.

“ I think it's more about being able to watch the young people in their authentic background, what they're doing...put them in a situation where you can watch their behaviour, see how they engage and how they're responding and things like that, you're opening yourself up to understand their mental health a lot better.

Residential Care Manager

“ ...to have someone there to keep her safe who isn't emotionally drained by it continuously because it's their job. It would give respite to the rest of the family...She would have benefitted from that independence and that freedom.

Parent of service user

This part of our report indicates how an alternative residential provision might be developed and how it could usefully fit with existing provision. What is notable is the extremely valuable contribution that researching lived experience could make to ensure that services are developed to really meet the needs of service users, their families and carers. Our interviews indicated that mental health professionals, service users, their families and carers are ideally placed to be involved at the development stage of any future services.

Examples of residential alternatives

As discussed above, our research has shown that professionals and those with lived experience would value a community-based, residential alternative to Tier 4 admission. As figure 2 below shows, Tier 4 admission refers to inpatient provision, as opposed to a community option that this research proposes. Such services do exist and appear to be well utilised by the system; however, they are not commonly available. Two examples of such services are shown on the following pages.

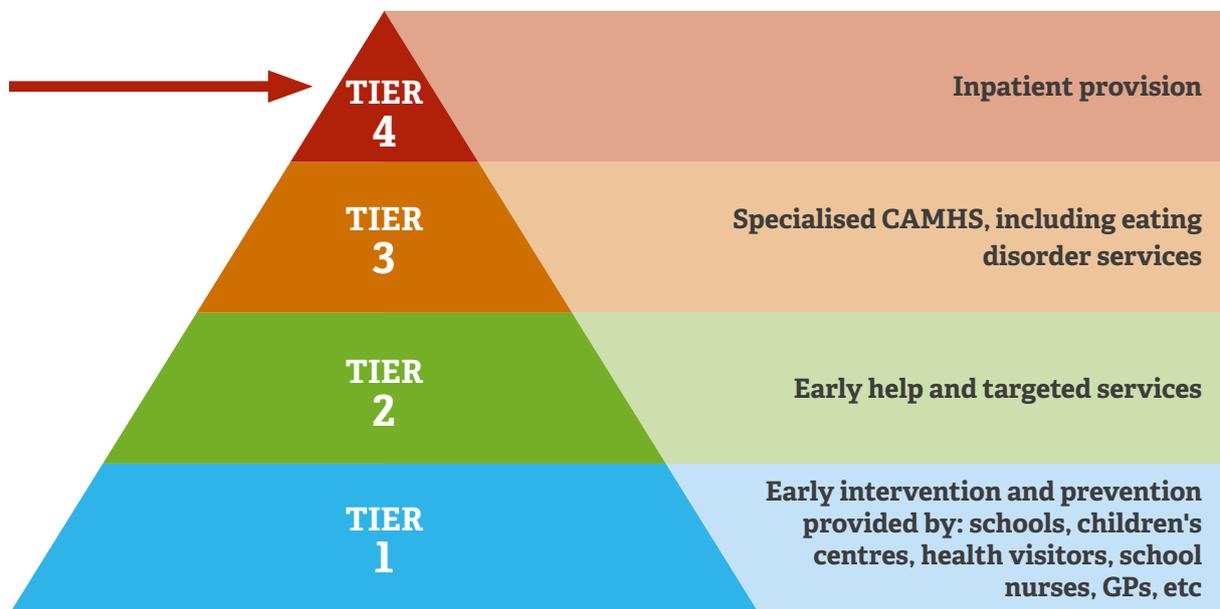


Figure 2: CAMHS tiers



Best Practice Case Study

Single Homeless Project in Hackney and Islington

Single Homeless Project is the largest homeless charity dedicated to helping Londoners in crisis. As part of a wide remit, the charity provides a supported accommodation service for young people in London with complex and high support mental health needs. Young people entering the service typically have ongoing or very recent histories of acute mental ill health and crisis. The service has seven bedrooms, four for young women and three for young men. Service users are aged between 16 and 21 and typically come to the service before the age of 18. It is not a time-limited service, but length of stay is usually 12-24 months.

Many young people step down directly from hospital where they may have had multiple admissions, while some are transitioning from children's homes and foster care into supported housing. Work with young people referred to the service begins before they move in. As individuals may have been in long term CAMHS inpatient hospitals, sometimes for up to 18 months, the team meets them where they are to consider the process for transitioning back to the community. Suitability assessments are done in hospitals and allow the young person a chance to be part of the decision-making process when referred. They jointly consider how their placement will impact them and the rest of the young people in the service and how to manage their move safely.

Making sure the fit is right is essential for the young people to minimise risk of conflict and ensure they are well placed to manage progress toward greater independence that comes with a move to community supported accommodation. There is a high degree of tolerance within the service, for example around issues of property damage, as the service supports young people to shift toward individual responsibility rather than enforcement of rigid rules.

Our approaches are rooted within trauma-informed practice. Partnership is an essential element of the service. Relationships with families and caregivers are often strong, a distinction from trends in adult services, and their involvement can be really important. Partnership with health professionals is also essential. In the local area, the NHS personality disorder service is well resourced and has provided clinical supervision for the team from a psychiatrist as required. Clear support planning by the team in partnership with the young person is also essential. This can include making sure there is a clear plan for managing medication, crisis and other individual goals, which are agreed – based on what works – with young people over time. This work is supported by a stable and consistent support team, which can be difficult to achieve, but at this service, everyone in the team has been there for over a year. The team comprises a service manager, senior practitioner and support workers.

The service was developed in response to local need and not commissioned by a local authority or NHS Trust, with individual placements purchased as required. This means the service is not always at full capacity and could in theory house young people from any local authority area, although there is high demand for placements and young people tend to come from Hackney and Islington.



Best Practice Case Study

The Hope Service and Extended Hope Service in Surrey

The Hope Service provides intensive community support and intervention to prevent, or shorten, a young person's admission to an inpatient unit and to prevent social care placement breakdowns which could lead to young people being placed out of the county. It supports young people aged 11-18 with complex mental health, emotional, social and behavioural needs. The service is both CQC and Ofsted registered and delivered in partnership with the ICB (integrated care board) and Surrey County Council, with Surrey and Borders Partnership NHS Foundation Trust as the health providers.

The service provides intensive support to young people in the community including outreach support to the children and their carers. The service utilises an extensive multi-agency therapeutic day programme with a highly skilled team of dedicated social workers, nurses, teachers, psychologists, art and drama therapists, psychiatrists, family therapists and activity workers. The Hope Service works using a multi-agency approach collaborating with education, social care, acute hospitals, the police, and third sector voluntary sector charities providing a joined up systemic approach for the most vulnerable children and young people within Surrey.

The flexible day programme offers structured therapeutic, educational, and personalised activities for young people ensuring it meets individual needs in a safe, supportive, and therapeutic environment. In addition to education, there is a focus on individual and group therapy, art and drama therapy, psychology, dialectical behavioural therapy, anger and anxiety management, assertiveness training and building practical social, emotional, and independent living skills.

Extended Hope is an out of hours support service providing young people with telephone or outreach support including mental health and risk assessments for young people who are suffering an emotional social or behavioural crisis. There is also a two-bedded unit providing respite for young people to get support or be assessed for up to seven days. A safe multi-agency discharge plan is put in place for the young people who may be struggling in their community. Also registered with Ofsted, this service is staffed by residential social workers and is supported by community psychiatric nurses who provide a safe and containing environment to understand and assess the young people's needs.

The entire service works holistically with young people, their families and carers to co-produce a plan of care aimed at preventing the escalation of mental ill health or intensive social care support. This results in avoiding the need for inpatient stays or numerous care placements and as a result, there are significantly fewer out of area placements than other mental health trusts.

Indicative costings of an alternative residential service

As part of this work, we have examined proposals and costings for two separate alternative residential services, which would be able to provide step-up, step-down and alternative provision for CYP experiencing mental health crisis. The proposed community-based service would cost somewhere in the region of £2,000 per week. Table 2 below contains current costs for other options available to young people experiencing mental health crisis. These have been drawn from a wide range of sources.

Type of service	Location	Age range	Weekly cost (per person)	Date of data	Information source
General admission (CAMHS)	National	12-18	£4,200	2019	NHS CAMHS Benchmarking Data (2019)
Secure unit (CAMHS)	National	12-18	£4,567	2019	NHS CAMHS Benchmarking Data (2019)
Unregulated mental health placement	Manchester	Individual case (13 year old)	£9,650	2022	Recently family court approval*
Semi-independent high needs placement	Richmond	16-17	£4,556	2021	FOI Request
Semi-independent high needs placement	Croydon	16-17	£6,275	2020	FOI Request
Semi-independent high needs placement	Croydon	16-17	£4,500	2020	FOI Request
Semi-independent high needs placement	Croydon	16-17	£4,720	2020	FOI Request
Semi-independent high needs placement	Croydon	16-17	£2,700	2020	FOI Request

*See www.theguardian.com/society/2022/oct/12/judge-approves-unlawful-placement-for-girl-13-at-risk-of-suicide

Table 2: Costs of residential/crisis alternatives for CYP

The table on the previous page demonstrates the current associated costs with both CAMHS and other forms of residential placement. We believe diverting some of the money currently earmarked for CYPMH into more residential models of care will improve outcomes, enable quicker recovery, and offer better value for money, with lower costs per individual supported.

Table 3 below demonstrates the percentage difference between each service and the community-based alternative.

Type of service	Weekly cost	% cost of community-based alternative @ £2,000 per week
General admission (CAMHS)	£4,200	47.6%
Secure unit (CAMHS)	£4,567	43.8%
Unregulated mental health placement	£9,650	20.7%
Semi-independent high needs placement (average weekly cost across 5 placements)	£4,550	44%

Table 3: Costs of different services compared to community-based alternative

Possible solutions – recommendations

Drawing on the experience of mental health professionals, young people, their families and carers, this report recommends the commissioning of new accommodation-based services located in the community that support young people at a time of mental health crisis. Such a service would be:



Led in partnership by the NHS, specialist housing and support providers and young people and their parents.

Based on the interviews and case studies in this report, we have learnt that such a service would only be a success if delivered by a collaboration of organisations working as a single team. On occasion, there is a breakdown in trust between these three parties so when developing new provision, partners would have to come together from the start with a clear joint working protocol.



Assets-based, focusing on young people's strengths rather than their problems, helping them to gain greater independence.

Based on our conversations, it is easier to achieve this by being supported in the least restrictive setting possible, i.e. in the community rather than in hospital.



Funded jointly by an Integrated Care System (ICS).

In the current system, CYP crisis care is sometimes paid for by local authorities, sometimes by ICS' and sometimes privately. A simplified system of pooled funding delivered through the new ICS structures would allow young people to access the care they need more efficiently. Funded in this way, it is likely that such a service would be significantly cheaper for the wider system.



Funded sufficiently to promote staff development and stability.

Creating an effective joint working environment between housing and health requires stability in staff on both sides. Long-term funding will facilitate this collaboration and allow for better support to CYP, their families and carers.



Convenient – close to home for CYP, their families and carers.

As we heard from the young people we interviewed, being close to home is of vital importance to feeling safe and secure. All too often the system is forced to place vulnerable young people out of area, which is unhelpful both for the young people themselves and the NHS staff trying to support them.



Sensitive to the age at which a young person would have to leave such a service.

Transitions from young people's services into adult services can be very difficult for everyone involved. Any new service would need to be flexible in how it manages this transition, ideally in line with the aspiration of the NHS Long Term Plan at 25. The service should not have to evict a young person on their 18th birthday. Considerations should therefore be made for the funding to follow the individual until aged 25.



Proactive in conducting a robust approach to evaluation.

This should include a jointly agreed outcomes framework between housing provider, NHS and parents and young people. This would allow the system to better understand what does and doesn't work in such a provision and use the evidence to spread and scale the model.



Mindful of the importance of the size and layout of the building in which the service is housed.

We heard from interviewees that access and security is important in how the building is designed. In addition, internal layout should factor in 'homeliness' and feel of the building; it should not feel too clinical and there should be clear demarcation from a hospital.

Conclusions

Our research has shown that:

- There is increasing demand across children and young people's mental health services for crisis care and challenges remain with accessing the existing options
- Access to services is prevented for all except for people with the most complex of mental health needs due to high thresholds, resulting in gaps within provision
- Existing services are under a lot of strain, with significant challenges in moving through the system for young people and their parents
- Examples of best practice are limited.

As the recommendations throughout the report have highlighted, changes could be made relatively easily with the establishment of ICS' to improve patient access and experience. For example, the system could fund a national platform for parents and professionals to access materials and advice on crisis services for young people and provide a dedicated crisis support line. We suggest making the current thresholds for residential mental health care for CYP more flexible, in line with the Long Term Plan.

Most importantly, we believe that ICS' could use their commissioning power and larger geography (when compared to Clinical Commissioning Groups) to further expand community provision to include alternative community-based residential services. These would significantly help the wider system to support young people experiencing a mental health crisis and alleviate workforce capacity within the NHS.

Current costs for crisis CYPMH services, often provided by the private sector, are exceptionally high, and do not always support young people in the most effective way. In this report, we have outlined an alternative, community-based residential approach, in which housing providers, the NHS and young people and their parents could come together and deliver a potentially more cost-effective and impactful solution. By taking such an approach, it could be possible to enhance the mental health support of parents and young people, like those we have spoken to throughout this report.

About the organisations involved

Care Research

Care Research is an independent research organisation that supports innovative, independent research designed to improve the care people receive. Care Research has completed work across a wide range of sectors including social care, education, healthcare, and the charity sector. The team is made up of academics from universities around the country who come together to develop bespoke, tailored research.

Look Ahead

Look Ahead is a specialist housing association and provider of tailor-made care, support and accommodation services. Look Ahead supports thousands of people across London and the South East with a diverse range of needs, helping them to make individual choices, achieve goals and take control of their own lives.

With 50 years' experience providing health and social care services, Look Ahead is proud to be the trusted partner of nearly 40 local authorities and health trusts, providing over 120 specialist support and care services for over around 5,000 people every year with a wide range of needs, including:

- Mental health
- Young people and care leavers
- Learning disabilities and autism
- Homelessness and complex needs.

Whether it's working with someone to achieve a positive change or providing specialist care, Look Ahead's experienced and passionate teams are committed to delivering high quality services across social care, health and housing that support independence and help transform lives.

The Wates Family Enterprise Trust

The Wates Family Enterprise Trust is an independent charity set up by the Wates family, the owners of the Wates Group. Launched in 2008, the Trust is integral to the Wates family's approach of being responsible business owners and its vision of being a force for good. The Trust's mission is focused on building communities and improving lives beyond tomorrow.



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Appendices



Appendix 1

Range of mental health professional roles in our sample

- CAMHS Liaison Clinical Nurse Specialist
- CAMHS Nurse
- CAMHS Nursing Lead for an independent provider
- CAMHS Referral Manager
- CEO of independent children's mental health service
- Children's Mental Health Counsellor
- Children's Mental Health Therapist
- Children's Secure Unit staff
- Children's Services CEO
- Children's Supported Accommodation Service Manager
- Clinical Commissioning Group
- Clinical Director for a residential company
- Commissioner of Children's Mental Health services
- Digital mental health services developer
- GP
- GP Mental Health Lead
- Local Authority Children's Mental Health Crisis Team Service Developer
- Local Authority Children's Placement Manager
- Mental Health Acute Inpatient Manager
- Mental Health Lead for the Clinical Ambulance Service
- Mental Health Nurse
- Mental Health Service Development Manager
- Mental Health Support Team Leader
- NHS 111 Mental Health Clinical Advisor
- NHS Mental Health Crisis Team
- NHS Tier 3+/Tier 4 Team Manager
- Primary Mental Health and Crisis Team Manager
- Psychiatric Nurse
- Residential Care Manager
- School Mental Health Lead
- Youth Work Service Manager

Appendix 2

2a. Parent/service user interview schedule

1. What's your experience with young people's mental health crisis/crisis services?
2. How did your parents support you and respond/what was your response when you noted that your child was experiencing mental health crisis?
3. Were there any specific struggles during your/your child's mental health experiences that you wish to discuss?
4. What support did you/your child receive?
5. What type of facility do you believe you/your child needed during a mental health crisis? What would your ideal service consist of?
6. Is there anything else you would like to raise or discuss in relation to mental health crisis/crisis services for young people?

2b. Mental health professional interview schedule

Semi-structured interview questions

1. Can you tell me briefly about your role and how it relates to young people's mental health crisis services?
2. Are you aware of any YP mental health crisis services in the area that you work in?
3. Do you believe there are enough YP mental health crisis services to meet the need in your area?
4. If you are presented with/become aware of a young person who is in the midst of a mental health crisis, what can you currently do? What are your current options?
5. Are you aware of any examples where a YP in mental health crisis did not receive the support they needed? What happened?
6. Do you believe any other services or service types would be useful to support a young person in that situation?
7. If you were to develop a service for YP experiencing mental health crisis, what would some of the key features of that service be?
8. What do you believe are the key barriers at the moment to developing new YP mental health crisis services?
9. Do you feel the lack of YP mental health crisis services impacts upon other areas of health and mental health provisions? How?

Possible other questions dependent upon individual role

10. Do you feel you have the required number of staff to effectively support a YP experiencing a mental health crisis?
11. Are you aware of the costs of providing a night in a psychiatric ward for a YP experiencing mental health crisis?
12. Have you known of any young people experiencing mental health crisis being sent to adult wards or other alternative locations?
13. Do you believe it is a simple process for families and carers to identify and contact suitable services for their YP who may be experiencing a mental health crisis?
14. As a general estimate, how many beds do you feel would need to be made available to be able to effectively meet the YP mental health crisis need in your area?

Appendix 3

3a. Ethics overview

Ethics

Following discussions with the NHS Ethics Review Committee, we were informed that our work did not require their independent approval due to our research not directing soliciting people from within the NHS. This led us to enlist the services of an independent consultant to sense check and offer ethical guidance on our processes. The results of this process can be found in Appendix 3b.

Receiving informed consent

All participants received the 'Mental Health Professionals Research Interview Participation Sheet' document (see Appendix 3c) prior to interview. This document outlined the aims and objectives of the research, the approach to data storage and the rights of participants to be involved with and withdraw their involvement and what participation involved. Prior to the interview being recorded, the interviewer offered the opportunity to talk through the document with interview participants. Once consent was given, the interview began and, for the record, the interviewee was asked to confirm that they had read through and discussed the information in the participation sheet and were willing to continue.

Data storage

Care Research is storing the audio interviews and transcripts in line with GDPR guidelines on a password protected, biometrically secured computer alongside an encrypted hard drive. Password protected transcripts have also been shared via a closed Google Workspace to share information with Look Ahead. All interview data will be destroyed 30 days after publication of the final research.

Rights to withdraw

Interview participants were able to withdraw their involvement in the research before, during or after the interview was complete. Interviewees were also informed that they were welcome to refuse or not answer questions if they did not wish to.

Maintaining anonymity

To maintain anonymity, the reporting of the professional interviews does not contain any identifying features such as the interviewees name, individually identifiable role title, employer, or personal characteristics such as gender, age or ethnicity.

3b. Independent ethics review guidance

Exploring young people and their families' experiences of mental health crisis care in England: Study Protocol review

Introduction to this paper

In August 2022, Louie Worth of Care Research asked Linda Jackson, independent research and evaluation consultant, to review the *Exploring young people and their families' experiences of mental health crisis care in England: Study Protocol* paper and associated materials. The aim was not to 'sign off' the protocol but to act as a critical friend, offering recommendations where relevant around the approach. This paper is a summary of key recommendations as the result of the process.

Overview of the review process

- **Discussion with Louie Werth** (2 September) to understand the background to the project
- **Review of documents** (15 September) including:
 - Care Research Look Ahead CYP Family Research interview – Mental Health Crisis Service Review: a four-page ethics protocol submitted as part of the NHS review
 - CYP families and carers interview participation sheet
 - MH CYP Family Semi-Structured Interview Questions
 - A link to the academic profile for Dr. Sarah Christie, interview lead
- **Discussion with Louie Werth** (20 September) to review the recommendations
- **Review of email** (23 September) with revised approach
- **Discussion with Louie Werth** (27 September) to review the revised approach
- **Development of this paper** (14 October) with summary recommendations

Summary of recommendations

Any research project asking people to reflect on a period of mental health crisis requires significant ethical and safeguarding consideration. Given the potential risk of re-traumatising the research participants, **the key recommendation was to consider the psychological safety of participants at every stage of the research and ensure there are adequate safeguarding processes in place.** The following recommendations explore this in more detail.

Refine the sample to include only people aged 18 and over

The original approach was to engage with any individuals, their families and carers who have used or potentially required mental health crisis support. This might have included young people aged under 18 alongside a family member or trusted adult. However, given the highly vulnerable participant group, sensitive subject area and the risks of re-traumatising participants, the recommendation was to exclude young people under the age of 18 from the sample and ask other participants (professionals, family members and young people aged 18-25) to provide insight based on their experiences instead.

Pre-screen potential participants before confirming an interview

The research proposal considered a series of recruitment methods including opting-in via an online survey and asking third party organisations to broker interviews with young people aged 18-25. Given these different routes to participation, the recommendation was to screen potential participants before approaching to set up an interview, as part of a pre-research safeguarding measure. This screening should be on an individual basis depending on an assessment of their vulnerability. For example, this assessment might exclude people who indicate that they are currently receiving mental health care in the survey or it might involve scoping conversations with practitioners that know the individual to get their informed opinion on the potential risks involved in them taking part in the research.

Have a clearer oversight of safeguarding policy and process

One of the key recommendations was to have greater clarity of the safeguarding process and how this might be adapted depending on the individual taking part in the research. For example, the safeguarding policy for a young person aged 18-25 recruited through a third-party organisation would be significantly different compared to that for a mental health advocate that opts-in to the research via LinkedIn. A key principle of a good safeguarding policy, particularly when working with people connected to third party organisations, is to follow their safeguarding policy. Another recommendation is to agree in advance a named person (e.g. a youth worker or mental health professional) as the safeguarding lead, to approach a) should there be a safeguarding concern for the researcher to report after the interview and b) who the participant can speak to more generally as part of a post-interview de-brief.

Ensure that informed consent (including understanding of confidentiality and the safeguarding process) is embedded in each stage of the recruitment process

Having informed consent is critical for this research project. A recommendation was to re-write the participant information sheet in a clear, jargon-free plain English, to be shared with people who had been screened to take part in the research in advance of the interview. The information sheet would cover the following areas.

1. **The aims and objectives of the research** – so participants are clear on the remit of their participation and what the research can and can't do (e.g. it can't 'fix' individual issues etc).
2. **Safeguarding and confidentiality** – that the interview is confidential unless the researcher hears something in the interview that makes them concerned for their or someone else's safety, at which point details will be passed on to the agreed safeguarding lead.
3. **Use of data** – explain the use of personal data as per GDPR requirements around knowing in advance what data will be collected, who will have access to it and how it will be stored, reported upon and then deleted.
4. **Informed consent** – how participants will be given the space to ask any questions and will be asked at the beginning of the interview whether they are willing to proceed based on the participation sheet/interview introduction.

Both the participation sheet and interview introduction will also **stress the primary importance of the participants' psychological safety**, and that they are taking part voluntarily and therefore can leave the interview at any time they wish without any consequences.

About Linda Jackson

Linda is a highly experienced research and evaluation consultant. She started her career at the consultancy OPM (now Traverse) in 2009, has been freelance since 2017, and is in the process of setting up her own consultancy, The Loom.

Linda has specific experience of conducting qualitative research with people in vulnerable circumstances or who have experienced crisis, including interviews with male and female prisoners, sex workers and people in recovery. She specialises in theory-based approaches to evaluation, has designed organisational outcome frameworks and has led formative and summative evaluations of programmes to help inform ongoing delivery. Linda has worked for a wide range of national community and voluntary organisations and government clients, including the Department of Health and Social Care, the Department for Health Northern Ireland, NHS England, Social Care Institute for Excellence, the British Red Cross, Ramblers and Macmillan Cancer Care. Alongside this, she has delivered work for various local authorities and hyper-local, community-based organisations.

3c. Participant information sheet

Mental health professionals research interview

Introduction

Thank you for expressing interest in our research. We want to raise greater awareness of the experiences young people have with mental health crisis and the services that are currently available to them. **We believe that speaking to professionals who manage, work for, or partner with mental health is crucial to us better understanding the needs of young people.** This brief document outlines the research we are conducting, what participation in the research involves, and what your rights are. The interviewer will run through these prior to the interview too and if you have any questions at all please do contact our research lead louiewerth@careresearch.co.uk.

About the research

Look Ahead Care and Support (<https://www.lookahead.org.uk/>) together with the Wates Family Enterprise Trust have commissioned new research into the current services available for young people experiencing mental health crisis. **As part of this work, the researchers, Care Research, are looking to interview individuals who manage, work for or partner with mental health services to discuss your experiences around mental health crisis provision,** what works and what doesn't, with a view to producing a report this autumn which will offer recommendations to health, housing and social care that can be taken forward. Our aim is to raise awareness and develop better ways of supporting people experiencing mental health crisis. We know that this can only occur if we listen to people working for and with young people's mental health services.

What does participation involve?

Participation in the research would involve a 20-30 minute audio recorded interview conducted through Zoom with a member of the Care Research team. We can of course keep the camera switched off if this is preferred. **All contributions would be anonymised (including their organisation). Every contributor will receive a £25 Amazon gift card for participating, which will be sent via email at the end of the interview during the call.**

The interview will focus upon your experiences around mental health crisis provision, what works and what doesn't. You do not need to answer all the questions you are asked, and our aim is simply to better understand your experiences. If you would like more information on the types of questions you will be asked, do contact louiewerth@careresearch.co.uk for more details.

How is my data stored?

All interview data will be stored in line with GDPR guidelines and will be destroyed 30 days after the release of the research report. Your contributions may feature in our final report. All contributions will be fully anonymised. Alongside this, any identifying characteristics such as personal characteristics (e.g. gender, age, location or specific role) or the service(s) you work for will be generalised in the report so as not to be identifiable.

Can I change my mind?

Yes! If before, during or after the interview you decide you do not wish to participate, just let us know. We will delete any interview data immediately and will cease your ongoing involvement.

What if I have further questions?

If you have any further questions, you can email our research lead louiewerth@careresearch.co.uk. You are also able to ask your interviewer any questions you have prior to the interview.

3d. Participant information sheet

Children, young people, families and carers

Introduction

Thank you for expressing interest in our research. We want to raise greater awareness of the experiences young people, their families and carers have with mental health crisis and the services that are currently available to them. **We believe that speaking with young people, their families and carers is crucial to us better understanding how mental health services can be improved.** This brief document outlines the research we are conducting, what participation in the research involves, and what your rights are. The interviewer will run through these prior to the interview too and if you have any questions at all please do contact our research lead louiewerth@careresearch.co.uk.

About the Research

Look Ahead Care and Support (<https://www.lookahead.org.uk/>) together with the Wates Family Enterprise Trust have commissioned new research into the current services available for young people experiencing mental health crisis. **As part of this work, the researchers Care Research, are looking to interview individuals who have experienced mental health crisis and/or their families and carers to discuss experiences around mental health crisis provision,** what works and what doesn't, with a view to producing a report in January which, will offer recommendations to health, housing and social care that can be taken forward. Our aim is to raise awareness and develop better ways of supporting people experiencing mental health crisis. We know that this can only occur if we listen to people, families and carers with lived experience.

What does participation involve?

Participation in the research would involve a 20-30 minute audio recorded interview conducted through Zoom with a member of the Care Research team. We can of course keep the camera switched off if this is preferred. **All contributions would be anonymised including personal details** such as gender, race, where you are based and the specific services you have experiences with. **Every contributor will receive a £25 Amazon gift card for participating, which will be sent via email at the end of the interview during the call.**

The interview will focus upon your experiences around mental health crisis provision, what works and what doesn't. The interview is part of a research project, so we would be unable to offer advice or tackle any specific issues you have had with your care. Our interviewees' emotional wellbeing is our top priority. The interview would be carried out sensitively by someone with a strong understanding of mental health. You do not need to answer all the questions you are asked, and our aim is simply to better understand your experiences – we want to give you a chance to tell your story. If you would like more information on the types of questions you will be asked, do contact louiewerth@careresearch.co.uk for more details.

How is my data stored?

All interview data will be stored in line with GDPR guidelines and will be destroyed 30 days after the release of the research report. We may share the interview with our interview transcription partners Go Transcript. This will also be stored in line with GDPR guidelines and is covered by the service's non-disclosure agreement – they will not be able to share the information or recording in any way. Your contributions may feature in our final report. All contributions will be fully anonymised. Alongside this, any identifying characteristics such as personal characteristics (e.g. gender, age, location or specific role) or the service(s) you work for will be generalised in the report so as not to be identifiable.

Can I change my mind?

Yes! If before, during or after the interview you decide you do not wish to participate, just let us know. **You can leave the interview at any time.** If you choose to leave we will delete any interview data immediately and will cease your ongoing involvement.

Confidentiality and safeguarding

We want all our interviewees to feel safe and respected. Anything you say during our interview will be kept confidential – we will not share what you have said with others. We may use anonymised quotes in our report and supporting materials (but without your name or any other personal details). However, if we hear something that causes ongoing concerns for someone's safety, we may need to refer this to Hackney Care Services. If this was the case, we will inform you of this at the time. This is a standard safeguarding practice within research for families, carers and young people.

What if I have further questions?

If you have any further questions, you can email our research lead louiewerth@careresearch.co.uk. You are also able to ask your interviewer any questions you have prior to the interview.

Glossary of terms

Term	Definition
Tier 4	Inpatient admission for children and young people
A&E	Accident and Emergency
CAMHS	Child and Adolescent Mental Health Services
CYP	Children and young people
CYPMH	Children and young people's mental health
CQC	Care Quality Commission
FOI	Freedom of Information
GDPR	General Data Protection Regulation
GP	General Practitioner
ICS	Integrated Care System
MH	Mental Health
NHS	National Health Service
PTSD	Post-traumatic stress disorder
SHP	Single Homeless Project Supported Housing Provider
YP	Young person
WFET	Wates Family Enterprise Trust



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