

# Health and care experience profile briefing

A summary of work to understand young people's experiences of transitioning from children and adolescents' mental health services to adult mental health services.

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## About the project

This work was undertaken as a pilot for Healthwatch England to help NHS England and NHS Improvement develop a qualitative research methodology for local health and care systems. It is one of a number of health and care experience profiles being developed that aim to help systems understand how joined up local care is. It supports looking at what standard of care a person should be getting, and asking locally what is and is not working, and explore why.

## National expectations and experiences

Healthwatch England mapped the national expectations and experiences of young people transitioning from Children and Adolescents Mental Health Services (CAMHS) to Adult Mental Health Services (AMHS). They looked at documents such as the NICE guidance<sup>1</sup> on transitioning from children's to adult's health and social care services, the NHS Long Term Plan<sup>2</sup>, and the Five Year Forward View<sup>3</sup>.

And research, such as the Care Quality Commission (CQC) review in 2018 which found examples of good practice, but also "a complex and disjointed system that produces disjointed support", with different services and teams not always collaborating to provide a joined-up approach to the planning and delivery of care and support<sup>4</sup>.

Integration of services that support young people's health and wellbeing is a critical issue during transitional care. Healthwatch England's research found that there are some well-established models for supporting and improving transition between children's and adults' services for young people with long term conditions, including mental health conditions. However, these models are usually context and service-specific, and the commissioning and delivery of mental health care for young people varies greatly across England.

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<sup>1</sup> NICE (2016) [Transition from children's to adults' services for young people using health or social care services \[NG43\]](#)

<sup>2</sup> NHS England (2019) [NHS Long Term Plan](#)

<sup>3</sup> NHS England (2014) [The Five Year Forward View](#)

<sup>4</sup> CQC (2018) [Are we listening? Review of children and young people's mental health services](#)



## Local expectations and experiences

Locally we mapped youth mental health service provision, both in the statutory and voluntary sector, examining the difference between the expected provision and young people's experience of care.

We examined documents such as the local Mental Health and Wellbeing Pre-birth to Age 25 years Needs Assessment<sup>5</sup>, the local system draft Long Term Plan<sup>6</sup> and other local plans regarding services. We compared this against the national expectations for care for transition from CAMHs to AMHs.

We undertook in-depth interviews with four young people aged 16 to 24 years, and four parent/ carers with current experience of transitioning to adult services. Using a qualitative approach enabled us to collect and analyse the detail around the transition experience, identifying the themes common across the narratives we heard. As part of this project, we had conversations with five local providers whose work includes supporting young people who are transitioning from children to adult mental health services. This allowed us to triangulate our findings.

Our research found that although there is a range of services providing support to children and young people, they generally do not work together very well. There is evidence of a move towards better integration through local place-based care using a patient centred, patient needs framework (iThrive)<sup>7</sup>. But it is not clear yet, how this will impact this transitional period of care, the navigation of the system or ease of access to appropriate services.

## What people told us

All the people we spoke to had felt they had had a difficult journey trying to access mental health support. Although the focus in this engagement was around how well services are joined up, it has also highlighted difficulties within the mental health system, that were not just an issue in the transition period.

A number of common themes emerged amongst the young people and parent /carers we spoke to around things like long waits for assessments, not meeting assessment criteria and delays in being referred.

Waiting lists for CAMHs can be long even for an urgent referral. It is difficult for people to wait for help when they feel ill, and we have heard that young people have deteriorated whilst waiting, reaching crisis and going to A&E

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<sup>5</sup> Cambridgeshire and Peterborough CCG et al (2019) [Mental Health and Wellbeing Pre-birth to Age 25 years Needs Assessment](#)

<sup>6</sup> Cambridgeshire and Peterborough CCG et al, (2019) [Draft Cambridgeshire and Peterborough Long Term Plan](#)

<sup>7</sup> iThrive (2019) [About the iThrive framework](#)



Private care and help from schools and colleges was sometimes sought to fill gaps in statutory care.

Three out of eight people said they had tried to access CAMHs more than once via their GP. And three out of eight had their referrals denied for CAMHs and AMHs both during and outside of the transition period.

“They [the young person] are still not in a good place. They try so hard, but as a parent, you worry if the system lets them down anymore, they are going to give up. Very scary for parents.” - parent

Some parents could not understand how their child could not meet the criteria for referral to CAMHs when they seemed so ill. One young person had been referred to the GP for a CAMHs referral from CHUMS and this took several months to then be denied.

“It’s never straightforward. It’s so frustrating, here we go again.” - parent

The feeling from people was that earlier intervention with less wait for help would have been better.

### Common themes from young people and families

- Waiting lists for CAMHs feel long for people, even with urgent referrals
- Accessing mental health support can be complex
- Services do not seem to be joined up very well, leaving gaps in care
- People need to be very ill to meet CAMHs thresholds
- Young people would like a point of contact, i.e., a Transition Worker, during transition between services
- People feel there is a lack of holistic care
- People don’t always know where to go for help
- Parents would really appreciate peer support when their child is unwell
- Young people would like earlier intervention of help
- Covid-19 appears to have affected care negatively at times
- There is a lack of understanding of autism, especially of women, in the healthcare system



## Integration of CAMHs and AMHs

### Moving from children's inpatient mental health services to adult services

Three out of eight young people had been in-patients in CAMHs, and each reported a problem going from CAMHs to another adult mental health service.

One out of county person, had had no plans for ongoing care at all; there had been a two-day gap until another placement could be found for them.

Another person with an eating-disorder had had a three-month gap leaving CAMHs inpatient care until supported living accommodation was found.

For a different patient with more complex trauma, finding appropriate therapy had been very difficult. The family felt that the right therapy was not available in the NHS.

**“I feel like we are being shoe-horned into a service that isn't the right service. There seems to be pressure felt to get discharged from CAMHs.”** - parent

Two families told us that the inpatient experience had not been good; lack of interest from staff, and young people negatively influenced by other inpatients were amongst some of the problems.

**“It would be best to not mix this young age group with other much older adults as they are in very different places as people.”** - parent

Others told us staff had been incredibly good.

### Moving from community-based children's to adults' mental health services

Three people had the experience of moving, or trying to move, from children to adult mental health services, although one of these was subsequently denied adult mental health care.

One parent told us that it was a “long-winded process” of having an assessment from CAMHs to then go to their GP for a further referral to adult mental health services. The waiting was disruptive for their child and they still did not know whether their referral would be accepted. They had also sought support from the child's college.

One young LGBTQ+ person had been discharged from CAMHs when they did not feel they had been helped by therapy. They were then referred to another service by their GP only to be referred back into adult mental health services.

### Difficulties referring into CAMHs and AMHs when age 17

Families told us that they feel it is hard for GPs to know whether to refer a young person aged 16/17 into CAMHs or AMHs. Fine tuning the timing for a referral at this age can be difficult. If the timing does not allow for a course of therapy in CAMHs for example, it would mean waiting then to refer into AMHs at the right age.



This wait can be hard for people who need support sooner. Families have told us cases where waiting has caused a deterioration in their child's mental health.

### Transition Workers

A Transitions Pathway was introduced to the local system in 2018 to give young people a point of contact where possible during their transition between services. Three out of eight people had a Transition Worker or Care Coordinator assigned to them. Whilst some people found this useful, others had issues contacting their care coordinator or getting help when they needed it.

One young person who was moved twice to different placements did not have a number to contact on the first move. On the second move, contact was very infrequent and disjointed between the hospital, the young person and the Care Coordinator. Contact outside the weekly arranged appointment did not seem possible.

“There is no one to talk to in between the weekly appointments.” - young person

“It has been very difficult for an autistic person who needs one familiar person for point of contact.” - parent

## Other difficulties in the mental health system

### Difficulty navigating mental health services

People said it was not always easy to find information about local services or know where else to go for help other than the GP. People did not always know about the countywide mental health services directory website - Keep Your Head<sup>8</sup>. And when they did know, it was not always easy to know which organisation to approach for help. And felt it would be helpful to have someone to signpost them through this information.

“We didn't know what to fight for or what the options were or where to go. We didn't feel there was anybody on our side.” - parent

### Poor communication from mental health services

Half of the people we spoke to said that communications from CAMHs and other services needed to improve. Families told us that there can be gaps in communications leading to feelings of frustration and that they have been forgotten. On transitions, communications had been poor between services.

A young person who'd had contact with Social Services since childhood explained that documentation was not thorough enough and there were often details missing.

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<sup>8</sup> SUN Network (2021) [Keep Your Head - children and young people's services](#)



They therefore needed to repeat information about themselves when in communication with these services.

Another person had had an unexpected discharge letter which was felt to be poorly written in terms of accuracy and tone. There had been no other communications about this.

“The discharge letter felt like a punch in the stomach”. - parent

### Treatment not meeting a young person’s needs

Three out of the eight young people told us that the therapy they had was not helpful. Therapy was often deemed as too short, not effective or not the right therapy for a person with a more complex case. No contact between therapy appointments seemed to feel difficult for young people too.

“The maximum chance to see a therapist was once a week which when suicidal is not suitable.” - parent

One young person had self-discharged from therapy after they felt it did not meet their needs. There appeared to be no follow up as to why this had happened from the provider.

### Crisis not always triggering a referral into mental health services

Three out of eight people told us that they’d had a mental health crisis or admission to hospital, but this had not triggered an immediate referral into mental health services.

Three young people had eventually been to A&E and were then referred or re-referred into adult mental health services. They felt that their crisis could have been avoided if earlier intervention had taken place. They had each tried to access help previously or had found their therapy had not been enough.

We heard how half of the families have felt that if their young person had had help earlier, they may well have not become so ill. And help navigating the right support at an earlier stage could have helped.

### Private care filling the gaps

Two out of eight families explained that they had sought private mental health support to fill the gaps in publicly funded support. This seemed to complicate care, especially during transition of services as any urgent care would be under the NHS. One family told us that private care notes from previous private care given, were not sought or considered under NHS care at any point.

“All that history (private care) didn’t appear to be relevant!” - parent



## Schools and colleges

Three families told us that schools also helped them with support during “gaps in statutory care”. And that schools seemed to have good information about the young people’s needs through communications with previous schools.

But this support sometimes seemed to complicate care. One family sought help from college whilst waiting for their young person to be discharged from CAMHs and referred to adult mental health services. As a result, they were told that their child could not be supported by both the college and CAMHs.

## Lack of holistic care

All the people we spoke to felt there was a lack of holistic care. This was particularly the case for people with complex needs.

“Nobody seems to stand back and think ‘what are this young person’s needs?’”  
- parent

## Difficulties for autistic people with mental health conditions

Half of the people we spoke to (four out of eight) were autistic. Two of them reported their feeling that healthcare staff lack autism awareness. Our recent Autistic Voices report<sup>9</sup> mirrors these findings, particularly for autistic females. Accessing care was more difficult for autistic young people as they needed adjustments to be made so services were accessible to them.

One young autistic woman said they gave up trying to get help at times because it felt too hard for them. Another said that they had sought help for mental health difficulties for many years before they were eventually diagnosed with autism.

“I was under multiple doctors, Children and Adolescent Mental Health Services (CAMHS), admitted to mental health wards, attended a special school and yet I went completely under the radar.” - Young female autistic adult

One young person had issues accessing support for their mental health when they moved to Cambridgeshire, although had been a CAMH patient at their previous address. They were eventually admitted to hospital due to their mental health and went into adult mental health services. A GP suggested trying a local charity where they were supported to try for an assessment for autism and then to find living accommodation.

“(The local charity organisation) have been phenomenal and I’m not sure I’d be here without them, but the rest of adult mental health services need a very good looking over.” - young person

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<sup>9</sup> Healthwatch Cambridgeshire and Healthwatch Peterborough (2021) [Autistic Voices](#)



### Lack of understanding of needs of LGBTQ+ young person

One young LGBTQ+ (Lesbian, Gay, Bi-sexual, Transgender, Questioning or other) person said they felt misunderstood by staff in mental health services. And felt that there needed to be a greater understanding around the unique issues for LGBTQ+ people. We triangulated this experience with accounts from local partners who shared concerns, particularly around the mental health support available for young people who are trans or questioning their gender, and who also have a diagnosis of autism or another neurodiversity.

“Many of our young people have the experience that as soon as healthcare providers find out they’re trans, they assume that’s the root of all mental health symptoms.” - Pip Gardner, Chief Executive, The Kite Trust

### The need for parent/carer support

Parents / carers who had peer support from those in a similar position told us how helpful this was. Others talked about how helpful they would have found peer support but were not aware of where to find this.

“The good thing that came of that was a regular support group for parents. Attached to this were advocacy mechanisms. In this group we made some changes for the better.” - parent

### Covid-19 - affecting care negatively

Over half the people we spoke to (five out of eight) thought that Covid-19 had negatively affected their care. One felt they had been an in-patient longer than they otherwise should have been and had no ongoing care planned on discharge. Another had a three-month gap between inpatient discharge from CAMHs and supported living accommodation.

One person had been moved to a non-local hospital due to lack of local beds and then needed referral back into the local system. This family felt they were often chasing to find out about plans for care instead of being kept informed.

“It has been harder to reach out for help during Covid-19.” - young person

### Stigma around seeking help for mental health issues

Self-stigma remains an issue and people can know about services, but do not access them. One family told us that where they live, it can be regarded as weak or negative to access mental health services for support, not just during transitions, but anytime.

“They know the services are there, but they don’t use them” - parent

### Lack of patient confidentiality

One young person told us medical letters had been copied to their parents when they would prefer that they were not.



## Recommendations

The feedback from young people and their families shows how access to and movement between CAMHs and AMHs can be difficult, with high thresholds for entry and long waits for assessments along with other difficulties.

There were many recommendations that arose from this piece of work. These have been shared with NHS England. We share the main ones here:

1. **Develop a more holistic, integrated mental health system for children and young people**, incorporating the voluntary sector and giving easier access to earlier interventions for support.
2. **Provide more help in navigating the local mental health services**. This includes more support from a Transition worker / Care Coordinator, so young people can have a single point of contact throughout their care. It is important to regularly evaluate this by the young people who use this service.
3. **Evaluate and understand why therapy or treatments are not suiting some young people**. If young people are not getting the care they need, this could lead to further rereferrals into the system, including crisis.
4. **Enable more trauma-informed services for complex mental health cases** to ensure that young people get the appropriate treatment
5. **Improve autism awareness training for staff, with appointed lead persons**.
6. **Improve LGBTQ+ awareness training for staff** to improve their understanding of gender identity and sexuality to ensure appropriate support and treatment is given to LGBTQ+ young people.
7. **Build on the current local engagement work focusing on young people with eating disorders** in order to continue evaluating current services.
8. **Ensure clearer conversations with young people** around what information they do and don't want shared with family members to ensure consent is obtained.
9. **Provide better information about local services for GPs, practices and social prescribers** so that people can be well signposted to the services available.
10. **Provide more peer support for parents and carers** and clear information where to find this.
11. **Improve communication with people waiting for mental health treatment** to ensure they know where they are in the system, and to prevent a deterioration whilst waiting.



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## What this project means to one young person

**Chelsia Lake, Associate Director of our Healthwatch, has endorsed this report saying:**

“As a young person having experienced difficulties in accessing mental health support myself, it is incredibly reassuring and comforting to know that work is being done to help improve services.”

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