Integration Index - Health and Care Experience Profile #1 - Engagement Report

A young person transitioning or who has transitioned from Children's Mental Health Services to Adult Mental Health Services. (Feb 2021)

Introduction - The Integration Index Project

Our Healthwatch in Cambridgeshire and Peterborough has been working with Healthwatch England and NHSE/I on a pilot project called the *Integration Index Project* to develop a qualitative research methodology for local health and care systems to help them assess how well they are doing at providing joined up care. It is a qualitative approach to enable systems to ask not just what is and is not working, but it also provides an opportunity to explore why. There were two phases to this work.

The first phase of work involved researching what the local system offers this health and care experience profile, what changes might be happening in the local system and what the plans are going forward for mental health services.

It has been recognised by the local system that there are a range of youth mental health services in Cambridgeshire and Peterborough, but they generally do not work together. There is evidence of a review of services locally and a move towards integration of services to local place-based care using a patient centred, patient needs framework (ithrive)[1].

It is not clear yet, how this will impact this transitional period of care, or the navigation of the system or ease access to appropriate services.

The second phase involved speaking to young people (and/or their families/carers) in more depth to find out how the transition from Children's to Adults' mental health services has been for them in terms of how well integrated this has been.

We then compared these experiences with how the system should be working according to the local system research.

Methodology

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[1] iThrive (2019) About the iThrive framework

From previous engagement work undertaken during the pandemic, we have learnt the importance of offering the option of attending a focus group or booking a 1:1 online meeting or phone call. This ensures no one is digitally excluded and also accommodates those people who are not comfortable taking part in a focus group.

For this work there was a strong preference from both young people and parent/ carers to book a 1 to 1 meeting. As some of the experiences shared were in fact very complex, with hindsight it may have been more difficult to accurately capture the level of detail that was possible in hearing from people individually.

We asked partner organisations who work with young people, if they would help us to promote our project using a poster and social media tools. We also asked them to tell us what they had heard from young people who have been through the children's to adults' mental health services transition. We learnt from these organisations that young people they work with had had many difficulties during this period of care.

Being in a third lockdown due to Covid-19, with the system being under immense pressure may have made recruitment to this work even more difficult.

We did though, manage to recruit and speak to eight people, which was the maximum number required for this pilot; three young people and five parent carers. We offered a £25 Love to Shop Voucher as a "thank you" to the participants. Most of the participants had then forgotten about the voucher by the time we spoke, which showed their real desire to help with system change. These are people with lives that have been very affected by their experiences and generally, they have a genuine desire to help in changing things for the better.

It should be remembered that we spoke to three young people and five parent carers so this is a small sample and should not be seen as being representative of the much larger number who use children's and adults' mental health services in our county.

Demographic data

The eight young people involved in this engagement were between the ages of 16 and 24 years; four white males and four white females. They were diagnosed with a wide range of mental health difficulties and included an LGBTQ+ young person, a person with a learning disability and four who had been inpatients or had had an admission to hospital at one time.

All of these young people were at different stages in the transition process:

Two were in the process of transitioning to adults' mental health services from CAMHs.

Two had transitioned within the past two years.

One had transitioned a few years ago.

One was discharged from CAMHs with no transition but now awaiting AMHs.

One had no transition after CAMHs despite family feeling it was needed.

One had not accessed CAMHs but accessed AMHs after a crisis.

Some of these experiences have been throughout the Covid-19 pandemic, which may have affected care.

The experiences we have heard are varied and each situation very different. When focusing on the transition from children's to adults' mental health services, it encompasses all services (NHS and voluntary sector), not just Cambridgeshire and Peterborough Foundation Trust (CPFT) services [2] Children and Adolescent Mental Health Services (CAMHs) and Adult Mental Health Services (AMHs). These transitions can be further complicated by difficulties with access to and meeting criteria relating to all these services, as well as waiting times for assessments and gaps in care. It is about the way the system works or does not work together, not just the transition within these two CPFT services.

Findings - Themes

Even though the experiences we have heard have all been varied, there are themes that run through these -

- **All the people we spoke to had felt they had had a difficult journey trying to access mental health support. This was felt to have affected the young person in question negatively at some point.**

One parent shared how they had felt -

> *"She is still not in a good place. She tries so hard, but as a parent, you worry if the system lets her down anymore, she is going to give up. Very scary for parents." (parent)*

- **Everyone we spoke to said they had little or no help navigating mental health services -**

  There is no specific mental health system navigation available for families who are seeking support. The GP is the main person people go to find help. The next step is dependent on the GP's knowledge of youth mental health services. A referral to CAMHs might follow, but the wait for an assessment can be long even for more urgent referrals. There would be no certainty of meeting the current threshold criteria. Often there is no support during this waiting time. If they do not meet that criteria, then young people and their families/carers are seeking support once again. Even when they have a list of organisations, it is difficult for people to know where to find the appropriate support for their specific circumstances.

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[2] Cambridgeshire and Peterborough Foundation Trust (CPFT) https://www.cpft.nhs.uk/

- **All the people we spoke to felt there was a lack of holistic care -**

  Young people and parent/carers mentioned that there seemed a lack of a more “holistic” approach to 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)

- **Most people (six out of eight) had little awareness of mental health services available locally**

  Young people and families are generally not aware of mental health services that are available to them at the outset of seeking help. The *Keep Your Head* website does not seem to be well known despite this being a “one-stop” website for mental health information and advice for people in our county, commissioned approximately 4 years ago. Even so, trying to sift through all of this information, it is not always possible to know which organization would be the best to turn to.

  Eventually some parents/carers become experts themselves, but this is usually because they have really had to research alternative services other than CAMHs or AMHs and often to fill in gaps of care. One parent had done a mental health first aid course to feel able to help her child because her child had not met the criteria for adult services. She wanted to be as well informed as possible to help her child.

- **Most of the families we spoke to (six out of eight) did not understand about the healthcare system**

  Families find it hard to understand the healthcare system. They are concentrated on finding help and support at a very difficult time in their lives.

  One family shared the way they had felt during their experience of trying to understand the system.

  “I didn’t feel we were being treated like human beings at one point (in this journey). 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. We don’t know anything about the funding. There is a lot of hope at every step of this journey…but it just hasn’t worked out”. (parent)

- **All parents stressed the importance of parent carer support**

  Some of the parents/carers who we spoke to talked about how good it would have been for them to have had support alongside other parents in a similar situation, so that they could in turn, maybe better support their young person. This was felt to be very important, but many parents were not aware of where to access this support.

One parent carer told us that whilst her child had been an inpatient at age 17, the parent support group was hugely beneficial to her.

"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)

- **Over half of the people we spoke to (five out of eight) thought that Covid-19 could be affecting care delivery**

The pandemic may have played a negative role in the care being offered or given in some cases, although it is hard to know exactly to what extent this was the case.

One family told us that their child may have been an inpatient for longer than expected but was then discharged without adequate planning for ongoing care.

Another young person was discharged to an out-of-town hospital unexpectedly and then was lost in the system. This meant an inpatient bed was not available and a referral was needed to get back into the system.

One person had a three-month gap from inpatient discharge into supported living accommodation.

In other cases, therapy had been delivered virtually, which has not been found to be ideal although understandable in the circumstances.

One young person said:

"It has been harder to reach out for help during Covid-19"

- **Over half of the people we spoke to (five out of eight) had experienced a long wait for CAMHs**

Waiting lists for CAMHs can be long even for an urgent referral with young people potentially deteriorating whilst waiting for an assessment or they seek private care in the meantime to fill the gap in care offered. Early intervention does not happen due to long waiting lists for CAMHs. Some young people have deteriorated significantly whilst waiting and have ended up in crisis or admission.

- **Over half of the people we spoke to (five out of eight) had experienced delays in accessing support from CAMHs or AMHs**

Some young people had had some delay of gaining support from either CAMHs or AMHs. They all suspected that they were ill enough for these services, but there was a delay in access, either due to referrals being denied due to not meeting criteria, delay from a healthcare perspective (not thought to be ill enough) or having been in crisis but this not triggering access to these services.

- **Half of the people we spoke to (four out of eight) said that communications between CAMHs and families was poor**

  Families have told us that there can be gaps in communications and young people and families can feel frustrated that they have been forgotten or not cared about.

  One family told us that the young person had had a course of therapy in CAMHs but then waited six months with no communications from CAMHs to then be assessed (because their age was reaching the age for AMHS) for ongoing care. A referral to AMHs was suggested via the GP. Another wait.

  Once within the system, some parents can feel they are chasing to hear about care instead of being kept informed.

  "It's never straightforward". "It's so frustrating, here we go again". (parent)

  One family had had a discharge letter without warning. The content of which was felt to be poorly written.

- **Half of the people we spoke to (four out of eight) said that not meeting CAMHs or AMHs criteria was an issue for them**

  Four families and young people had told us that at some point meeting the criteria from CAMHs or AMHs had been difficult. When the young person does not meet the CAMHs or AMHs criteria, this may have several consequences.

  When a young person might eventually have their referral denied, this can make them feel very lonely and uncared for with the uncertainty of where to turn to next for support.

  Families cannot understand how their child is not meeting CAMHS criteria when they feel their child is so very unwell.

  During the waiting time, a young person's mental health can deteriorate quite significantly, leaving families very stressed and struggling and then possibly trying to find other help because they feel so desperate. At this point people often do not know where to turn to. Some families have turned to schools and colleges for support or have used private care.

  The young person can end up being very unwell and in crisis with trips to A&E. Then they might meet the criteria to enter CAMHs or AMHs because they have deteriorated to such an extent.

- **Half of the people we spoke to (four out of eight) said that autistic people seek help for many years**

  Young people can go for many years seeking mental health support before they are eventually diagnosed with autism. This has resulted in many years of pain and suffering for many people.

  "I was under multiple Drs, CAMHs, admitted to mental health wards, attended a special school and yet I went completely under the radar". (young person)

- **Half of the people we spoke to (four out of eight) said that there seems to be a lack of understanding amongst healthcare staff around the needs of autistic people**

  Young people have told us that they can feel “labelled” and are then treated differently when autistic. They feel that there is little understanding around sensory overload or that they may interpret language differently. People can feel very isolated, lonely and misunderstood because of this.

- **Three out of eight people we spoke to think that schools and colleges are filling gaps in care**

  Three families have shared how the schools and colleges their children have attended, have tried to help fill the gaps while young people have waited to be seen in CAMHS or AMHs or when they may have finished a short course of therapy followed by a gap in support. This extra support has been very welcome and helpful in difficult times, however sometimes parents/carers have had to push for this to happen too.

  One family told us that CAMHs had told the family that the young person could not be seen by both the College and by CAMHs. The family were trying to fill the gap in care whilst waiting for CAMHs to discharge and then for a referral to be made to AMHs. The family felt very frustrated by this situation, especially when the young person was still not well. This resulted in the College stopping counselling too, although an open door was offered. The referral is still going ahead for AMHs. The young person is waiting to hear about this.

  Another parent told us that the young person’s school had been fantastic. They had been very supportive throughout other gaps in care, having offered counselling in the sixth form. They had been given an information pack through the sixth form, from Winston’s Wish Charity[3] supporting bereaved children and their families, which was very useful. A quiet space was offered for the young person to go to when needed.

  There seems to be good and positive dialogue between families and schools and schools have responded well in these cases. Colleges also seem to have

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[3] Winston’s Wish - https://www.winstonswish.org/about-us/

known about the young people's needs through communications with previous schools.

- **Three out of eight people we spoke to told us about the difficulties finding support**

One young person told us the frustrations that had been felt when approaching a service outside CAMHs for help, for example, after being discharged from CAMHs, but being told they are either too ill or not ill enough for a service.

"At 17, I approached IAPT and had the usual "you're too ill" or "not ill enough". (young person)

The same frustrations come when being discharged from CAMHs and then not meeting the criteria for AMHs.

- **Three out of eight people had a Transition Worker or Care Coordinator assigned to them**

A Care Coordinator (CC), not Transition Worker, was the term used by families and young people. The word Transition was only used once in terms of a "transition group".

A Care Coordinator or point of contact was provided for some but not all. Of the two presently going through the transition process, a CC was assigned as part of a bridging service to AMHs for one, and for the other, a CC had not been assigned. Another young person had had a CC under CAMHs during being moved from one inpatient placement to another for an eating disorder. For the other experience, the young person was older and had spent many years seeking support, where care was often disjointed. Their CC was assigned after a crisis admission and then entering AMHs a few years ago.

One young person and one parent told us that sometimes the care coordinator or their point of contact was part-time, so it was not always easy to contact them when needed. If a weekly arrangement for contact had been set up, contact outside this time did not appear possible. Young people can find this difficult to have periods where it seems impossible to contact that person.

For one young person with an eating disorder, they were moved to three different inpatient care wards around the County. The first move there did not seem to be a number for the point of contact assigned to the young person, for the second move, there was a point of contact, but this was only every six weeks. This young person had not found this helpful. Now in supported living accommodation with a weekly point of contact, but again, no contact offered in between this. Their experience has been very painful for them.

When there has not been a point of contact, it can be even more difficult for autistic people -

"It has been very difficult for an autistic person who needs one familiar person for point of contact." (parent)

- **Three out of the eight did not find therapy helpful**

  Some young people have felt that the therapy they had was not helpful. This has been more the case for a young person who is LGBTQ+, someone with an eating disorder and a complex trauma case.

  One young person told us that they had not felt understood by CAMHs staff and the therapy offered was not helpful to them.

  "I just didn't find the therapy helpful".

  They were then discharged from CAMHs and told they did not meet the criteria for AMHs. The GP made a referral to the Tavistock Centre where the young person was eventually told that they should be seen in AMHs. A convoluted journey for this person with months of waiting for help and support.

  Another young person in supported living accommodation felt their therapy was not helpful for an eating disorder.

  One older young person told us that they had had several episodes of therapy and their autism had gone undiagnosed for years.

  Therapy was often deemed as too short and not enough to deal with the difficulties being felt by the young person. No contact between therapy appointments seemed to feel difficult too.

  "The maximum chance to see a therapist was x 1 a week which when suicidal is not suitable." (parent)

  One parent felt that there was not much therapy for someone with a Personality Disorder. "There seems very little care for Personality Disorders."

- **Three out of eight people spoke of the problems of mixing all ages in adult wards**

  Some families have highlighted that mixing young adults with older people who have mental health difficulties is not ideal.

  "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)

- **Two out of eight highlighted the complications of using private healthcare alongside NHS care**

  Two families explained that they had sought private mental health support to fill gaps in public funded care, which can complicate the care, especially during transition of services. Urgent care would be under the NHS and private care notes from previous private care given, would not be sought or considered under NHS care at any point.

One parent explained that assessments done by private mental health consultants were not consulted by NHS doctors, with NHS doctors redoing assessments that have been previously done by private doctors (even when they also work in NHS).

"All that history (private care) didn't appear to be relevant!" (parent)

Families then need to explain the young person's history, sometimes many times, due to the NHS not accessing this data.

- **Two out of eight commented on their weekly appointments for therapy**

  Young people have told us that weekly appointments for therapy appear to be the maximum support offered for therapy with no chance for contact in between. Even this is felt not to be enough for a young person who is feeling unwell mentally.

  "There is no one to talk to in between the weekly appointments." (young person)

Comments were made by one individual on the following points:

- **Difficulties with living on County Borders**

  One family who lives on County borders but have a GP in the next county and not in Cambs, have felt denied a certain service that the GP could not refer to, even when a young person had been in school in Cambridgeshire for several years. They could access some other hospital services within Cambridgeshire.

  The family's young person did not meet the criteria for AMHs in the neighbouring county. Support now would be through their GP. They would have liked to have had the opportunity to seek access to Cambridgeshire services as the young person had been in school for several years in Cambridgeshire. Other healthcare appointments in the past with a Paediatrician had had to be in the neighbouring county despite schooling in Cambridgeshire which had complicated things for them.

- **Difficulties post discharge from inpatient care at 18**

  One parent from another county has told us that their child was placed in a mental health inpatient bed in Cambridgeshire for several months. On discharge, there was no ongoing care or support afterwards at all age at 18. A&E was the only option to access an adult mental health bed on discharge from the inpatient unit.

  "There was nothing in place after discharge. Going to A&E was the only option". (parent)

  It is still not clear if this was due to their home county paying for that inpatient bed or whether being in another wave of Covid-19 was also of concern or both. This was a very difficult and worrying situation for the whole family as there was no social care offered, no assisted living option offered and the young person was not deemed independent yet. The family told us that there were no plans at all going forward.

- **Difficulties in knowing when to refer to CAMHs/AMHs for healthcare professionals with poor consequences for young people**

When a young person presents with a mental health need at the age of 16/17, it seems to be understandably difficult for GPs to know if they should refer to CAMHs or AMHs. Young people can deteriorate further while this decision is being made if they have no other support in place. A delay in deciding for this referral can then move the young person along nearer to AMHs age which then might not allow enough time for therapy to start and end in CAMHs before another assessment to decide ongoing care.

The initial decision to refer may be hard knowing the high thresholds in place.

One family have told us they felt that due to a wait in decision for a CAMHs referral, despite the GP offering weekly appointments for support, the young person had deteriorated significantly and reached crisis point, therefore eventually meeting the criteria for entry. This family is convinced that if the young person had had help earlier, they would not have become so ill.

- **Stigma around seeking help for mental health issues**

One family told us that 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) People can know about services, but they do not access them. This is unhelpful for young people and families needing support.

- **NHS mental health services did not meet the needs of young people experiencing complex trauma**

One family told us they felt that their young person who was 17 with complex trauma related needs, did not necessarily fit into services offered by 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)

- **Discharge letters**

One family told us that they had received a discharge letter for their young person, which could have been better worded. The tone was upsetting and assumptions had been made with the history not completely factually correct, which at the time was very upsetting.

"It was like a punch in the stomach". (when they had received the discharge letter) *(parent)*

- **Disengaging with services**

  One young person disengaged with services. This was thought to be partly due to a change in counsellor.

  A resulting discharge letter did not appear to be concerned with why this had happened.

- **Issues with Confidentiality**

  One young person felt that at 16, confidential medical letters from CAMHs can go to parents when they do not need to. Young people do not necessarily want that to happen and would prefer more privacy. This should be a choice that young people can make. Lots of other young people have said the same about confidentiality to this young person.

  "It makes you feel you cannot trust the counselling service." (young person)

Comparing the local offer for this health and care experience profile

As a guide, we referred to the following documents and guidance as we compared the local offer for a young person transitioning or who has just transitioned from children's to adults' mental health services with the experiences we have heard:

- CPFT Transitions Protocol (2015)[4]
- The Cambridgeshire and Peterborough Emotional and Wellbeing Local Transformation Plan for Children and Young People (2019)[5]
- the NICE guidelines for Transitions from Children's to Adults' Services for young people using health and social care services (2016)[6],

1. **Age of Transition** - ***planning (within CAMHS) should start three to six months before expected time of transition (age 17) except for young***

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[4] CPFT Transitions Protocol (2015) Transition protocol_CAMHS_AMHS v4 Mar 15.pdf

[5] Cambridgeshire and Peterborough CCG (2019) Local Transformation Plan for children and young people's mental health and emotional wellbeing

[6] NICE (2016) Transition from children's to adults' services for young people using health or social care services [NG43]

people with learning difficulties (age 18), young people in South Lincolnshire.

- For the young person with a complex case, timely planning did take place.
- The two young people who had been inpatients under CAMHs until recently, some attempts at planning ongoing care seemed to be done. However, one resulted in a discharge with no ongoing care or plan. The other with a three month gap in care waiting for supported living accommodation.
- One person appeared to have no planning in place, only an assessment near the age of 18 having had a gap in no communication from CAMHs.

2. **Flexibility of age in Transition** - ***Some flexibility around timings of transitions, depending on age and diagnosis.***
    - There does seem to be some evidence of present flexibility of timing of discharge from CAMHs for a complex case.
    - For the other young person transitioning at present, there did not seem to be any flexibility. They had had a recent six month gap in communication from CAMHs after a period of therapy, then assessed, then discharged with an advised AMHs referral through the GP.
    - We have heard two more recent past cases where there has been no flexibility on discharge as an inpatient, leaving gaps in ongoing care. One had a gap into inpatient care in AMHs and the other a three month gap into supported living accommodation.

3. **Types of Transition** - ***a young person may make a transition from CAMHs to one of a range of services.***
    - During these transitions, apart from CAMHs and AMHs, young people and families engaged with the education system and Primary Care, three people were in touch with social services and one was being helped to seek independent living accommodation through a local charity organization which had been delayed due to Covid-19.
    - During this process though, families sought help from schools and colleges and private care to help fill gaps in care being sought from either within CAMHs or whilst waiting for assessments for CAMHs and AMHs. This has, in turn, complicated the care pathway at times.
    - For the two presently going through the process –

  - One complex case was transitioning from CAMHs to an AMH service. The service being offered was not felt to be the right one for the child.
  - One present transition was referred back to Primary Care (GP) from CAMHs and was waiting to hear if their referral had been accepted into AMHs and which service that might be. The young person was still unwell.
- One past transition was from CAMHs inpatient to AMHs inpatient into another county. There was a short gap between the two while the system found the next inpatient care.
- The other past inpatient transition was from CAMHs inpatient to supported living accommodation under AMHs with a three month gap in care.
- Three other past transitions were referred back to Primary Care (GP) for next steps. One of these was advised by their GP to then approach a local charity organisation, where they found the support invaluable. This led to a diagnosis of Autism after many years of seeking help and trying various therapies, finally to gain a true understanding of their history of difficulties.

"(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)

- One young person disengaged with the services partly due to a change in counsellor. There was no consultation with the family.
- One young person had had therapy with CHUMS who then wrote to the GP that they access more therapy via CAMHs. This did not trigger an immediate access to CAMHs. Family waited several months for this.

4. **Transition as part of a collaborative care planning and shared decision-making approach** - ***planning care should be part of the care planning irrespective of whether this is a Care Programme Approach (CPA) or non-CPA care planning. This process is the responsibility of a Care Coordinator.***

   We do not know which approach of planning people have been under.

A Transition Worker has been called a Care Coordinator (CC) by everyone who had one that we have spoken to. They will be referred to as a CC in this document.

- In the two present transitions, there is evidence that one young person has been assigned a Care Coordinator (CC) as a point of contact for care and planning which aligns with the ambitions of the Transitions Pathway that has been developed locally.
- The other present transition experience has not had a CC assigned.
- One recent inpatient was assigned a CC when being moved to different locations for an eating disorder. This was not felt to be very effective as previously explained.
- One past experience a few years ago, showed a young person was assigned a CC after a crisis and being admitted to AMHs. This was a very positive experience for the young person. This came though, after a long journey of seeking care, waiting for assessments, gaps in care and reaching crisis before being ill enough to be accepted into AMHs.
- Some young people have found contact with the CC is not felt to be frequent enough and contact is not always possible if the CC is part time.
- In one past experience, there was mention of a “transition group” after a crisis admission. This group met over a 4-week period. The outcome of this was that the young person was offered art therapy which the family felt was not enough given that the young person had been suicidal.

5. **Documentation - *The referral and a copy of the care plan should document the young person’s and parents’ wishes and the reasons for their wishes and the young person’s capacity to make decisions about their own healthcare.***

It is very difficult to know the details of documentation. However, there was some discussion around this with this cohort.

- One family had had a phone call and a letter sent to them regarding discharge from CAMHs, which is expected and per protocol, but they had had a 6-month gap since their last contact with CAMHs with no communications.
- One family had had a discharge letter which they felt was badly worded and poorly written. The young person had disengaged with

services and there seemed to be no discussion with the young person or the family about why this may have happened.

- One family explained how past private care notes had not been relevant within the NHS care which seemed such a shame when it contained previous valuable assessments that had been done and other valuable information.
- One young person who had had contact with Social Services throughout child and adult services, explained that documentation did not appear thorough enough with details missing. This young person still felt they needed to repeat information about themselves.

Local Transition Pathway

Since the CPFT Transition Protocol in 2015 (reference 4) was written, a Transition Pathway has been developed locally introducing a Transition Worker (or Care Coordinator as families have called this) into the care provided as a point of contact for young people and their families. It is unclear from the Local Transformation Plan (LTP) for Children and Young People's Mental Health and Emotional Wellbeing 2019 (reference 5) how well this has been working, as this document explains that the data from young people using this pathway has not been collected, despite attempts made to do this. The refreshed LTP document for 2020 has not been published yet but is due to be finished by the end of March 2021.

Recommendations

Suggestions from young people and families to providers and commissioners of services

- Work towards making services more person-centred and try to look at people more holistically when they are using healthcare services.
- To build on the Transitions Pathway – young people tell us they would find it very helpful to have a single point of contact who they can contact all throughout their care (transition worker or care coordinator) This contact ideally needs to be more flexible and approachable and available more than x1 a week. To help increase the amount of these workers.
- Educate children, young people and families on mental health and the importance of seeking help and support when needed. There is still stigma around having mental health needs. This would be particularly important in the more deprived areas in Cambridgeshire.
- Better information for parents so they know what support is available to them. Initiate more groups forming locally. Promote through schools and colleges so they are known.

- More flexibility for families who live on county borders in terms of accessing services in one or another of the counties. Complications can occur when young people attend school in one county but need to access healthcare services in another.
- Better working between NHS care and Private care especially when a significant amount of care for someone has been within the private sector.
- Ensure there is up to date staff training to increase awareness around Autism within the healthcare profession in all areas but especially mental health services. We have heard from many people of all ages how they have sought mental health support, but that their Autism was not identified for a long time, therefore their needs have gone unmet for many years. Mental health support that is tailored for Autistic people is very much needed.
- Ensure better access to healthcare and adjustments for this for people with autism. For example, rather than only having the telephone as access, maybe a chat option with a GP via messenger or voice texts might work better for some people with autism who find telephone conversation difficult. Ensuring there are “autism champions” in a hospital setting as a point of contact to help those with autism or learning disabilities.
- Ensure training for teachers and support staff in schools, so they are more aware of autism and the possible needs of children and young people with autism. This may help in enabling more children to be identified and perhaps diagnosed and supported earlier.
- Consider introducing a six-month education-led “health” check-in with young people who have ADHD/Autism.
- Person-centred training for mental health staff, so there is a better understanding that young people are individuals and are not the “labels” or a “diagnosis” they have been given. Support the “person” not the “label”.
- Ensure mental health staff have a better understanding for young LGBTQ+ people and their needs. A specialist service should be considered for these young people to ensure their specific needs are met.
- Allow for the fact that some young people may be able to continue their education after the age of 18 even if they have an Education, Health and Care Plan (EHCP) in place.
- More trauma-informed services. Long term costs of inappropriate therapy services are very high. Allow for other ways of accessing specific services within the NHS system.
- There is a postcode lottery for some services. This should be a consistent offering in all areas.
- Ensure clearer communications with young people around confidentiality of letters to families and whether the young person wants to share this information.

Further Recommendations from our Healthwatch

- Develop a mental health system for children and young people allowing for-
  - proper navigation of the system for a better "fit" for the young person.

  - easier access to earlier interventions for support for young people.

  - a smoother pathway in mental health services which integrates with the voluntary/charity sector, that is more specialized to suit the needs of young people, until age 25/30.
- To build on the current work focusing on young people with eating disorders. Continue to build on understanding their needs especially during transitions by engaging regularly with them and their families.
- Considerations might be made around options for therapy. Therapy was not felt to be effective by a young LGBTQ+ person, a complex case and for someone with an eating disorder.
- To continue and enable more options for drop-in clinics for young people to access support in a flexible, informal manner.
- Ensure good promotion of the countywide website *Keep Your Head* throughout existing community groups, schools, colleges and universities so that young people and families are aware of its existence. A possible local campaign might help in promoting this.
- Better information about local services for GPs, practices and social prescribers so that people can be better signposted to the services available.
- Families need to have better navigation around the mental health system including for the mild to moderate needs. Ideally, this should be someone trained specifically in mental health who can advise on which services are on offer to young people to help them find the right "fit" for their specific circumstances, especially when CAMHs do not accept the referral for the young person.
- NICE guidelines (2017)[7] - *Transition between inpatient mental health settings and community or care home settings*, states that any inpatients who are admitted to a specialist inpatient mental health setting outside the area in which they live, have a review of their placement at least every three months.

  Following this guidance should help ensure named practitioners from the person's home area and the inpatient ward can work together to ensure the placement is reviewed regularly, so that it does not last longer than necessary, and that discharge planning takes place as needed.

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[7] NICE Guidelines (2017) – Transition between inpatient mental health settings and community or care home settings - https://www.nice.org.uk/guidance/qs159/chapter/Quality-statement-2-Out-of-area-admissions

- Understand that young people may disengage with therapy but then may need to return to it again. Allow for flexibility around this. Ensure services have a good understanding why young people disengage with services. There may be changes that could be made to reduce this happening. Perhaps a phone call could be made, or a questionnaire sent to the young person and/or family.
- Discharge letters should be worded as empathetically and as accurately, in terms of medical history, as possible.
- Ensure that qualitative data is collected from the young people who use the Transitions Pathway before they are discharged to another service. It is important to capture this data so the service can be evaluated from their point of view. This could be in the form of a questionnaire or a phone call.

Conclusion

The feedback from young people and their families shows how access can be difficult to CAMHs and AMHs with high thresholds for entry, long waits for assessments and difficulties in the movement between the two services in the community and as an inpatient. The services are not always working in an integrated way and young people can suffer more due to this.

Young people and their families have told us how the present system is frustrating and difficult to navigate. It would be helpful to have better navigation of the provision especially for young people with mild to moderate mental health needs. Parental support when children are going through therapy or when they are an inpatient has also been highlighted as an important need by parents.

There is evidence of a Care Coordinator (CC) being assigned to some young people but not all. When a CC is assigned, this has had mixed results. It can be very positive and work well, but there can be some problems with this as discussed; contact is mostly weekly with no contact in between, in one case this had been quite infrequent where communications could have been better and the CC being part-time can make contact more difficult.

It would be interesting to see if any data has been collected on the experiences of young people who have used the Transitions Pathway in CPFT over the past year as this data is yet to be collected. Building on the plans of having an accessible point of contact during care would be very useful for young people and their families.

Covid-19 has played a role in how care has been delivered but it is difficult to know just how much this would have influenced decisions that have been made.

However, overall, families still appreciate the efforts that healthcare staff make in trying to deliver good care, despite the pressures they are under, especially during the pandemic.

The local system is reviewing the Early Help Support Offer (0-25 years) which includes the mental health services offer to older children and adolescents.

There are many transitions happening in the life of a young person in adolescence already without the difficulties of also transitioning through mental health services.

There is a case to be made for a more specialist youth mental health service which is commissioned up to the age of at least 25 years which meets the specific needs of this age group. This system should include good integration with the voluntary sector and other services, for example, housing and social services, and should provide good navigation for young people and their families. This would also remove the problem for GPs and professionals trying to decide whether to refer for CAMHs or AMHs around the age of 17, which can cause a long wait and complications for the young person.

Different therapy options might be considered. We heard from a young LGBTQ+ person, a complex case and a person with an eating disorder, how therapy had not been felt to be helpful.

As a system, it would be important to remember a focus on earlier intervention, educating young people and families about mental health, the prevention of poor mental health and increasing resilience.