

# Health and care experience profile #1

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## What are the characteristics of this health and care experience profile?

A young person with a mental health condition(s) who is transitioning or has recently transitioned from child and adolescent to adult mental health care services.

## Rationale

This Profile:

- Demonstrates a timepoint in service users' lives where integration between services is both inevitable and crucial.
- Provides the opportunity to explore both integration between the different health services involved and integration with other relevant services and organisations including education, community support, housing and/or social care.
- Reflects a key commitment of the NHS Long Term Plan - a new approach to young adult mental health services for people aged 18-25 [to] support the transition to adulthood.<sup>1</sup>

## What kind of care should this Profile be able to expect?

Integration of services that support young people's health and wellbeing has long been acknowledged as a critical issue during transitional care at this stage of life. There are some well-established local 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> NHS England (2019) [NHS Long Term Plan](#)





National-level guidance from the National Institute for Health and Care Excellence (NICE),<sup>2</sup> published in 2016, is not focused specifically on mental health conditions but highlights that transition support in any health or social care service should:

- Involve the young person and their family or carers, primary care practitioners and colleagues in education, as appropriate.
- Address all relevant outcomes, including those related to education and employment; community inclusion; health and wellbeing, including emotional health; independent living and housing options.

It also states that:

- Health and social care service managers in children's and adults' services should work together in an integrated way to ensure a smooth and gradual transition for young people.

More specifically, in planning the transition from children's to adults' services, there should be an annual meeting to review transition planning, or more frequently if needed. The outcome should be shared with all those involved in delivering care to the young person. This meeting should:

- Involve all practitioners providing support to the young person and their family or carers, including the GP.
- Involve the young person and their family or carers.
- Inform a transition plan that is linked to other plans the young person has in respect of their care and support.

The young person should have a single practitioner as their 'named worker' to coordinate their transition care and support. Amongst the named worker's responsibilities, they should:

- Oversee, coordinate or deliver transition support, depending on the nature of their role.
- Be the link between the young person and the various practitioners involved in their support, including their GP.
- Help the young person navigate services, bearing in mind that many may be using a complex mix of care and support.
- Proactively engage primary care in transition planning
- Direct the young person to other sources of support and advice, for example peer advocacy support groups provided by voluntary and community sector services.

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<sup>2</sup> NICE (2016) [Transition from children's to adults' services for young people using health or social care services \[NG43\]](#)



To help the young person become familiar with adults' services, service managers should ensure that a practitioner from the relevant adult service(s) meets the young person before they transfer from children's services. This could be achieved through arranging joint appointments, running joint clinics, or pairing a practitioner from children's services with one from adults' services.

Older guidance from the Social Care Institute for Excellence (SCIE)<sup>3</sup> focused specifically on mental health service transitions for young people, reiterates the key points above that:

- Staff need to work collaboratively with other professionals and agencies; staff should know how each other's services operate in order to provide coordinated and joined-up support during transition.
- Managers should ensure that services are working together strategically; multidisciplinary services are needed to incorporate both children's and adults' mental health services, as well as voluntary sector providers, non-health agencies and GPs.
- When assessing needs and planning transitions, the focus should be on the young person's wellbeing across their whole life, including their family, friends, housing, school, college and work.

Looking forward, the NHS Long Term Plan<sup>4</sup> committed to:

“A new approach to young adult mental health services for people aged 18-25 [that] will support the transition to adulthood ... We will extend current service models to create a comprehensive offer for 0-25-year-olds that reaches across mental health services for children, young people and adults. The new model will deliver an integrated approach across health, social care, education and the voluntary sector.”

### **What does the evidence tell us about experiences of integrated care for this Profile?**

The challenges experienced by young people during their transition from children to adults' services are well recognised across many sources - including Healthwatch insight, other public and professional bodies, academia and the charity sector. At this timepoint, many young people with ongoing needs disengage with services or fall through the cracks.<sup>5</sup>

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<sup>3</sup> SCIE (2011) [Mental health service transitions for young people \[SCIE Guide 44\]](#)

<sup>4</sup> NHS England (2019) [NHS Long Term Plan](#)

<sup>5</sup> NICE (2016) [Transition from children's to adults' services for young people using health or social care services \[NG43\]](#)



In 2019, the Royal College of Paediatrics and Child Health (RCPCH) asked young people to share their experiences of transition from children to adults' services.<sup>6</sup> They highlighted six key factors needed to create a good transition process:

1. Recognise and discuss **individual needs** in young people-friendly terms.
2. Look at transition **holistically**, to include advice on social, emotional, educational, geographical, employment, relationships and physical health.
3. Adult services to make social connections and have a long term relationship with young people, to provide **continuity of care**.
4. **Multidisciplinary teams** are important and should meet regularly to prepare the young person for transition.
5. Signpost to local services, resources and knowledge.
6. Support young people with their **mental health**.

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“My daughter was with CAMHS for her mental health for 7 years... CAMHS kept her on until she was almost 20, due to the complex nature of her mental health needs, saying they would keep her on until she transitioned to adult services.

She had a bad mental health meltdown, resulting in her wanting to kill herself. I phoned CAMHS for an urgent appointment, only to be told on the phone that she had been discharged back to the GP as she doesn't meet the criteria for adult mental health services. We went to the GP, who did an urgent referral to adult mental health, which was again rejected...

Why are young people dumped when they become adults? [...] My daughter's needs haven't changed, just because she is now classed as an adult.”

- Shared with Healthwatch England through our engagement with people across the country about the NHS Long Term Plan

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Research by the Care Quality Commission (CQC) with 180 young people found that the provision of services to support their health and wellbeing were often

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<sup>6</sup> RCPCH (2019) [Young people's experiences of health transition](#)



fragmented, poorly coordinated and relied on their parents and carers to take the lead.<sup>7</sup>

Although this research was not specifically focused on young people with mental health conditions, CQC built on these findings in a later review of children and young people's mental health services (CAMHS).<sup>8</sup> This review gathered evidence from 10 health and wellbeing board areas across England, engaging through focus groups and one-to-one interviews with over 1,300 children, young people, parents, families, carers and staff across the systems.

The review 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. Common themes identified within the examples of good practice included collaboration and strong communication between different teams and services, putting the young person at the centre.

The young people engaged with highlighted that the transition from children to adults' services is a key turning point in both their care and their life more generally - and as such, this time can be especially stressful. Poor transition planning was a common barrier to young people getting the support they needed; where there was no effective process to ensure the transition of their care, young people fell through the gaps. For some of these young people, this contributed to their mental health problems escalating and they had no adequate care in place.

Young people also commonly complained about having to repeat their personal narrative to multiple professionals because services had not adequately shared information with each other. For some of those who were newly engaging with adult mental health services, this meant having to undergo an assessment from scratch.

Good communication and information sharing between services, along with a gradual, flexible and person-centred approach to transition were found to be key enablers of a positive move into adults' services for young people.

These findings are supported by the wider academic literature. For example, Broad *et al* conducted a qualitative thematic analysis of youth experiences of the transitions from CAMHS to adult mental health services.<sup>9</sup> This work reviewed the

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<sup>7</sup> CQC (2014) [From the pond into the sea: Children's transition to adult health services](#)

<sup>8</sup> CQC (2018) [Are we listening? Review of children and young people's mental health services](#)

<sup>9</sup> Broad *et al* (2017) [Youth experiences of transition from child mental health services to adult mental health services](#). *BMC Psychiatry*



findings of 18 studies with 253 unique service users - spanning the UK, USA and Sweden. The studies explored the perceptions and experiences of young people who received mental health care in both CAMHS and adults' services. The positive factors that were valued by these young people included having a person-centered plan for transition that adapted to their individual, holistic needs. They felt having to repeat themselves to multiple professionals was hard work - as such, they considered joint working and good information sharing between the services involved in their care to be important.

## What kind of care should this Profile be able to expect if they live in Cambridgeshire and Peterborough?

The NICE (2016) guidelines - see reference 2 - for "Transitions from children's to adult's services for young people using health and social care services" sets out very clear recommendations and advice on this. We looked at whether our local systems are mirroring this guidance.

The *NHS England Long Term Plan*<sup>10</sup> p 51, sets out a clear vision for the NHS and the care it delivers for the following ten years. It explains the plan for a new model of care to deliver an integrated approach across health, social care, education and the voluntary sector.

In Cambridgeshire and Peterborough, we can see the progression of work towards this goal through the local *Sustainability and Transformation Plan (STP)*<sup>11</sup> work streams that are now in place.

Regarding transition for children going into adult mental health services, it can be seen from past engagement with young people and their families, through our Healthwatch and the local Clinical Commissioning Group (CCG), local protocols and STP papers, that this area of mental health services has needed improving for some time but work in this area has been progressing slowly for the better.

There are presently many services to support the mental health needs of young people, either commissioned by our CCG or via voluntary or charity organisations, but they often work in silo and not in an integrated way. This has been recognised by our local trusts and commissioners and work is underway to move the system into a more integrated way of working taking into consideration the diverse communities in this County. However, funding and workforce gaps are an ongoing barrier to this work.

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<sup>10</sup> NHS England (2019) [NHS Long Term Plan](#)

<sup>11</sup> Cambridgeshire and Peterborough STP (2020) [STP Board Report Update 23 November 2020](#)



## Cambridgeshire and Peterborough Local Transformation Plan for Children and Young People's Mental Health and Emotional Wellbeing - refreshed 2019/20 <sup>12</sup>

To put the needs of children and young people into context, '*The Local Transformation Plan for Children and Young People's Mental Health and Emotional Wellbeing (2019) for Cambridgeshire and Peterborough*' explains there are very mixed, diverse populations within the county with many pockets of very deprived areas in Peterborough, Fenland and pockets of Cambridge.

National prevalence data suggests that in Cambridgeshire and Peterborough there are almost 34,000 children and young people aged 2 to 25 years with a diagnosable mental health disorder:

- 1,800 pre-school children
- 6,400 primary school children
- 8,700 secondary school children
- 5,200 young people aged 17 to 19 years
- 11,700 young adults aged 20 to 25 years

The Joint Strategic Needs Assessment data, July (2019)<sup>13</sup> suggests rates of emotional disorder are particularly high in 17-19-year-olds, especially girls, at 22.4% for Cambridgeshire and Peterborough combined.

In 2017/18 there was a notable increase in the hospital admission rate for self-harm in the 10-24-year-old age group, with trends increasing since 2012/13. This is set against a fairly static national trend.

### Historical evidence of local system transitions work

Cambridgeshire and Peterborough NHS Foundation Trust (CFPT) - the primary NHS provider of secondary mental health services for children and young people - first developed strategic protocols for transitioning between CAMH and AMHs in May 2008. This document is no longer available online but was reviewed as part of the research for this project.

A 2012 mapping of children and adolescent mental health and social care services in Cambridgeshire and Peterborough was undertaken by the NHS National Institute

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<sup>12</sup> Cambridgeshire and Peterborough CCG (2019) [Local Transformation Plan for children and young people's mental health and emotional wellbeing](#)

<sup>13</sup> Cambridgeshire Insights (2019) [Children and young people outcomes](#)





for Research (NIHR)<sup>14</sup>. This piece of work does not include any service user experiences. It says that there was no national policy at that time around what a good transition should look like but refers to the National Service Frameworks (NSFs)<sup>15</sup> at the time, to help set the standards for good healthcare. It mentions CFPT implementing their transitions protocol from CAMHs to AMHs which seemed an important step forward.

Since then, there have been attempts made to improve the transition process between children's and adults' services, and there has been more interest around this in recent years.

### Feedback from children, young people and families

Our Healthwatch has received feedback from young people, their families and local organisations who support young people, that demonstrates problems within transitioning from children's to adults' mental health services. Feedback from local organisations, detailed more on page 25, suggests that separate funding for each service domain (children's and adults') does not help in improving this transitional period for young people.

Our local Healthwatch engaged with more than 600 young people about mental health in two reports published in 2017 - *Minding Us*<sup>16</sup> and *Being Happy Being Me*<sup>17</sup>. The two reports looked at young people's attitude towards and understanding of mental health in Cambridgeshire and Peterborough as part of a project to support the redevelopment of children's mental health services. The reports also included young people's experience of using mental health support services.

The findings were included in the '*Cambridgeshire and Peterborough Local Transformation Plan for Children and Young People's Mental Health and Emotional Wellbeing*', which is refreshed every year.

### Improving access to services

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<sup>14</sup> NIHR (2012) [Child and adolescent mental health and social care services in Cambridgeshire and Peterborough](#)

<sup>15</sup> GOV.UK (2012) [National framework for NHS continuing healthcare and NHS-funded nursing care](#)

<sup>16</sup> Healthwatch Cambridgeshire and Healthwatch Peterborough (2017) [Minding us - Improving services for young people at greater risk of mental ill-health](#)

<sup>17</sup> Healthwatch Cambridgeshire and Healthwatch Peterborough (2017) [Being Happy, Being Me](#)



The transitional period between children's and adults' services was highlighted in our reports as being a problem area in the plan in 2017, including amongst the more vulnerable groups of children such as young offenders and LGBTQ+ young people.

We made several recommendations, one of these was to aim to improve the transition period between children's to adult's mental health services.

Around this time, some overall improvements were made to the system such as more self-referral opportunities and more drop-in clinics.

- A mental health website called *Keep Your Head*<sup>18</sup> was developed to provide mental health information firstly for young people then later for adults and professionals.
- A digital texting support offer called *KOOTH*<sup>19</sup> was also commissioned with good results - this is still in use.
- Discussions were continuing around how to improve transitions and integrate services better, but still there remained unmet needs in youth mental health services as we highlighted in our reports at the time.

## Present and ongoing evidence of local system change around transitions

Cambridgeshire and Peterborough Clinical Commissioning Group (CCG) were asked to supply our Healthwatch with the system-wide policies and pathways and any relevant papers to show what young people should expect when transitioning from children's to adults' mental health services. Unfortunately, due to workload and system pressures, few papers have been provided.

We were sent a Transitions Protocol from 2015, which was due to be refreshed in 2017, although this does not seem to have happened, and the document is no longer in the public domain. It was a comprehensive protocol detailing what should happen during this period of care. This included when the planning for any transition between services should happen. Also, it explained how there is some flexibility and management around when the transition might take place for certain young people with specific mental health difficulties and in terms of age, for example, psychosis or emerging severe personality disorder (pages 6 and 7).

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<sup>18</sup> Keep Your Head (2021) [Keep Your Head - Children and young people's mental health](#)

<sup>19</sup> Kooth (2021) [www.kooth.com](http://www.kooth.com)



Most of the rest of the information in this document has been developed from our working knowledge and relevant documents in the public domain - many of which are in draft.

There is evidence that work towards the national vision of the NHS Long Term Plan has progressed within the local Sustainability and Transformation Partnership (STP) draft framework document, *'Working together for Mental Health in Cambridgeshire and Peterborough - A framework for the next five years'*<sup>20</sup>. This sets out the key priorities and next steps for our health and care system to achieve the aspirations of the *Five Year Forward View for Mental Health*<sup>21</sup>.

This document also sets out plans for integration of services and community based, person-centred care with a focus on prevention, community-based care (integrated) and specialist care services.

- Page 89 sets out a table to compare the local and national implications of the NHS's Five Year Forward Plan.
- Page 84 and 85 set out the pathways for mental health care, including integration of mental and physical health care.
- Page 86 states how they will work together to implement a shared vision for Mental Health.

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**“There are three clear themes from strategy work to date: Sustainability, Integration and Capacity and Demand”**

- **Working together for Mental Health in Cambridgeshire and Peterborough (2017)**
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This integrated vision of care is being rolled out in the form of Primary Care Networks, Integrated Health Care Systems with a governance structure split into North and South Alliances, incorporating Think Communities and local population-based intelligence. The North and South alliances are place-based alliances, which oversee and drive delivery of health care priorities in their locality.

It is recognised locally that the young people's mental health organisations often work in silo but there is evidence there will be a recommissioning of these services and changes in these pathways in 2021 to a more integrated approach. Tendering is underway for this.

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<sup>20</sup> Cambridgeshire and Peterborough CCG et al (2017) [Working together for Mental Health in Cambridgeshire and Peterborough](#)

<sup>21</sup> NHS England (2014) [The Five Year Forward View](#)



In preparation for this, in November 2019, a ‘*Mental Health and Wellbeing Pre-birth to Age 25 years Needs Assessment*<sup>22</sup>’ was done locally in partnership with the CCG, Cambridge Community Services (CCS), CPFT, Cambridgeshire County Council (CCC) and Peterborough County Council (PCC).

This document presents a service mapping for the county. Pages 44 - 51 lists all the publicly, voluntary and charity funded services.

The transitions from child to adult mental health services is listed as one of the main areas of risk for young people in this report.

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**“Although there are various services across Cambridgeshire and Peterborough to support those suffering with mental ill-health, they work in silos, there are long waiting lists for some services and some service users who do not meet the thresholds for some of the services.**

**An integrated approach is essential to ensure that no child, young person or perinatal woman is left unsupported due to a lack of seamless care.”**

- Cambridgeshire and Peterborough CCG et al (2019) from ‘*Mental Health and Wellbeing pre-birth to age 25 years Needs-Assessment*’

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This assessment also helps identify some of the present gaps in services. These being that the services work in silo, staff mental health training in schools is not really mapped or known and there is a lack of dual-trained staff in both physical and mental health, despite knowing that these needs will inevitably overlap.

The STP draft *Cambridgeshire and Peterborough Long Term Plan*<sup>23</sup> gives evidence that work is already underway to integrate services. Page 38, the section about mental health, explains the vision for more integrated services and funding, showing the thinking and questioning around integrated and smoother pathways for services.

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<sup>22</sup> Cambridgeshire and Peterborough CCG et al (2019) [Mental Health and Wellbeing Pre-birth to Age 25 years Needs Assessment](#)

<sup>23</sup> Cambridgeshire and Peterborough CCG et al, (2019) [Draft Cambridgeshire and Peterborough Long Term Plan](#)



Cambridgeshire and Peterborough local authorities updated the STP Board members on work towards children and vulnerable adolescents' mental health programme in November 2020 (see reference 11). There are three phases of work.

Isos Partnership, an independent research and consulting organisation, has been jointly commissioned by Cambridgeshire and Peterborough local authorities, the CCG and the Police to support them in reshaping their current model of Early Help and offer of support for older children and at-risk adolescents. The ambition is that, following this review, there will be a clear plan of action for Early Help (including older children) agreed across the partnership.

There is an overarching-question -

How well is the offer of Early Help meeting the needs of children and families in Peterborough and Cambridgeshire and how can we build on existing strengths to optimise the offer of early help going forwards?

Then three sub-questions -

1. Does the fact that Cambridgeshire and Peterborough operate different models of Early Help cause difficulties?
2. Within the overall envelope of Early Help, how well are support and services for older children and adolescents working together to identify needs and prevent them from escalating?
3. How well are the mental health needs of children and young people in Cambridgeshire and Peterborough being addressed?

There are three phases to the work:

**Phase 1** - A significant evidence gathering process was completed in January and February 2020, collating views on Early Help from key staff within children's services, housing, health partners, the Police, Youth Offending Services (YOS), schools, colleges, and the voluntary and community sector. Phase 1 focuses on pre-birth to 5 years.

This information gathering process did identify eight key challenges to be addressed and three of these are more specific to older young people.

Three of the eight key challenges found were -

- 1) The delivery model for "at risk" adolescents is fragmented.
- 2) There is a lack of distributed responsibility for children's and young people's mental health.
- 3) More could be done to maximise the contribution of partners and the community.

**Phase 2** - Develop an integrated delivery model focused on the development of a new integrated delivery model which was presented to the Child Health Executive



Board in September 2019. Members strongly supported the proposed integrated delivery model concept and recognised all the hard and effective work that went into its development.

This work plans a series of virtual workshops focused on the three key areas: Core Early Help Offer, Mental Health Offer and Adolescent Offer.

This shows three outputs:

1. A delivery model for working with at-risk adolescents across Cambridgeshire and Peterborough.
2. A refreshed early help strategy with revised vision and priorities.
3. A refreshed children and young people mental health vision and outcomes framework, considering what an offer for lower-level support for emotional wellbeing should look like, commissioning priorities and the importance of measuring outcomes.

This work is progressing but timescales for work are likely to be impacted by how the present pandemic evolves. It is understood the roadmap will need to be flexible enough to manage this without losing momentum. This programme is looking at large scale, system wide change. Sufficient resource needs to be allocated from across the partnership to develop the workstreams.

The full ISOS report commissioned by the CCG, *Cambridgeshire and Peterborough Strategic Review of Early Help, Sept 2020*<sup>24</sup> is here.

### Local Transformation Plan for Children and Young People's Mental Health and Emotional Wellbeing 2019

The Cambridgeshire and Peterborough *Local Transformation Plan for Children and Young People's Mental Health and Emotional Wellbeing* (reference 12) was first developed in 2015/16 to enable a clear vision and path forward on all the streams of work. It is refreshed each year and the current version is from 2019.

It includes the local need, relevant data, what engagement has been done with service users, recurrent and non-recurrent funding in each work stream and plans for focus on work going forward. It is linked to the NHS Long Term Plan 2019 and many of the key-deliverables are detailed within the local Cambridgeshire and Peterborough Local Transformation Plan for Children and Young People's Mental Health and Emotional Wellbeing 2019. These appear to be in line with the 2016

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<sup>24</sup> ISOS (2020) [Early Help Strategy progress presentation](#)



NICE guidance [NG43] on transition from children's to adults' services for young people.

The transition from children's to adults' mental health services is recognised in the *Cambridgeshire and Peterborough Local Transformation Plan for Children and Young People's Mental Health and Emotional Wellbeing 2019* as being a potentially difficult time for young people.

**A Transitions Pathway** - was implemented in 2016 within the specialist CAMHs provision. The *Cambridgeshire and Peterborough Local Transformation Plan for Children and Young People's Mental Health and Emotional Wellbeing 2019* explains that the facilitation of transition workers and peer support workers to work alongside young people during their transition improved facilitation of services and created a smoother transition for young people into adults' services.

However, there are only three transition workers and three peer support workers in place and whilst this may have helped some young people, the feedback our local Healthwatch has received is that this is just not enough to deal with the workload. The service has seen an enormous increase in numbers of young people.

An analysis of data from the Transitions Service reveals that since the service commenced in 2018, the number of 17-year-olds treated in community CAMH services has increased from 352 in 2016/17 to 582 in 2018/19.

This is an increase of an additional 230 17-year-olds; this is significantly above the original set target for the *Cambridgeshire and Peterborough Children's and Young People's Mental Health and Emotional Wellbeing Plan 2019/20*, a service which aimed to support an additional 100 17-year-olds per annum.

This document explains that the transitions team won an award at the Positive Practice in Children and Young People's Mental Health Awards. A CQUIN (Commissioning for Quality and Innovation) assessment was also made on the service with positive outcomes. This is a monetary incentive to improve quality of care. It has helped working practices between children's and adults' services and has aided funding to help young people transition to adults' services and other services more smoothly. The document also states that there is more information on the quantitative and qualitative data on the Transitions Pathway, but we have not been able to access this data due to the current pandemic situation.

However, and importantly in terms of evaluation of this service from a young person's point of view, this document points out that it was difficult to get young people's feedback on their transition due to the young people having moved onto other services. Without this feedback it is difficult to evaluate the experiences they had.

What is encouraging is that the commissioners support the need to engage and co-produce with young people. They use young people's lived experience to help develop the mental health strategy and provide improved pathways for those up to



25 years. There is hope that this will improve transitions for mental health care for young people, and those who may also have additional needs.

### Autism Strategy Board

The new all age Autism Strategy Board for Cambridgeshire and Peterborough is an example of integrated, co-production work to plan more integrated services.

The Board will enable and support services for autistic people to work together to improve their experiences of health, social care and other important things such as employment and life skills. There are multiple agencies involved in this work and it is planned to be a co-production of work with the aim of easier, more integrated pathways for autistic people.

Our Healthwatch held a focus group in February 2021 to listen to people's experiences and ideas to develop and improve these services. This will feed into the Autism Strategy work.

### Local Services

*The Mental Health and Wellbeing Pre-birth to Age 25 years Needs Assessment November 2019* maps the children and young people's mental health services across Cambridgeshire and Peterborough.

Pages 44 - 51 of the needs-assessment explains how some of the services were developed to improve access and create a more long-term and sustainable population-based approach to mental health care.

Cambridge and Peterborough Foundation Trust (CPFT) delivers the Children and Adolescent Mental Health Services (CAMHS) and Adult Mental Health Services (AMHS) - such as community mental health services and acute mental health inpatient services in Cambridgeshire and Peterborough.

There are three main local areas for Children and Young People Mental Health Services in Peterborough, Huntingdon and Fenland and Cambridge.

Under normal circumstances, all referrals to CAMHs are made via a Single Point of Access within the Cambridgeshire Multi-Agency Safeguarding Hub (MASH) referral unit. Urgent referrals are dealt with within 24/48 hours.

Children's mental health services end at 17 years of age, except for young people with learning disabilities who can access the service until 18 years of age.

Children's inpatient services are up to age 18.

### CPFT Adult Mental Health Services (AMHs) (17/18 to 65 years)

AMHs are also spread across Peterborough, Huntingdon and Fenland and Cambridge. These include the Neighborhood Teams, Locality Teams, Specialist Services, inpatient wards, and urgent care.





Referral is generally via the GP although there are some services that adults may self-refer to, for example IAPT<sup>25</sup> (Improving Access to Psychological Therapy) psychological wellbeing service.

### CPFT CQC ratings

CPFT employs over 4,000 staff across more than 50 sites and ten registered locations. The trust provides 315 inpatient beds across 24 wards, 211 of these are mental health beds and the other beds provide community rehabilitation. 36 beds were for children's mental health. The trust had an overall budget of £225 million in 2019/20. The trust had a surplus of £4.1 million for 2018/19.

CPFT were given a CQC rating of Good<sup>26</sup> in September 2019. However, for specialist community mental health services for children and young people the CQC said the rating of *responsive* went down because times from referral to treatment start exceeded 18 weeks for 24% of patients. However:

- The services referral criteria did not exclude patients who would have benefitted from care.
- Staff assessed and treated patients who required urgent care promptly and patients who did not require urgent care did not wait too long for assessment. Staff followed up patients who missed appointments.
- The service ensured that patients, who would benefit from care from another agency, made a smooth transition. This included ensuring that transitions to adult mental health services took place without any disruption to the patient's care.
- The service met the needs of all patients including those with a protected characteristic. Staff helped patients with communication, advocacy and cultural and spiritual support.
- The service treated concerns and complaints seriously, investigated them and learned lessons from the results, and shared these with all staff.

### The iThrive framework<sup>27</sup>

Cambridgeshire and Peterborough have been an accelerator site for using the iThrive framework, which is an integrated, person-centred and needs-led approach to delivering mental health services for children, young people and their families.

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<sup>25</sup> CPFT (2021) [Psychological Wellbeing Service \(IAPT\)](#)

<sup>26</sup> CQC (2019) [Cambridgeshire and Peterborough NHS Foundation Trust - Good](#)

<sup>27</sup> iThrive (2019) [About the iThrive framework](#)



This is being embedded into the system-wide change. Workforce gaps and funding have continued to be barriers in progressing this change, but this remains the plan and focus.

### Primary Care Mental Health Service (PCMHS)

In 2017, CPFT and Cambridgeshire and Peterborough CCG rolled out the *Primary Care Mental Health Service* (formerly known as *PRISM*) (2018)<sup>28</sup> as this is a core part of the mental health component within the Cambridgeshire and Peterborough STP draft Long Term Plan - reference 23.

This aimed to create a sustainable and long-term mental health service model by focusing on a population-based approach to mental health care with the GP being the responsible clinician for ages 17-65. It was commissioned to fill in the gaps between primary and secondary care within mental health. It also aims to provide a softer transition between secondary care back to the GP. In 2019 the PCMHS were receiving up to 1400 referrals per month.

This draft Cambridgeshire and Peterborough STP Long Term Plan, (ref 23) page 38, section 117, states that the plan is for mental health services to become more embedded in primary care networks, developing and delivering services that reflect the particular health, wellbeing and environmental needs of each neighbourhood, including pharmacy, coaching and peer support.

The document also adds that as a system, we will be moving traditionally secondary care-based services into primary care, focusing secondary care staff on more specialist interventions. It is also contributing to the local STP 'Change Priority 1: at home is best'. This priority emphasises the importance of proactive local care closer to home and helping people to help themselves.

They have secured national early implementation transformational funding to help achieve these aims, and this work will be externally evaluated and used to inform national policy.

The SUN Network provided an experience evaluation for the service in September 2019<sup>29</sup> along with another by York Consulting in Dec 2018<sup>30</sup>. But these reports do not give any insight into how the service has been used by young people from 17 years of age, or how it may have helped any transition from children's to adults'

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<sup>28</sup> CPFT (2021) [Primary Care Mental Health Service](#)

<sup>29</sup> SUN Network (2019) [Primary Care Mental Health Service - Service User Experience Evaluation](#)

<sup>30</sup> York Consulting (2018) [Evaluation of the Primary Care Service for Mental Health \(PRISM\): Stage One](#)



services. Generally, positives seem to outweigh the negatives for this service in these evaluations.

### Emotional Wellbeing Service

The Emotional Wellbeing Service (Jan 2018)<sup>31</sup>, formally the Wellbeing Practitioners' Team, is another key element of service redesign. It covers Cambridgeshire and Peterborough and is hosted by Cambridgeshire Community Services NHS Trust (CCS).

The service was created due to the recognition that there was a gap in provision of service within the “Getting Advice” and “Getting Help” quadrants of the iThrive framework, adopted in Cambridgeshire and Peterborough.

The emotional wellbeing service works alongside schools and those professionals within the community to support their work with children and young people with emotional and mental health issues. This is one of the key priorities of the NHS England Long Term Plan 2019.

The service includes training and advising staff on emotional wellbeing of their students. The service works with primary and secondary schools in the county. It has recently expanded into Fenland and East Cambridgeshire.

### Fullscope<sup>32</sup> Supporting Wellbeing and Connecting Communities

Fullscope is a recently established consortium of seven charities with a shared mission to improve the mental health and well-being of children and young people in Cambridgeshire and Peterborough. It is hosted by Centre 33 and funded via Big Lottery Fund and other grants.

The aim of Fullscope is to work collaboratively to enable communities to raise happier, healthier children who are resilient and empowered in their mental well-being. As a group, the overall size, scope and reach represents a significant sector of the Cambridgeshire and Peterborough mental health system. The consortium builds strength and capacity and facilitates joined up planning and working.

Fullscope have become involved with system changes around the “front door” of the local system. They are presently looking at why young people are turned away from CAMHs and what their pathway prior to this has been. They are also doing another piece of work on looking at referrals to CAMHs which will be interesting to review later this year. This work may well be key to changes that follow within the

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<sup>31</sup> Cambridgeshire Community Services NHS Trust (2021) [Emotional health and wellbeing services](#)

<sup>32</sup> Centre 33 (2021) [Fullscope - supporting wellbeing and connecting communities](#)



local mental health system; they believe helping young people and families navigate the system is key.

It is thought they will be key in helping to integrate local mental health services up to the age of 25. There are conversations around more local projects to help with integration and supporting young people's wellbeing. In bringing organisations together, they can respond collectively in providing mental health services, influencing local policy and approaching funders.

### Keep Your Head

The Keep Your Head website (see reference 18) was commissioned as a one-stop place for mental health information (publicly funded, charity and voluntary orgs) firstly for children and young people (CYP), then for adults and health professionals.

### How Are You Peterborough<sup>33</sup>

H.A.Y (How Are You?) Peterborough is part of the Peterborough Mental Health Exemplar project which aims to join up services. Peterborough Mental Health Exemplar is a partnership project between CPFT, Greater Peterborough Network, Peterborough City Council, CPSL Mind and the SUN Network.

It is one of 12 national NHS England community mental health pilot sites that are using innovative approaches to transform community mental health services to provide "joined up" physical, mental health and social care support that is easy to access and meets the individual needs close to where they live.

SUN Network is undertaking engagement around this project over the next six months to evaluate how well the changes are working. It will see if it has improved communication between services.<sup>34</sup>

### Public information on transitions in services

We tried to find patient focused information on transitioning from children's to adults' mental health services through internet based research, e.g. a Google search using the words "moving to adult mental health services Cambridgeshire" and searching providers' and commissioners' websites.

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<sup>33</sup> H.A.Y. Peterborough (2021) [How Are You Peterborough - about](#)

<sup>34</sup> SUN Network (2021) [Peterborough Exemplar - Help design the assessment of mental health services](#)



There is useful information on the local offer on Cambridgeshire County Council website for supporting young people aged 14-25<sup>35</sup>. This has some information on what young people could expect at the time of this transitional period. Similar information was available on the Peterborough City Council website<sup>36</sup>.

The Peterborough website includes information co-produced with Peterborough based parent carer charity Family Voice for parents of young people with special educational needs.

In Cambridgeshire, local charity Pinpoint<sup>37</sup> also provides information to support transitions for young autistic people and those with learning disabilities.

Both Family Voice and Pinpoint offer useful support for parents supporting young people through transitions.

CPFT, the main provider of CAMHs and AMHs has just updated its website and it was hard to find information on moving to adult services. However, an online search found a pre-pandemic YouTube<sup>38</sup> video made by CPFT regarding what it might be like to come to adult mental health services - and is introduced by a young person. This is a great idea and a very useful way of introducing which staff one might meet. It would be good to do another one when there are changes to services.

This same video can be found on an information page for the East of England Collaboration in Leadership for Applied Health Research and Care (NIHR) 2018<sup>39</sup>. And was a result of an important piece of collaborative work in 2016 that CPFT did with two other trusts from Norfolk and Suffolk Trust, and Hertfordshire Trust.

Young people worked with NHS practitioners and researchers to look at what was needed to help make a good transition from children's to adult's mental health services.

Other good outcomes that came of this include:

- plans to use a transitions booklet<sup>40</sup> (an idea of this can be seen in this link to presentation slides (slide 34) done by CPFT and NIHR CLARHRC, East of

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<sup>35</sup> Cambridgeshire County Council (2021) [Local offer - preparing for adulthood](#)

<sup>36</sup> Peterborough City Council (2021) [Local offer - preparing for adulthood](#)

<sup>37</sup> Pinpoint (2021) [Transition to adult care](#)

<sup>38</sup> CPFT (2017) <https://www.youtube.com/watch?v=FFOTSN29hfU>

<sup>39</sup> NIHR (2017) [Transition from Child and Adolescent Mental Health Services](#)

<sup>40</sup> Cambridgeshire and Peterborough CCG (2017) [Working with young people in transition](#)



England Research, about this piece of co-produced work between practitioners and young people). This booklet was part of the transitions CQUIN in CPFT which is explained earlier in information on the transition pathway (page 14)

- interface meetings between children’s and adult’s services; and,
- the introduction of three peer support workers and two Band 6 transitions workers.

*The Keep Your Head website* came up in internet searches about transitions. This was developed locally as a one stop website to go to for mental health information, firstly for young people, then also for adults and professionals. However, no information on transitioning from children’s to adults could be found on this website. The words “transitions”, “moving to adults’ services”, “CPFT transitions booklet” and “leaving CAMH” were used in the search engine text box. There was nothing under the “resources” or “leaflets” tab.

Recent feedback seems to show that although this website is available, many people do not know it is there. However, it has been well used by professionals.

## What does the evidence tell us about the experiences of this Profile?

### Mental health survey

As part of the work around the upcoming re-commissioning of the youth mental health services in 2021, the CCG ran a survey to ask young people their views on access to youth mental health services.

This generated feedback about the frustrations of waiting times regarding service transitions in general.

CCG Commissioning Support Manager - Children and Young People’s (CYP) Mental Health, has shared some of the feedback with us here -

1. Many CYP quoted long waiting times into services and moving between services - *“by the time I had help, I’d forgotten I’d been referred and had sought help through other channels.”*
2. Some CYP said they would find it helpful to have more information when they are waiting/transitioning in between services - *“I needed help asap, but it would have been good to have information for the meantime” and “communication so you are not wondering what is going on [when in between services]”.*



3. One young person provided a quote below which illustrates the frustrations of being passed between different services - no smooth or seamless transition service to service.

They said *“It would be easier if you weren't passed from different people. GPs recommend ringing certain people and then when you ring them, they advise ringing GP. Nobody seems to know the right pathway or avenue, so you get passed allover.”*

4. One young person highlighted that being made to wait in between services created a feeling of not feeling safe.

They said, *“I did not feel safe and they did not take that into account whilst making me wait for services and support.”*

5. The issue of having to repeat your story was also quoted as a frustration relating to transitioning in between services. One person said, *“[It would be good not] having to repeat my story.”*

6. And finally, a young person told the CCG it would be helpful if we *“stopped restructuring and rebranding the services!”*

### Mental health summit

We have noted further engagement being done with young people recently (January 2021). The CCG attended a virtual mental health summit in Peterborough. Here several local schools came together with the CCG attending<sup>41</sup>.

In this article in the local Peterborough Telegraph newspaper, it quotes lengthy discussion highlighted flaws in the current system and the heavy toll Covid has taken on pupils, but it also prompted optimism after promises to work together to improve services going forward.

The CCG expressed the need to improve youth mental health services including the transition from children's to adults' mental health services.

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*“How we support young people as they transition into adult services is also really important.”*

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<sup>41</sup> Peterborough Today (2021) [Action promised after Peterborough pupils lay bare mental health struggles](#)



## - Cambridgeshire and Peterborough CCG

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It is promising that the CCG is attending an event like this and listening to young people. Despite some investment in services over the last few years, it is not good to learn that young people are still reporting not knowing where to find help unless they are at crisis point, that there remain long waiting lists for assessments, and there are worries about how the pandemic will increase the need for support for young people.

Unless solutions are found, there will continue to be young people without the support they need. This will need attention alongside working on improving transitions in care. The CCG have suggested a working group of young people going forward to help improve these services locally.

### Recent Feedback from young people and organisations

Since starting this piece of work with Healthwatch England, some young people and some local organisations (more details on following pages) have given us some feedback around the transition period.

We learned:

- Young people can be discharged from CAMHs when they feel they still haven't had the support they have needed. They then may or may not meet the criteria for adult's mental health services and if so, would have to wait some time for this, leaving a gap in support with no other offer and a repetition of their journey.
- Young people with added challenges, e.g. LGBTQ+, can be bounced back and forth to the First Response Teams instead of being in longer-term supported mental health care.
- The timing of referrals into youth mental health services around the age of 17 is difficult for GPs who cannot be sure whether they should refer to the children's or adult's part of the services. This is complicated further by long waiting times which may mean when an assessment for CAMHs finally happens, it is time for the adult's service to take over and the young person may not then meet that criteria which can be different for each service. All of this adds to long waits without sufficient support. Young people's mental health can deteriorate significantly during this waiting time.

Feedback from autistic people and people with learning disabilities:





- Transition into adult’s mental health services without any prior planning about what to expect can be very difficult for an autistic person as any change can be difficult to manage.
- Autistic people can go years without the support they need. They may wait a very long time for an assessment for suspected autism.
- Feedback from someone with high functioning Autism and mental health difficulties felt that the services do not cater for their needs and that there is a lack of understanding around Autism amongst healthcare staff.
- Parents/carers of young people with severe learning difficulties have told us it is very difficult to get support when transitioning into adult mental health services.

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“Very difficult to get mental health support for a young person with learning difficulties transitioning from children’s to adult services.

She needs the techniques that would be used for a child, yet she is legally an adult at 18. Children’s services (CHUMS) won’t support as 18, adult services via NGOs Mind etc won’t support because she wouldn’t be able to access the talking therapies available (understanding roughly that of a 5 or 6 year-old), social workers don’t seem to know of anything available and as mum I’m left (alone) bearing the brunt of my daughter’s frustrations and anger.

Also needs better join up between social service and NHS to provide a more streamlined service. School has helped as best they can but need professional psychological assessment and input.”

**- Parent carer feedback shared with Healthwatch in February 2021**

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### Eating disorder services

Eating Disorder Services are a current focus in the Cambridgeshire and Peterborough Local Transformation Plan for Children and Young People’s Mental Health and Emotional Wellbeing 2019 - see reference 12. These have received additional funding recently and have expanded to try to address the increase in demand and fill any gaps in care provision.



Sadly, in Cambridgeshire and Peterborough, there were five deaths within the Eating Disorder Service between 2012 and 2018.<sup>42</sup> Although these are historical, they add to the local sense that the focus on Eating Disorder services is important.

In February 2020, the Clinical Design Group for the Adult Eating Disorders strand of the New Care Models (NCM) programme in the East of England carried out an online questionnaire to gather the views of carers of young people going through transitions and received 47 responses - please see [Appendix A](#) for full details. Some participants left free text comments about their experience of transitions - most of the comments were negative, such as:

- Nothing, all too little, too late
- No real transition took place as she moved from CAMHS
- No aspect of transition went well

Some were positive, hinting at what 'good' transition looks like, e.g.

- Was warned in advance, given tips to cope
- The services were very linked with the same manager taking responsibility

In addition, a Lead Governor in CPFT gave us some feedback from the work - see [Appendix A](#). They reported that people shared mixed experiences and inconsistencies around transitions, most of which was around transition to university, but some covered CAMHS. It was concluded that too few have a good transition, saying more joint funding is needed to join services, clear protocols are needed, and a transition worker is key.

### Face to face video conferences

A Transformation Manager in CPFT also shared the themes with Healthwatch from the face-to-face video consultation undertaken with families and young people around Eating Disorders in 2020.

Several recommendations were made around:

- better communications between services,
- engaging carers in transitions,
- supporting carers,
- streamlining processes to University and providing support in the interim - transition key workers needed as a point of contact
- consistency of home care support team
- shorter waiting times for services to prevent a relapse.

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<sup>42</sup> BBC (2020) [Anorexia: How the eating disorder took the lives of five women - BBC News](#)



As regards work going forward, there are productive discussions with the CAMHs Eating Disorder NCM sub-group to develop a joint transitions position statement. The statement will include actions to be further developed as part of the Eating Disorder CAMHs and Adult models.

### Feedback from local organisations

Three local organisations - The Kite Trust, Centre 33 and Rethink, who all work with young people and / or parents and carers, have given an overview on how the transition period can affect young people.

**Centre 33**<sup>43</sup> are a long-standing youth mental health charity in Cambridgeshire and Peterborough and are part of the Fullscope consortium. Centre 33 are seeing huge numbers of young people in need of signposting and support from several different agencies.

As Centre 33 is seen as a specialist organisation in helping the 13 - 25 age group, they are referred to from all types of professionals such as Children and Adolescent Services (CAMHs), Adult Mental Health Services (AMHs), A&E, First Response Team (FRS), GPs, schools and self-referrals from young people.

The voluntary sector has a key role to play in the provision of early intervention community-based mental health services for this age group.

There is a strong case to be made for improved funding for a more specialist integrated young person-focused service alongside counselling for an age group with such complex needs, supporting them in a more holistic way over longer periods of time.

**The Kite Trust**<sup>44</sup> support LGBTQ+ young people, and work with many young people who have accessed mental health services. They find these young people have numerous difficulties in both accessing and being understood by mental health services.

Many young people have said in the past that they do not meet the threshold for adult services, so they either fall off the radar and spiral when they turn 17, or they get so nervous that they won't meet the threshold that that in itself sparks enough anxiety to trigger a bad mental health episode that does meet threshold.

Please see [Appendix B](#) for further difficulties that the Kite Trust have told us young people experience with mental health services.

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<sup>43</sup> Centre 33 (2021) [Centre 33 - Supporting young people up to the age of 25](#)

<sup>44</sup> The Kite Trust (2021) [The Kite Trust - for young people](#)



Rethink<sup>45</sup> run a local support group for parents/carers who care for people with mental health difficulties. Rethink told us about the difficulties around the transition period between services and the potential confidentiality problems for parents/carers at this time.

A young person may be involved with several such agencies with special skills in working with young people. They will often have different policies about the age range they deal with and how rigidly they stick to this. The challenge is to work with the young person to negotiate transitions between one set of services and another so that as far as possible that person's needs continue to be met. (Please see Appendix B for further details).

## Conclusion

A more integrated way of working between children's and adult's services is needed locally which is recognised by our local system. Despite Covid-19, we can see positive evidence of the progression of work and plans for integration of services at STP level which is very positive.

The CCG have engaged with young people recently and we have advised this should happen on a regular, ongoing basis, so that new pathways are evaluated by the young people using these services.

There is a CPFT Transitions Protocol, but this is from 2015 and does not appear to have been refreshed since then.

Developing the Transitions Pathway appears to have helped some young people, but it is important to gain a regular perspective from people who use the Transitions Pathway service - which is not currently happening.

The new Autism Strategy is also encouraging with plans for a better more specialist service underway. Autistic people and people with Asperger's who have used services or who have tried to find services will feed into this piece of work from our Healthwatch's focus group and from other organisations who support them. We will keep integration of services in mind.

We are told that this integrated, person-centred, needs-led (under the i-Thrive framework), local-based work planning will be a main focus on the services locally going forward based on the plans set out in the NHS Long Term Plan and The Five Year Forward View. It appears our local system is also working towards meeting the 2016 NICE guidance on transition from children's to adults' services for young people, but according to people's feedback, there is more work to be done.

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<sup>45</sup> Rethink (2021) [Rethink Carer Support: Cambridgeshire and Peterborough](#)



The Fullscope Consortium have begun an important piece of work around the Single Point of Access “front door” to try to enable better and easier access to mental health services for young people. Their work on CAMHS referrals will be reviewed later this year which may be key in system changes going forward.

It should be highlighted that from the feedback we have had, the problems do not lie solely with transitions within the system at this age (16/17) but also when a young person needs to enter the system at the crucial cross-over time from CAMHS to AMHs. Health professionals who need to refer into the youth mental health system can find it hard to know which service to refer to. This often can be a very difficult and lengthy process for young people who are unwell, with some people deteriorating in the meantime.

It is clear that this is not only about ensuring smoother transitions for young people, but it is about improving the system and the access to it overall.

Integration of services is really important. Removing the crossover from CAMHS to AMHs at 17 would be helpful, so that people are not stuck in an endless cycle of assessments and waiting lists with gaps of no support when unwell. Having other options and some navigation for young people when not meeting the criteria for CAMHS and AMHs and making the most of the excellent voluntary sector that is already doing great work with young people is crucial.

Prevention and early help are key here too, which is partly what the Emotional Health and Wellbeing Service (EHWS) are working with schools to do. Ensuring that staff in schools are trained in mental health and feel confident to help young people when they seek support.

Educating young people and continuing to break down the stigma around mental health still needs more work.

Ensuring funding for a robust healthcare workforce is also crucial. Enabling dual staff training in both physical and mental health and working hard to support and retain staff is a must. (the Emotional Health and Wellbeing Service (EHWS) is helping with this)

However, many challenges face our local system as they do nationally, making the change from silo working to an integrated one challenging. This includes many local deprived areas, funding shortages, workforce gaps, and now the Covid-19 pandemic and system-wide economic effects to consider.

We are now in the third lockdown and the pressure on our system from Covid-19 is very high. Staff are once again being redeployed across services to deal with the current crisis and now the Covid-19 vaccination roll out.

The fallout from this pandemic is yet unknown. This will undoubtedly affect work progress and may change the needs of the population going forward.



We will be engaging with young people and parents/carers further about their experiences of transitions from children's to adult's mental health services to see how they compare with the recommendations made by the NICE guidance (2016) the national NHS Long Term Plan 2019 and the CPFT Transitions protocol sent to us from service leaders.



## Appendices

### Appendix A

**Clinical Design Group for Eating Disorders** (strand of the New Care Model (NCM) Programme, CPFT) in the East of England carried out some engagement work with an online questionnaire survey in February 2020. A total of 47 responses were received from Carers across the Eastern Region.

Question three was about transitions: ‘If your loved one has experienced transitions, e.g., between services (community teams / inpatients) or clinicians, or between places, e.g. home / university overall how well do you think they went?’ The average score was the lowest for any of the questions asked, at 2.2 out 5.

The free text option was used by most of the participants and some of the comments related specifically to the CAMHS to Adults transition. Most of the comments were negative, e.g.

- Nothing, all too little, too late
- No real transition took place as she moved from CAMHS
- No aspect of transition went well

Some were positive, hinting at what ‘good’ transition looks like, e.g.

- Was warned in advance, given tips to cope
- The services were very linked with the same manager taking responsibility
- No gap between the two services

Transitions was discussed at the CPFT online carers support group on 10th November 2020. Most of the discussion was about the transition from home to university but parents/carers whose loved ones had experienced transition from CAMHS to Adults fed back comments very similar to those in the questionnaire ranging from ‘It was a mess’ to ‘The staff were incredible’.

A lead Governor at CPFT concluded that *“there is unacceptable inconsistency with too few young people and families having a good experience. Transition can and does work and there is no mystery about what good transition should look like - the NICE guidance on Transition from Children’s to Adult Services is clear and unambiguous. Locally, I think we should explore any barriers to successful transition with the professionals and endeavor to problem-solve these. My pessimism is that there is a ‘cliff edge’ in funding between CAMHS and Adults (the words of a very senior NHS manager, not mine) ‘it’s no wonder there is a problem’. My optimism is that I see an acceptance that funding has to be increased and that there is a lot that can be achieved through establishing clear*



*protocols. For me, a ‘named worker’ to manage the transition and stay in contact with the young person and their family is vital.”*

### Transitions

The CFPT Transformation Manager shared the face-to-face feedback from the online video engagement in 2020 around eating disorders.

WHO: Children and adult services

WHAT: Improve transitions between CAMHS and Adults and between services in different parts of the country, e.g. home to university, re-locating

#### HOW/SUGGESTIONS

- Increased communication between CAMHS and adult services to ensure smooth transition.
- Engage carers in transition from CAMHS to adult services for continuous support for the patient.
- Streamlined process/discussion of transition to University and support provision in the interim.
- Support/training for carers during transition.
- Transitions Key Worker / Peer Support roles to be vital in supporting those transferring to another service or location
- Consistency of the home support team/NCM (New Care Model) will hopefully address this
- Patient and carer highlighted the benefits of shorter waiting times to avoid relapse

#### Progress so far

Productive discussions with the CAMHS ED NCM sub-group to develop a joint transitions position statement. The statement will include actions to be further developed as part of the ED CAMHS and Adult models.





## Appendix B

### Feedback from local organisations

Despite some changes to the system in recent years, we are still hearing that young people are experiencing problems accessing services and during transitions to adult services.

We know this because we asked some of the organisations in Cambridgeshire and Peterborough who work with young people who need mental health support, to give us their views on the transitions from children's to adults' mental health services.

The Kite Trust (LGBTQ+), Centre 33 (Counselling Services), CPFT (CPFT/CCG Eating Disorders), Rethink (Carers of people with mental health difficulties), YMCA. They told us the following -

#### **Rethink - November 2020**

Children and Young People with Mental Health Conditions - Transition to Adult Mental Health Services - Integration

#### **Background**

The prevalence of mental health issues for children and young people has increased dramatically in the past ten years or so. It is also well known that the peak years for onset of a severe mental health condition are ages 15 to 25.

Services have always struggled to a greater or lesser degree to arrange smooth transfers of care to adult mental health services for those who need them. In the 1990s in Cambridge the NHS Trust provided a Young People's Psychiatric Service (YPPS), which was closed when cuts had to be made.

In recent years there has been a lot of interest in new ways of working in this area. The NHS Long Term Plan recommends the development of 0-25 mental health services and there has been good research into attempts to develop these. In Birmingham changes were made but not generally sustained whereas in Norfolk such a service was successfully set up.

The CCG and CPFT have recognized this transition as problematic for many young people for several years. CPFT introduced new posts - "transition workers" - but there were only 2 (I think) for the whole area. One of the post holders has told me she has made little impact, and that whilst transfers are meant to always take place at a pace that suits the individual patient, with transfer meetings taking place, these things often don't happen.

Thus, many of the challenges are simply within CPFT. But many other agencies may have been involved with the young person and this is where **well integrated services** are so important.



For children and young people, Education has its own routes to assessment and treatment and its own responsibilities and sources of support alongside the NHS. Young people will often be involved with further education, and/or university, and may be getting to grips with the benefits system, with agencies that provide support into employment and housing agencies that specialise in accommodating people. They may also come across criminal justice services with specialist youth offending teams.

### **Carer Experience**

Rethink Carer Support works primarily with the families of adults with mental health conditions so my knowledge of the family experience around young people is limited. However, partly directly and partly through Pinpoint and Family Voice I have noticed the following:

- Many young people are simply discharged back to the care of their GPs when mental health services are no longer needed; this may be a positive step but may be couched in terms of “you won’t meet the criteria” for adult mental health services.
- This is sometimes described by young people and their families as “falling off a cliff”.
- As well as mental health treatment, these young people will often have a range of related needs -further education, help into employment, help into housing, financial difficulties, specialist support e.g.sexuality etc. One young person may be involved with several such agencies with special skills in working with young people. They will often have different policies about the age range they deal with and how rigidly they stick to this. The challenge is to work with the young person to negotiate transitions between one set of services and another so that as far as possible that person’s needs continue to be met.
- Capacity and confidentiality rules are very complicated between a young person and their parents as they go through stages of adolescence into adulthood. At worst from a parent’s point of view it can feel like going overnight from being fully involved in decisions about your loved one’s care to being totally excluded.

### **The Kite Trust**

For the young people we work with and who engage with mental health services, there’s a significant proportion who are trans or questioning their gender, and who also have a diagnosis of autism or another neurodiversity. The intersection of these identities can make transitions particularly difficult without additional support - e.g., having to explain their gender all over again to a new service and risk of being misgendered when working with new teams, and having to navigate new spaces and processes without support in adult services.



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 - so often referred for a long unsupported wait for the Gender Identity Clinic rather than supported through local mental health services during that time of transition.

Sometimes CAHMS even tells the young person to come to us instead - due to local misinterpretation of what our services provide.

Many have said in the past that they don't meet the threshold for adult services, so they either fall off the radar and spiral when they turn 17, or they get so nervous that they won't meet the threshold that that in itself sparks enough anxiety to trigger a bad mental health episode that does meet threshold.

Many report no follow up care after self-harm related visits to A&E as it doesn't seem to trigger a route into adult mental health services.

Many have experienced their GPs only chasing referrals when patients ask them to, never proactively, which places a demand on young adults to stay on top of their own care pathway when they're experiencing poor mental health.

We generally find there is poor FRS knowledge/understanding of LGBTQ+ young people's needs and a lack of connection between those who enter crisis at 17/18 being directed into longer term support from those crisis services.

Many have voiced support for a 16-30s mental health service and those who use inpatient services say 18 year-olds in mental health units with 60-70 year olds is not ideal.

Many feel stuck in an endless cycle of assessments and waiting lists when moved between services.

We tend to see our young people bounced around and back and forth to crisis services and the first response team, as opposed to long term engagement with CAMHS and then adult services. From our experience, CAMHS seems very reluctant to even diagnose, and therefore the young people don't have a chance of meeting the adult threshold. Young people have explained that by the time they reach 17, they were so exhausted by the process that they are just relieved to leave.

#### YMCA<sup>46</sup>

Trinity House Manager, Cambridge, told us that many resident young people they work with have had huge problems with transition to adult services.

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<sup>46</sup> YMCA (2021) [YMCA - family support](#)



## Centre 33<sup>47</sup>

Charity organisation supporting young people up to the age of 25 with mental health, caring responsibilities, housing, sexual health etc.

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<sup>47</sup> Centre 33 (2021) <https://centre33.org.uk/>

