

Young People's Views of the Transition to Adult Mental Health Services

November 2021





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Summary and key findings

Northamptonshire Clinical Commissioning Group have already found that children and young people who require transition to adult services have experienced persistent difficulties in receiving care that is continuous, efficient, clear and supportive. Instead, many young people and staff have highlighted that transitional care becomes disjointed, confusing, or disappears altogether during this period. Addressing these pathway gaps and challenges is now a priority for the Northamptonshire system.

In this project we sought to hear from a group of children and young people to discover their thoughts, views and experiences of the transition between CYP mental health services (Child and Adolescent Mental Health Services - CAMHS), to adult mental health services - how it felt, how it worked or didn't work, and how it could be improved. We also sought the thoughts, views and experiences of those leaving care about the preparation, the process, the aftercare, and how their experiences continue to affect them today.

Transition from CYP mental health services to adult mental health services

- The young people all struggled with the transition from CAMHS to adult mental health service, with some experiencing a decline in their mental health and physical health, exacerbated by the stress of the process. They felt abandoned, unsettled, and confused and found the process stressful.

“I felt like I was thrown to the side as I was 18.”

- Most found that the written information they were given was overwhelming and too much for them to take in while they were experiencing a crisis.
- The young people did not feel listened too and would have preferred to have more discussions about their care and more options.

“I didn't feel like I had a choice in my care when I moved from child service to adult services.”

- All would have preferred more face-to-face meetings to explain the process and available services to them. Being able to have more time to discuss what was happening would have helped them process the changes and develop important relationships with the new services.

“I thought it would be a gradual move and that I would get to know people well before the actual move but that didn't happen.”

- We were told of examples of poor communication between children's and adult service, and it was felt that there should be a better handover and that services should work together more closely.

“The communication between the service I was using and the service I was going to was non-existent, it just wasn't working.”

- Having more options for where to go in a crisis would have been beneficial.



- Some of the young people had found particular services helpful, including the information hub, crisis cafes and sessions run by Mind - although they may not have had to use them if there had been a better transition to adult community services, resulting in them not reaching a point of crisis.
- Four of the young people had accessed private therapy, and all found it more beneficial. The therapists had more time for them, and they could build relationships without being limited by the number of sessions.

“When you go to private therapy you are paying for each session and there is not a limit, so you’re not scared that if you open up, they are going to just leave. You’re knowing that at your next session you can carry on working through what you’re going through.”

Care Leavers' Mental and Physical Health Support

- The young people we spoke to had not yet left care but were all over the age of 16.
- Two of the young people felt they had control of their own health, but one would have liked more control. Two told us how their personal assistants or social workers helped them manage their health.
- The young people had some understanding of how to access general physical and mental health services and support, although had limited experience of doing so and did not have detailed knowledge of local services, such as mental health support. This implies that more could be done to explain the range of services available to them if they need them once they leave care.



Recommendations

Transition from CYP mental health services to adult mental health services

1. As well preparing young people early for transition to adult mental health service, there should be more contact with them during this time to enable them to process the changes and be able to voice any concerns.
2. Young people should be listened to and given a choice in the care they will receive as an adult. All the options should be explained to them face-to-face and any written material should be written in a way that is easy to understand. Young people could co-produce a 'transition pack' with mental health professionals.
3. Relationships with individuals within services are important to people and, where possible, they would benefit from the chance to have a main contact they can get to know in adult services. The process of building these new relationships should begin before transition.
4. Children's and adult services should communicate better with each other and ensure that there is a proper handover of paperwork and knowledge so the understanding gained about young people and information shared by them is not lost.
5. Young people would value having drop-in wellbeing hubs and greater use of online support. More options for where they could go in a crisis would be beneficial, similar to the wellbeing cafes.
6. Private therapy worked well for young people and aspects of this could be incorporated into adult mental health services, such as having a choice in who they see for therapy (and being able to change therapist if they want to), having remote access to counsellors, and being able to choose when they see a therapist and for how long, so the help is there when they need it and does not come to an end before they are ready.
7. Further research could be undertaken with a broader group of participants to explore the experiences and needs of a more diverse group of young people. It was easier to recruit young women to talk about their experiences of mental health services so the needs of young men should be explored, including whether they are accessing mental health services in the first place.

Care Leavers' Mental and Physical Health Support

1. Spend more time explaining to young people in care the range of services available to them if they need them once they leave care.
2. Support young people to access services themselves before they leave care so they have experience of doing this while they can still be helped.
3. Undertake further research with those who have left care to understand what would have helped them.



Background

Northamptonshire Clinical Commissioning Group have found that children and young people who require transition to adult services have experienced persistent difficulties in receiving care that is continuous, efficient, clear, and supportive. Instead, many young people and staff highlight that transitional care becomes disjointed, confusing, or disappears altogether during this period.

There are significant differences in how care is approached and delivered between Children and Young People (CYP) and Adult mental health and social care teams. At times, this creates a cliff-edge in the transition process, where care severely and rapidly reduces. Techniques and resources to support CYP service users are markedly different in adult services. At times, this creates a culture-shock for young people during and after transition, which can increase anxiety, compound mental health presentation, and bring about new care needs.

Young people leaving Care are a particularly vulnerable group - both due to being at increased risk of mental health issues during childhood, and due to being at increased risk of social disadvantage, isolation, exploitation, and long-term mental/physical health conditions. Young people in this position have poignantly commented, "We don't leave care. Care leaves us" - which leads to disproportionately frequent use of urgent/emergency departments, compared to non-care leavers.

There are several care teams, processes, and resources designed to manage the transition pathway and meet the needs of young people. However, there is insufficient awareness across the system regarding the specifications of these services, referral criteria, or contact details. There is also a need for a consolidated 'road-map' of all health and care transition resources for young people, to support a thorough gap analysis and inform new pathway design.

Addressing these pathway gaps and challenges is now a priority for the Northamptonshire system. The Northamptonshire Children and Young People's Summit (November 2020) pledged that the 'voice' of children and young people will inform how change is made at every step of the transformation journey.



Method

What we did and who we spoke to

- By working with local contacts including Northamptonshire Young Carers¹, Northampton and Kettering General Hospitals, respectively, Pause Northamptonshire², WI support Limited³ and reaching out to people on social media we recruited six young people with experience of the transition from CYP mental health services to adult mental health services. By chance, all five
- Six people identified as female and were from the North Northamptonshire Council area. The views of five of these six people were gathered at a focus group held in an accessible venue (The Community Courtyard⁴) in Northampton in July 2021. The other person shared their views via an interview through PAUSE Northamptonshire.
- The questions were developed in conjunction with Northamptonshire Clinical Commissioning Group (CCG) to ensure the feedback gathered would address their questions.
- Three people were also interviewed by video and this feedback was used to develop internal training material to be used by the CCG and NHS. Their feedback will also help to improve service delivery in Northamptonshire.
- We recruited four young people from a residential children's home and held a focus group with them in May 2021 looking at their experiences of transition into adults' health care services. All members of this group identified as male and were over the age of 16.
- We contacted local community organisations and shared the questions that we delivered at the focus groups. This was in the hope that they would get back to us with young people's (services users) opinions/experiences. However, due to Covid-19 restrictions we were unable to engage with young people. Virtual engagement was considered but unable to be completed due to the nature of online security for young people in care.

Limitations

- The focus groups were conducted during the coronavirus pandemic when people were still cautious or restricted to meet in person.
- The focus groups were set up during the summer once restrictions were eased. However, it was still difficult to engage with young people as we were unable to use the 'normal' engagement methods, this would have been face to face focus groups and interviews where we would attend schools, six forms and colleges, as we found this is the best way to engage with young people when attend their place of education or their accommodation.
- Both points above made it difficult to recruit participants.
- The care leavers were all over the age of 16 but had not yet left care so could not comment on their experiences of the complete transition process.

¹ <https://www.northamptonshire-carers.org/young-carers?locale=en>

² <https://www.pause.org.uk/what-we-do/>

³ <https://www.facebook.com/WiSupportLTD/>

⁴ <https://communitycourtyard.org/>



- Some young people were attending school from home and engaging in lessons virtually, so they were more reluctant to attend another online event.
- Schools did not want to add pressure to students in committing to engagement when education was the priority and students were encouraged to focus on work that had been delayed due to Covid.
- Young people were attending education face to face and then virtually, due to 'bubbles' and isolating due to other students contracting Covid-19. This inconsistency made it more difficult for both parties to engage.
- Once schools, six forms or colleges had returned, Covid restrictions did not allow visitors to attend.

Data analysis

- The focus group comments and interview feedback were reviewed to identify the main themes, including the key risks to effective transition and recommendations for how to improve the processes involved.
- The interviews were developed into documentary films that will be shared with local NHS staff to help inform their work. Comments from the films have been added to the feedback presented in this report. Each training film was entitled:

- Overall experiences
- Was there enough time?
- How did you manage the move?
- Did you know where to go or who to contact?
- Initial experiences of using adult mental health services
- What would you do if you were in charge?
- Why is private therapy more helpful?



What young people told us

Transition from CYP mental health services to adult mental health services

We asked young people at a focus group and one interview to share their thoughts, views and experiences of the transition between CYP mental health services, to adult mental health services - how it felt, how it worked or didn't work, and how it could be improved.

How it felt to move between CAMHS and adult mental health services

Impact on the young people

How did the move between CAMHS to adult mental health services feel for you?

Most young people said that this transition felt **rushed** and although they knew it was going to happen, they felt that it wasn't talked about enough beforehand consequently making them feel **unsettled**. Most of the group explained the feeling of being 'left to fend for yourself' once they were 18 and the expectation of being independent because they were now adults. Some young people expressed that this feeling automatically led to the presumption that adult service would be **worse**.

One young person was happy with the relationships they had made with staff at CAMHS and felt that they would lose this when transitioning to adult services.

"They expect you to be independent because you are 18, but I knew that wasn't going to work for me."

"Unsettling."

"You are left to fend for yourself."

"I felt like I was thrown to the side as I was 18."

"Acceptance of how rubbish it is."

"I knew it wasn't going to work for me."

"It felt rushed, even though I knew that it was going to happen. But people didn't really speak about it before. I had been with CAMHS since I was 11 so I made good relationships with staff and people there and didn't want to lose that when I went to adults."

"If I were to describe my transition period in one word, it would be 'confusing'."

"I've lost faith in the service because of how they've done the transition, I think it caused me more trauma than good."

"I honestly don't think I can say that anything worked well during my move to adult mental health services."

How do you feel your experiences of the move to adult mental health services affected you or continue to affect you?

The difficulties the young people experienced with the transition process led them to feel further **stress** or **rejection**.



“At the time I was really unstable, it made me unwell because I was acting out and didn't want to lose more people as I had lost so many people in my life and this just felt like further rejection so I started self-harming again.”

“It had to get to the point where I was admitted to St Mary's before I was offered help. I didn't meet the criteria before that.”

“I have seizures which I believe are brought on by the transitions process.”

“It made me reluctant to seek help, I felt deflated.”

How did you manage the move to adult mental health services yourself?

Managing the transition process themselves was a **struggle**, especially to navigate through unknown services when they were in crisis, resulting in some experiencing worse mental and physical health.

“I don't know that I did anything as I became unwell at that time as it was at the same time as an anniversary. It took me a while to settle but then it did make me grow up quite a lot.”

“I didn't manage.”

“I went to the GP and they offered me CBT. When the CBT stopped there was a steady decline. I didn't know where to go. A family member called 111 and I was advised to go to A&E or a crisis café. I attended a crisis café and had to pay £20 for a session with Mind. It is the only service I like and that has worked.”

“I think I just Googled 'what support is available for adults with mental health in Northamptonshire' and it led me to the NHFT website which then had links to crisis cafes and crisis houses and the timetable. The website itself is very wordy and I was in a crisis point and desperately looking for somewhere and there was all this long text I couldn't read, so I had to get my mum to help me. In the end we did find [help] and went to Corby and then Kettering and then Rushden.”

“Things got really bad in terms of my mental health and I was going to crisis cafes and crisis house. From there I saw the crisis team and they ended up referring me to adults' services, but because I had no communications from them wither, things just spiralled again and I ended up being admitted to an in-patient unit.”

“I honestly didn't, I deteriorated quite badly. I lost myself, I was in and out of hospital and then my physical health went down because my mental health went down.”

Involvement of the young people

Did you feel listened to during the move to adult mental health services?

The young people **did not feel listened to** or valued and had concerns about the ways their parents were involved, such as talking to the parents instead or breaking confidentiality.

“I felt like I was in a bin bag, just rubbish they were throwing out.”

“There was a lack of confidentiality when letters were sent home that had detailed what we had discussed.”

“When parents attended I felt they were talking to my parents and not me.”

“Sometimes assumptions are made (about sexuality, gender and the reason that we are there).”



“No not at the time, even though I knew it was going to happen I didn't feel prepared.”

“It varies from different services whether I feel like I'm listened to or not, because I'm under two different services. I'm under the eating disorder service in adult services and they're generally really helpful and they ask me how I'm feeling and what I want from my care. I haven't seen anyone else from adult mental services apart from when I was an in-patient. During my time there I felt that I was not listened to at all and they were trying to throw diagnoses at me and I wasn't get any therapy while I was there, I wasn't getting any support outside, I wasn't getting any support form the community, so I was just left there with nothing.”

Did you feel you had a choice in your care as you moved to adult mental health services?

The young people did **not** feel like they had **much choice** in the decisions about their care and treatment.

“I wasn't given many options with things, but there were a few people who had time to listen to me. It's the consultants though that have all the power with changing your meds, etc. and these are the people that know me the least.”

“I didn't feel like I had a choice in my care when I moved from child service to adult services.”

Did you feel enough time was given to moving between CYP and adult mental health services?

Even though there may have been enough time for the transitions process, the young people felt they were **not given enough** long enough or frequent enough **support**.

“There was a bit of time, as I knew it was going to happen but wasn't very support during that time and I think it left me to get really unwell.”

“No as appointments were not long enough or often enough.”

“I don't feel like there was enough time... it was very miscommunicated and I didn't actually end up speaking to anyone for at least four months and then two weeks before I was discharged, which is really quite sudden, I got a call from my psychiatrist who said they were going to take me off my medication and discharge me. So I basically had two weeks to prepare for not having any support. I didn't really know what to expect but I haven't been in adult services and I didn't know if that was just the norm.”

“No, not at all. I felt quite rushed and hadn't had enough time to process it all, I process thing slowly anyway, and they knew that, so I think they should have given me a bit more time... there was no understanding, there was no break from how I was feeling or [being told] what was coming next, there was no plan. It was literally just ‘we're changing your schedule’”.

What worked well

What do you think worked well during your move to adult mental health services?

The young people valued the **relationships** they were able to make with certain individuals, especially those they had known through CAMHS.

Having access to the **information hub** and sessions with **Mind** were also valuable for some.

“I was able to stay in touch with my keyworker from CAMHS for a bit. I didn't really notice much change in the move but when I had settled in adults, it made me grow up quite quickly.”

“There is great communication with their team when they kick you out of their service.”



“Some individuals care ‘one good egg in a bunch.’”

“I was given the number for the information hub.”

“I attended a crisis café and had to pay £20 for a session with Mind. It is the only service I like and that has worked.”

“I was given a list (leaflet) of crisis cafes (I used the information).”

“I could say the crisis café were quite helpful, but it wasn't like the weekly support that I needed at that time.”

What did not work

What didn't work well during your move over to adult mental health services?

The main areas the young people thought did not work well were around the **communications between service**, the **timescale** and the **'gap' in care** while being in between services.

“The communication between the service that you are leaving and the service that you are going to is poor.”

“There is a lack of preparation and short timescales.”

“A letter or phone call to discharge from CYP services isn't good an in-person meeting would have been better.”

“I got told by a letter instead of by a person, so I didn't get to see anyone, I didn't get to see their body language or anything.”

“There is a gap between not being able to access CAMHS as too old and being too young to access IAPT.”

“I didn't know anyone, and I didn't get to meet anyone in adults whilst I was still at CAMHS. No one really knew me, they just read my notes but that doesn't tell you what I am like as a person.”

“The communication between the service I was using and the service I was going to was non-existent, it just wasn't working.”

“The move from CAMHS to mental health was very scattered. They lost my paperwork so they didn't really know what I was going through, they tried to understand but because they lost my paperwork they couldn't fully assess the whole situation so I have to go through the whole story of what was going on and why I needed support. At the time I got very frustrated because I already had told them and my mental health got worse because I didn't understand what was going in and it was scattered, which made me more anxious and not make sense at all.”

“There wasn't an actual referral made from children's services eating disorders team to adult services eating disorders team, it was only when I got to a crisis point I was referred to the adults team. When I went into the crisis house team the UCAT crisis team saw me there and made a referral. I was admitted to the children eating disorders team in 2017 and then in 2019 I was discharged from their service but I was still seeing a psychiatrist in CAMHS, so it wasn't a transition as such but the adults team now have actually looked through my notes and saw what I struggle with.”



Access

What are some of the issues you experienced when trying to access mental health services as an adult?

Two young people told us how it was **hard to get help early on**, either due to unhelpful primary care staff or not meeting the criteria before reach crisis point.

“I felt like you are left to get on with things on your own, you're not taken seriously and it's hard to get appointments. My GP doesn't understand and then I am told I don't meet the criteria for Campbell house so felt like no one was believing me.”

“It had to get to the point where I was admitted to St Mary's before I was offered help. I didn't meet the criteria before that.”

Did you know where to go, or have someone to contact, if you were unsure about something or needed advice about accessing adult mental health services? Were they helpful?

Whilst the young people were given various **information** to help them access adult mental health services, most of them found them **difficult to use**, either because they did not feel comfortable reaching out, were overwhelmed by the volume of information or the people they tired to contact did not help. One person found the information about crisis cafes helpful.

“Yes I was given contacts but didn't feel comfortable in reaching out because I hadn't done that before and it was scary. I still felt like a kid.”

“I got a massive booklet with lots of long words in it which I didn't want to read.”

“I got a number for an out of hours service but it is only open 8-8. When I called I was told that I would get a call back but I didn't.”

“I was given a list (leaflet) of crisis cafes (I used the information).”

“I was given the number for the mental health hub, which was a helpful direction to go in.”

“I got given leaflets but didn't really know what places to go [to] but I had another service involved who directed me to the right place by sending me links to website, which was easier to click on and go straight to. It took quite a while for me to understand but then I understood and went to places where knew I was ok to talk about what was going on and didn't feel ashamed.”

“When the CBT stopped there was a steady decline. I didn't know where to go.”

Support

How well were you supported to manage a severe decline in your mental health? Was a Safety Plan created with you, that mapped out your options?

The young people were specifically asked about the support they were given to manage a severe decline in their mental health. Only one person had a safety plan (crisis plan) but they did not use it. The others were all **still waiting or discharged without one**.

“I had a safety plan (crisis plan) but didn't use this when I was unwell.”

“I am 24 and I am still waiting.”

“I am still waiting for a phone call.”

“No, I was just discharged and ended up in a crisis.”



“I didn't get one from CAMHS but I did from Mind which I pay for.”

Other comments

Other comments give at the focus group all reflected areas where the young people had felt **unsupported**, including around **gender and LGBT+ issues** and in their **difficulty in getting help from CAMHS**.

“When I expressed feeling of not feeling ok in my gender, I was told it was because of my hormones.”

“There is a lack of LGBT+ support and understanding.”

“In 4 years, I had only 2 appointments with CAMHS and I wasn't sent to another service. I had to seek them out for myself.”

“My mum had to beg and constantly call CAMHS to get them to see me. She has helped me with the process of finding me services and has kept me motivated against a system that works against me.”

“If I had got the help I had needed when I was younger, I wouldn't need as much help now.”

It is worth noting that there was a lack of engagement from BAME and male young people.

How it could be improved

Preparation

Who prepared you and what support did you have before you moved over to adult mental health services?

Most young people did not feel prepared for moving to adult mental health services, with some being supported by family and others not. **More could be done to better prepare young people**, with the comments above showing that two-way **conversations that help build trusted relationships** are valued and more would be beneficial.

“I didn't feel prepared, but people did tell me what was going to happen. Then it just sort of happened.”

“No one.”

“My mum prepared me.”

“I wish I had the support from my family, but my family do not believe in mental health.”

“I have prepared myself.”

“My mum tried to prepare me as much [as possible] as they communicated more to my mum than me and I got annoyed because I was the patient and I should be told what is going on. I was being fed one thing from my mum and another thing from what they told me and I got more frustrated and angry, which then didn't help how I felt and it started to break up the friendship between me and my mum because my mum tried to help but she didn't know what to do.”

“I didn't understand because I wasn't in the right place to understand. I think there was a leaflet with the letter, but I didn't understand the leaflet, nor did anyone else. It was harder because I'm dyslexic, so I couldn't read, but I was also embarrassed to ask the people who were supporting me because I didn't tell them that I suffered with mental health because I wanted to disconnect and for everyone to think I was normal.”



What things did you expect to happen that didn't and how did that affect you?

Young people expected to get more of a '**handover**' from CAMHS to adult mental health services, expecting service to **work more closely together** and to have time to **build relationships** with people or to process what would happen. One person suggested giving young people a '**transition pack**' that was co-designed by young people with **information** about where they could get support, as well as taking the time to **discuss the transition** with them.

"I thought it would be a gradual move and that I would get to know people well before the actual move but that didn't happen."

"I expected to be transferred smoothly."

"I expected an 'end' meeting when I was leaving a bit like you have for a crisis meeting."

"I expected to be transferred to an adults service."

"I didn't know anyone, and I didn't get to meet anyone in adults whilst I was still at CAMHS. No one really knew me, they just read my notes but that doesn't tell you what I am like as a person."

"No, not at all. I felt quite rushed and hadn't had enough time to process it all, I process things slowly anyway, and they knew that, so I think they should have given me a bit more time... there was no understanding, there was no break from how I was feeling or [being told] what was coming next, there was no plan. It was literally just 'we're changing your schedule'".

"I expected to be moved but to still get the care that I was getting from the younger service, but in an 'older' way, instead of having to fend for myself. It was like the film 'Hunger Games', you were fighting for yourself."

"If I was in charge of the transition process, I would make sure that at the age of 17, not 17 and a half, but 17, or even younger than that, that they had information, that I'd spoken to them about adult services and whether *they* wanted to transition and whether I felt like they would want to transition, and I would offer them a transition pack - that could be done by email or a booklet and it would be designed by young people and mental health professionals. It would have the information about what adults service there are and what you can do during the transition period if you need support. I didn't get that information and think it would have been really helpful for me. I'd make it so it wouldn't be wordy because when you're in a crisis you don't want to read essays. I'd make sure they had enough time to process that change and actually discuss their care with them and ask them how they felt their care was going and what sort of support they need."

"I would probably have a meeting a month, or maybe two months [before transition], depending on that person and how they would feel about it because everyone is different. I'd rather have a one to one session with whoever they are working with before they get swapped over to a different service."

Safe spaces and peer support

Something about having a safe space to go to and/or peer support?

The young people were asked what they thought about having safe spaces to go to and about peer support. Most **would value** this, including having **drop in wellbeing hubs** and greater use of **online support**, particularly if they do not find peer support helpful.



“I would have really liked this, this wasn't an option for me then it would have been good to have a friend or someone that had been through the same thing as me to help.”

“Covid has impacted peer support but has opened up other opportunities (online).”

“There used to be an open wellbeing hub in Kettering. You could just go there and there would always be someone to talk to. But it has closed.”

“I don't always feel listened to or understood even by my peers.”

Did you know where to go in an emergency for your mental health or if you needed a safe space?

Most young people (but not all) **had an idea of where they could go in an emergency**, despite not all having a Safety Plan (see above), however most mentioned A&E as an option after or before crisis cafes and some **more options would be beneficial**.

“I know if I want to die, and I have got a plan for this, then I normally go to A&E but this doesn't help as you just get assessed and sent away. Sometimes I have gone to the crisis cafes. It would be good if there were more options.”

“I don't know.”

“A crisis cafe or as a last resort A&E.”

“Yes, you call the hub, the crisis team or A&E”

“A friend, who then ends up calling the police.”

“I feel like there was a safe space for me to go, because I knew there was a safe place to go because I went out of the way to Google it myself, it wasn't because I was given than information by children's services, I had to find out myself what support was available.”

“I think they tried to show me as best as they could but I didn't understand because I wasn't in the right place to understand, so I probably knew deep down that I didn't [know of a safe space]. I guess really the only safe place you could go is the hospital, which is the last place you want to go because they make you feel awful for being there. So the only safe place you would [choose] would be your own company, and that's not safe.”

“I did know where to go for an emergency with my mental health, there was either A&E or 111, which I have called a few times, and generally they've been helpful but there have been a couple of times when I've called 111 and they didn't really have an inkling about mental health and just assumed it's all physical.”

“A family member called 111 and I was advised to go to A&E or a crisis café. I attended a crisis café and had to pay £20 for a session with Mind. It is the only service I like and that has worked.”

Suggestions from experience of private therapy

Four of the participants pay or have previously paid for therapy and offered up some suggestions of things that work well from this, such as **remote access** to appointments, having **people that engage** and listen, being able to see a **specialist** in their conditions, having **more choice** about who they see and appointment length, and **not being limited** by a set number of sessions.

“They actually want to engage with you because you are paying, especially if they are students.”



“My therapy sessions can be face to face but COVID has opened up the possibility of having sessions over zoom, facetime or over the phone. This has been quite beneficial because I can talk about my feeling in a safe space, like my home, rather than going into a more clinical setting”

“They can choose how long the sessions last for and they are not limited to 6-week blocks.”

“There is a choice over who you see and you are able to request someone else if you do not get along with someone.”

“The therapist/counselling or talking therapy was found through existing organisations (Mind and Northamptonshire carers) or online.”

“I started with private therapy because when I was discharged from the in-patient unit I didn't receive any communication from psychiatrists, which I was told I was going to see within two weeks of my discharge (I'm still yet to see one and it's been almost four months). I went online and there was some blurb about fees and everything and we had an initial meeting over Zoom at first (which was free) for me to get to know her and her to get to know me, after we had that initial assessment it would have been £45 per session but because I get PIP I get the concession rates of £25 for a 50 minute session. I feel like my therapist covers all bases because I struggle with different problems, like OCD, low mood, eating, self-harm - lots of different problems and you can't really get one service to treat all of them. But with the private therapists, she's trained in all of that and you can actually look for private therapists specifically for certain conditions. That's been really helpful for me as if I work on one problem the others get worse so it was good to work on them as a whole.”

“I ended up looking at private therapy because I did art therapy and other therapy with my service and it got to the point where it just wasn't working or you only had a certain number of sessions and they would get to the stage where you were deep into it but then only had two or three sessions left and you were then left to fend for yourself. Whereas when you go to private therapy you are paying for each session and there is not a limit, so you're not scared that if you open up they are going to just leave. You're knowing that at your next session you can carry on working through what you're going through, even with current life. That's the main point for me as I constantly have something going on in my life and I used to let everything bottle up and then explode and that's when I would have crisis. When I started private therapy I had fewer manic episodes, maybe one every two months, and was able to reduce medication and feel more awake all the time and become the person I never thought I would become. So it was worth me paying £40 each session. I guess she [the therapist] acknowledges that I'm a person and have feeling and I don't actually have to hide who I want to be. I guess she's the reason that I'm able to succeed in life.”



Care Leavers' Mental & Physical Health Support

We also sought the thoughts, views and experiences of those Leaving Care about the preparation, the process, the aftercare, and how their experiences continue to affect them today.

Current health

Previous access

What health checks have you had (from the age of 15)

Some young people had received **primary care check-ups** (dentist, GP, optician) and one had received a **Looked After Child (LAC) medical**, although those in foster care did not get that. Two had had a **CAMHS assessment** and one had organised their own **sexual health check**.

Managing their health

Have you felt in control of your own health?

Two young people felt they **had control** of their health, although they were advised. One person **would like more control**.

“I’m advised, but overall I have control.” - Age 17

“There is a lot of nagging but I am in control.” - Age 18

“I’m not in control at the moment but I would like to be.” - Foster care, age 17

What role does your personal assistant/social worker play in your health care?

Two young people highlighted ways in which their personal assistant or social worker had **helped them manage their health**.

“My PA has got me off cannabis. It has been 22 days so far, I have worked hard. I am motivated for my baby who is due in August.” - Age 18

“My social worker makes sure that I have the relevant health checks.”

“I have never thought about it.”

What would make you attend A&E? What circumstances?

The young people understood that A&E is there for **accidents and emergencies**.

“Broken bone.”

“Emergencies.”

“A rusty nail in my foot.”

“It’s Accident and Emergency, it’s self-explanatory.”



Preparation for accessing health services

The young people we spoke to had some **understanding of how to access general physical and mental health services and support**, although had **limited experience** of doing so and **did not have detailed knowledge of local services**, such as **mental health support**. This implies that more could be done to explain the range of services available to them if they need them once they leave care.

The young people **did not have any expectations** about what should happen to support their health when they left care and did not feel there was any help with their health that they wanted but were unable to have.

Have you been shown how to make a doctors and dentist appointment?

“Yes it’s sort of common sense. I was told where my doctors was and the phone number.”

“You just google Specsavers and call the number for the opticians.”

“I have not been shown but I know how.”

Do you know who to contact for health concerns, including mental health?

“NHS - through the website. If you search NHS it will come up.”

“Ambulance if it is an emergency or A&E (for physical health).”

“For my mental health, I have not been in that situation so I don’t know what I would do.”

“Mental health - I have self-coping mechanisms. I know what to do to make me happy.”

“Mental health - call the NHS.”

Do you know where to access mental health support?

“My GP”

“The NHS”

“Childline”

Other comments

There was some discussion about sexual health services and where sexual health checks could be undertaken. There was a lack of knowledge about where they could get free condoms from. Not all young people knew that they could access free contraceptives. There was also some discussion around their understanding of whether you needed regular sexual health checks and testing if you wore a condom.



Response

“It is widely acknowledged that the structure of mental health services often creates gaps for young people undergoing the transition from children and young people’s mental health services to appropriate support including adult mental health services. The NHS Long Term Plan sets out a commitment to 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 CCG funded this engagement and co-production project to give young adults the opportunity to shape the development of an Enhanced Service Offer for 18-25's that will go live in April 2022.

The Enhanced Service will introduce young adults to the comprehensive crisis pathway available across Northamptonshire, to ensure co-produced, personalised Safety Plans are in place for each young adult to help avoid unnecessary attendance at emergency departments. The service will be structured similarly to the Care Leaver model, using the Personal Assistant (PA) approach to ensure a flexible, holistic approach to care.

It will have the capacity to work with CYP from 16 years, building trust and gaining a robust understanding of needs, and to remain involved with young adult up to the age of 25 to ensure a gradual transition into adulthood. The ethos and culture of the service will be solution-focused, strengths-based, personalised, flexible, and able to work with a complex set of needs, regardless of diagnosis.

Additionally, the Care Leavers Team is mobilising a 12-18 month pilot that will increase Clinical Psychology, MH practitioner, and MH apprentices within the Care Leaving team responding to mental and emotional needs of Care Leavers.

Transition from childhood to adulthood is a priority focus in Northamptonshire for both the Adult Mental Health Programme and CYP Transformation Programme, and joint governance arrangements across both programmes will oversee the achievement of outcomes.”

-Northamptonshire Clinical Commissioning Group (NCCG)





Acknowledgements

We are very grateful to all those who took the time to share their views and experiences with us. We would especially like to thank all who shared our survey, including:

- WiSupport Ltd
- PAUSE Northamptonshire
- Northamptonshire Young Carers
- The Community Courtyard



About Healthwatch Northamptonshire

Healthwatch Northamptonshire is the local independent consumer champion for health and social care. We are part of a national network of local Healthwatch organisations. Our central role is to be a voice for local people to influence better health and wellbeing and improve the quality of services to meet people's needs. This involves us visiting local services and talking to people about their views and experiences. We share our reports with the NHS and social care, and the Care Quality Commission (CQC) (the inspector and regulator for health and social care), with recommendations for improvement, where required.

Our rights and responsibilities include:

- We have the power to monitor (known as “Enter and View”) health and social care services (with one or two exceptions). Our primary purpose is to find out what patients, service users, carers and the wider public think of health and social care.
- We report our findings of local views and experiences to health and social care decision makers and make the case for improved services where we find there is a need for improvement
- We strive to be a strong and powerful voice for local people, to influence how services are planned, organised and delivered.
- We aim to be an effective voice rooted in the community. To be that voice, we find out what local people think about health and social care. We research patient, user and carer opinions using lots of different ways of finding out views and experiences. We do this to give local people a voice. We provide information and advice about health and social care services.

Where we feel that the views and voices of Healthwatch Northamptonshire and the people who we strive to speak on behalf of are not being heard, we have the option to escalate our concerns and report our evidence to national organisations including Healthwatch England, NHS England and the Care Quality Commission.

Find out more at www.healthwatchnorthamptonshire.co.uk

healthwatch
Northamptonshire





About Young Healthwatch Northamptonshire

Young Healthwatch Northamptonshire are a group of young people between the ages of 11 to 24 who are health and social care champions.

What we do:

- Look at local health and social care issues
- Give young people a voice for all aspects of health and social care locally.
- Work with professionals on the health and wellbeing of young people locally and nationally
- Set our own work plan
- Learn new skills
- Report back to the Healthwatch Northamptonshire Board

We are always looking for more young people to join us. Please get in contact



[Facebook.com/younghealthwatchnorthamptonshire](https://www.facebook.com/younghealthwatchnorthamptonshire)



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n our code)



[yhwnorthamptonshire](https://www.instagram.com/yhwnorthamptonshire)

If you are a professional that wants to work with us please contact us on the details on the next page or email

younghealthwatch@healthwatchnorthamptonshire.co.uk

Young
healthwatch
Northamptonshire



About Northamptonshire Clinical Commissioning

Group

In April 2013, the NHS changed so that local doctors and other medical professionals and patients can have more influence in how and what the NHS spends its money on. Local doctors/general practitioners (GPs) formed Clinical Commissioning Groups (CCGs) which are the local organisations responsible for spending the majority of the local health budget on services from hospitals and community nurses to operations and prescriptions.

These changes mean that decisions which affect local people will be made by local clinicians. It also means that local patients, carers and specialist groups are able to directly contribute to improving the services that affect them.

NHS Northamptonshire Clinical Commissioning Group (NCCG) commission services on behalf of the 781,712 patients across Daventry, Northampton, Wellingborough, Kettering, Corby, East Northamptonshire and South Northamptonshire. This means that the services that you receive following a visit to one of the 68 GP surgeries and at the two hospitals in Northamptonshire have been largely commissioned by us.

The Northamptonshire CCG have put systems and processes in place to ensure that clinicians and patients are at the heart of our decision making. Northamptonshire CCG covers a large area and we know that the towns and villages within the area are different. This is why we have divided our 69 GP surgeries into four localities covering:

- Daventry and South Northants
- East Northants and Wellingborough
- Kettering and Corby
- Northampton

For more information, please go to: <https://www.northamptonshireccg.nhs.uk/about/>



Northamptonshire
Clinical Commissioning Group



About Connected Together

Connected Together Community Interest Company (CIC) is the legal entity and governing body for Healthwatch Northamptonshire.

The remit of the Connected Together CIC includes:

- Contract compliance
- Legal requirements
- Financial and risk management
- Sustainability and growth
- Agreeing strategy and operations
- Agreeing policies and procedures



Connected Together
First for Community Engagement

Connected Together CIC is a social enterprise and a partnership between the University of Northampton and Voluntary Impact Northamptonshire. It aims to be first for community engagement across the county of Northamptonshire and beyond.

By using our expertise and experience, we can help you in delivering community engagement programmes including workshops, research, surveys, training and more. Contact us to find out how we can help your community.

We welcome ideas and suggestions for projects that benefit Northamptonshire and its community.

Find out more at www.connectedtogether.co.uk





Appendix - Focus group questions

Mental health transitions

It might be a good idea to ask the group to spend a couple of minutes each describing their transition process to the facilitator/ group, in their own words - before we start going through these questions. It will prompt young people to cast their minds back and reflect from the outset. It might not involve them analysing their feelings straight away, but just recall the process (how did it start, what actually happened, who was involved, what were the significant points/ meetings/ actions that took place). It would also provide some really valuable information for us to take away and start building a flowchart picture (something that could eventually show a 'current versus future' model).

1. How did the move between CAMHS to adult mental health services feel for you?
2. What do you think worked well during your move to adults mental health services?
3. What didn't work well during your move over to adult mental health services?
4. Who prepared you and what support did you have before you moved over to adults mental health services?
5. How do you feel your experiences of the move to adult MH services affected you or continue to affect you?
6. What things did you expect to happen that didn't and how did that affect you?
7. How did you manage the move to adult MH services yourself?
8. What are some of the issues you experienced when trying to access mental health services as an adult?
9. Did you feel listened to during the move to adult MH services?
10. Did you feel you had a choice in your care as you moved to adult MH services?
11. Did you know where to go, or have someone to contact, if you were unsure about something or needed advice about accessing adult MH services? Where they helpful?
12. Did you feel enough time was given to moving between CYP and adult MH services?
13. Something about having a safe space to go to and/or peer support?
14. Did you know where to go in an emergency for your mental health or if you needed a safe space?
15. How well were you supported to manage a severe decline in your mental health? Was a Safety Plan created with you, that mapped out your options?



Care leavers

1. What health checks have you had (from the age of 15)
2. Have you felt in control of your own health?
3. Have you been shown how to make a doctors and dentist appointment?
4. Do you know who to contact for health concerns?
5. What role does your PA play in your health care?
6. Do you know where to access mental health support?
7. What would make you attend A&E? (What circumstances)
8. Once you'd left Care what support did you get for your mental health?
(For those who had left care)
9. What things did you expect to happen that didn't and how did that affect you?
10. Is there help with your health (physical and mental) that you wanted and were unable to have?



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