I didn’t get any support. I wasn’t really talked to about how I felt. I didn’t really understand it at first, and seeing my sister in an institution upset me. It was all overwhelming. [Brother, 13]

I’m all for parents having the ability to look after our child because we can, but similarly I wouldn’t want to do all my own dental treatments. [Parent]
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1. Introduction

During Autumn/Winter 2019, Common Room were commissioned by Leeds Community Healthcare NHS Trust as the lead provider for the CAMHS/Tier 4 New Care Model in West Yorkshire, to carry out a series of 1:1 discussions with family members of young people who had recently received CAMHS inpatient and intensive community treatment in the region. This included siblings, parents and stepparents. The main brief for this work was to explore families’ perspectives on the NCM plan, as well as following up and consolidating the previous report, *Conversations with young people and families about the West Yorkshire CAMHS New Care Model (Spring 2018)* to check in with how the NCM was working in practice. The discussions were aimed at gaining insight from family members’ individual experiences of the current services, systems, and pathways, in order that service provision can better accommodate and support these family members.

Throughout this report, direct quotes from parents and siblings are indicated by *pink italics*. Elsewhere in the text wherever possible we have used the actual words of those we interviewed.

The following shortened terms have been used:

- NCM: New Care Model (West Yorkshire CAMHS)
- YP: Children and Young People who are receiving or are at risk of receiving inpatient care currently or in the recent past
- (J) or (L): Initial of young person, anonymised where necessary
- Parents: Parents, step-parents and significant carers
- Families: Parents and siblings
- CAMHS: Child and Adolescent Mental Health Services
- ED: Eating Disorder
- IP: Inpatient CAMHS unit
- OT: Occupational Therapist

2. Methodology

During Autumn/Winter 2019, Common Room carried out a series of 1:1 discussion with family members of children and young people who had recently received CAMHS inpatient and intensive community treatment in the region. The discussions were about the family members’ perspectives on the New Care Model plan for West Yorkshire. Most discussions were conducted in family members’ homes.

This report outlines key messages from... 9 mothers, 6 fathers, 1 stepfather and 3 siblings aged 11-14. The age range of the young people in CAMHs care was 14-17 years. The participants’ collective personal experience covered CAMHS inpatient and community services in Leeds, Halifax, Kirklees, Sheffield, York, Calderdale and Wakefield.
Collectively, the participants had experience of engaging with NHS, third sector and private sector services. All gave formal consent to share their views in this report, and we have used random initials so as not to be identifiable. All IP and CAMHS services have been anonymised.

The discussions began with an explanation of the NCM approach and model, using the illustration 'West Yorkshire CAMHS New Care Models' [see appendix 5]. Participants were then asked a series of questions to prompt discussion of their thoughts and feelings about the new proposals based on their own experience [see appendix 4]. These questions were used as a framework for guiding the discussions.

3. Key messages from families

The themes we have drawn out in this report were things which were consistently touched upon by several parents and siblings.

1. Parents experienced having to step in to help co-ordinate their child’s care when what they wanted was more communication, better joined-up services, and more support themselves.

2. Siblings wanted options to get support for themselves, and generally experienced not being involved, having to step back and feeling left behind.

3. Parents wanted the very best care for their child, but where they experienced inadequate support in the community and not having the capacity, information or relevant expertise themselves, an admission into hospital felt like the only option.

4. A hospital admission could often result in a feeling a relief for families, giving well needed respite and reassurance that their child is safe.

5. Parents felt that the inpatient provision and systems need to be integrated much better into the wider system of care to ensure smoother transition, better experience before and after admission and to help reduce readmission.

6. Families voiced frustrations in navigating rigid pathways to access care and a feeling of limited or no options. Many felt they were on a predetermined path towards hospital admission despite feeling that appropriate community care would be better.

7. People were overwhelmingly in support of the principles within the New Care Model, but mostly the different elements of this didn’t resonate with their experience. Overall parents were unaware of the Care Navigator role or how the Care Navigator could support their individual case.

Many of these key messages echo and build on those from our previous conversations with CYP and families about the NCM.
4. Recommendations

There are some strong messages from families throughout the report and various suggestions for service provision which could be implemented to support the NCM, including

- Provide more flexibility within community and inpatient provision to address how families can access support during crisis, out of hours and after discharge. This could be an outpatient provision to ease transitions and provide more intensive community support
- Give clearer identification and transparency about who is care coordinating any case and who is overseeing a young person’s transition in and out of inpatient units.
- A comprehensive information leaflet available to all parents could inform and reassure them better when their child is admitted to an inpatient unit. This could be co-produced with parents.
- Spaces provided and practice in IP units could better mirror positive activity and relationships in the community.
- Explore support options for siblings and parents, such as peer support groups and access to confidential talking therapies
- Continue to explore and respond to service user and family experience - to inform service learning and development

Parent and sibling experiences are outlined in detail in the body of this report. The themes strongly echo findings from our previous ‘Conversations…’ report in 2018, where we spoke in-depth to young people themselves about the NCM.

A note on representation: It is important to consider that the families we spoke to, by the nature of them taking part are unlikely to be representative of all families and parents receiving support in the wider system. They described themselves as onboard and supportive, and also often feeling like a nuisance, a problem, or causing a fuss. As a parent you go with the flow because you think they’re the experts and they know what they’re doing. One parent described how they were told by the OT that they were the only family that has actually engaged [in the family activity], she said so many parents just won’t engage in stuff like this. The information in this report is from families who have been given a voice, who came forward and were willing to talk, but we should be mindful of those not represented here, for whatever reason.
5. First impressions of the New Care Model

Families very much supported the model’s aims to increase community support and ease transitions, however many people we spoke to continue to explain that the hospital admission felt necessary and important for not only the YP, but the whole family.

“It could be amazing if that actually worked” [Parent]

It was clearly voiced that it is essential to drastically improve care in the community, in order for the NCM to be effective in reducing admissions. It is apparent for many that hospital often seems like the inevitable [and only] option due to the community support failing not only their YP but also the whole family. For example, one mum told us, hospital stay for our daughter was necessary… needed to save her life.

“It’s a good idea, hospital is not the ideal environment to be in” [Parent]

Families appreciated that services are strained, but to be able to be less reliant on inpatient care they felt the NCM would have to offer more flexible, personal and intensive support approach. Furthermore, the actual usefulness of IP was generally questioned, bar a few cases.

“I think [the NCM] is a brilliant idea. This makes sense to reduce or avoid hospital. We would have preferred to avoid and inpatient stay, and I’m not sure how useful it was, they just contained her safely.” [Parent]

Many families voiced fears about readmission for their YP due to the lack of appropriate support in the community. Abrupt discharges without a plan, and a real gap between IP and community care, has left families feeling vulnerable and afraid, but expectant of readmission. For example, describing how, we have seen quite a lot of YP leave the unit fairly quickly only to come back in or to another facility.
6. Care Navigators

Families were supportive of plans to introduce Care Navigators across the system, and felt their input may help avoid admission and access better services in the community. None of the families recognised the Care Navigator role playing a key part in their child’s care navigation, and their role wasn’t entirely clear. Some knew about them because of a random interaction. They felt it would be helpful to find out more about the Care Navigator’s role and how to access their support.

Families felt that the Care Navigator could be useful to explain the system, in the earlier stages as an advocate or to help preparing the YP, particularly through difficult, complex changes such as admission to hospital or sectioning. When we were faced with a possible move to PICU it was really scary, the most frightening prospect… the Care Navigator could have been useful for explaining what was happening… navigating the system, understanding us and helping us understand, and maybe bringing literature.”

“The most essential thing, if things aren’t very hopeful, is that they [Care Navigator] need to be experienced, have broad range of initiatives at their fingertips.” [Parent]

It felt important for families to feel confident not only in what the Care Navigator’s role is, but also their competency, as “how much teeth they have will determine how good the outcome is”.

7. What are the current difficulties with services? How might the NCM help?

7.1. Difficulty getting early and appropriate interventions or support in the community

As already touched on in our 2018 report, families felt it crucial that the services can ensure early intervention of appropriate [and intensive support where necessary] support in the community. They need to be quick with support otherwise it’s not helpful. This is key for preventable, shorter and less traumatic admissions and recovery. Unfortunately, though, for many families this isn’t happening and there doesn’t seem to actually be such a thing as ‘early intervention or intensive support.

“That’s where it goes wrong, right at the start” [Parent]

Despite many families feeling that an IP stay was probably inevitable and unavoidable, they did voice that, with hindsight, the right support at the right time may have reduced the length of the IP
admission, even in challenging situations. For example, one parent was clear We could have had a shorter admission if she’d got help sooner.

Families voiced frustrations at feeling like the services are only working at ‘crisis’ point. This echoes to what YP have told us about difficulty accessing support due to rigid pathways and criteria, and feeling they aren’t taken seriously until they’re not coping at all, or hospital. Their experience was that the approach isn’t proactive enough and that more early intervention is key for the success of the NCM. One parent described; I feel angry she had to get in such a terrible state before she was admitted.

“It shouldn’t be my daughter having tried to kill herself, and the response for support being ‘oh we can probably book something in about 6 weeks’ time.’ There is no compassion or sense of urgency” [Parent]

7.2. Parents are overseeing their child’s care

Echoing our previous report, we heard how the parental role can massively change when a child is unwell. It was unanimously felt that as a parent you had to become proactive and ‘hands-on’ in terms of navigating services and fighting for treatment. Parents said they felt they were fulfilling a role similar, to a care co-ordinator, often feeling like a problem or an irritation when they were just trying to help [their] child.

“It’s been like a job, writing emails, documenting what we’ve said, endless debates. You feel like you’re always fighting, sometimes you question are you just causing a fuss” [Parent]

Some parents told us how they needed to fit this new commitment round their own employment arrangements - e.g. feeling lucky they worked from home, or in other cases they’d cut down their hours, risked nearly losing job, or stopped working altogether to support the whole family’s needs as well as caring for their child, it was a no brainer I wasn’t going to go to work to leave [my child] to suffer.

“[K] needed to be supervised at school at mealtimes but they couldn’t provide this, and nor could the CAMHS team, so I had to stop work to supervise her meals at home – this was horrendous at times, fraught with difficulties and tension” [Parent]

Time off work to take a highly active role in their child’s care presents financial pressures for parents as well as having emotional implications.

“No matter how understanding [your employer is], there’s always that expectation that you need to go back and you can’t mess them about… it’s stressful, that whole uncertainty, it affects your security, your peace of mind, it’s another element on top of everything” [Parent]

Despite wanting to do whatever’s necessary for their child, parents voiced strong fears about wanting the experts’ help, as they weren’t mental health professionals themselves and were also too emotionally involved. Many parents said their experiences had made them feel like they were
failing as parents. It's their job not ours, nor are we particularly clear sighted enough in the situation to do that job ourselves anyway.

“I wanted to look after her, but if she was getting looked after by professionals… when it’s the end of their shift they can go home, but at the end of my shift looking after [B] I am at home. It’s my whole life. If that’s what it has to be then you just have to cope. But it would be so nice to have options, even to know they’re there.” [Parent]

“We’re the experts on [our child] but not on an eating disorder, so we do turn to the ‘experts’. But that didn’t work in our case, as time went on, we started to lose faith in how we were as parents, that we couldn’t actually do this.” [Parent]

The parents we spoke to felt that they were a vital part of their child’s support, but were poorly equipped to handle the mental health aspects and desperately wanted advice and support themselves, which we discuss in more depth in the section on Parents want to feel supported.

“We were making it worse at home because we weren’t getting support, so we were triggering her and not knowing what to do” [Parent]

7.3. The entire family is profoundly affected

“[K] is not the only one affected by it, that’s the main thing to understand” [Sibling]

Families told us about the significant impact and their various difficulties, and how this affects every part of your families’ life. Parents found it hard work juggling things with the other kids and really worried about how it impacted them, often describing lots of tension and arguments in the home.

“We’re so damn tired. Our personal life has gone, all our energy is on [K], but we still need time to do normal family and couple things” [Parent]

The practical implications on families can be far reaching. For example, we were told our own eating has gone out the window, it’s horrendous… we’re sorting the kids out before we leave [to visit] then not back until half 9. We’re not looking after ourselves right now. And another parent described how they were struggling financially, travelling here and there my fuel bill has tripled, buying extra special foods, it did put a strain on us.

“Ultimately [our child’s] mental health is affecting our [family’s] mental health, it’s that simple” [Parent]
The profound emotional impact on families was a recurrent theme from our discussions, whilst despite families understanding the situation could be difficult, it was widely felt that the system can add to the stress... both for the YP and the parents, the whole family.

“At home it has been a massive change” [Sibling]

7.4. Families want to be supported better when their child is unwell

Some families described being able to access family therapy through the inpatient unit, but there they reported no continuation of this into the community, and on the whole a lack of local support specific to families.

“It’s like they can’t really deal with how this tears a family apart; they don’t seem to be proactive.” [Parent]

The experience of families receiving support from an IP varied, but in general it was felt to be inflexible and not very useful, with families wanting more choice, more options, something personal and more helpful.

“There’s no resources for you, nothing for you as a parent, we go to family therapy but that’s it. I don’t know what it’s meant to be achieving, it feels like a tick box.” [Parent]

7.5. A feeling that resources could be used more effectively

Families felt that more efficient use of funds and resources across the mental health care sector is essential for services to improve. They felt that staff were really frustrated at being faced with impossible choices and really try to help but are clearly under too much pressure. In addition to the need for early appropriate intervention, concerns were voiced about wasted resources caused by delayed or inappropriate intervention resulting in greater costs down the line, both financially and emotionally.

A common message implied to several families from CAMHS was that hospitalisation would enable easier access to better treatment, but families felt that in reality this was often not the case.

“CAMHS suggested hospital admission would mean quicker and better treatment, psychology support and 1:1s, but this didn’t happen.” [Parent]

Whether hospitalisation was the right intervention or not, the high risk of readmission remains a real concern for families. It was felt that as the resources weren’t used effectively to prevent admission initially, this compounds later on with many families fearing and expecting a readmission, which further drains resources. This is discussed more in depth later in the report in the inpatient section.

8. Might the new model make anything harder or worse for families?
8.1. Hospital admissions can be positive, providing respite for whole family, which was felt necessary and unavoidable in some cases.

There was a shared sense of families feeling glad when their child was admitted, as they felt hospital was keeping them safe, and they couldn’t carry on at home. Siblings voiced feeling safer themselves, and in a calmer environment at home, whilst parents voiced a feeling of more normality and freedom at home. We were told, for example, “we obviously really missed [J], but we were able to do stuff that we’d not been able to do, knowing that she was looked after, we weren’t worried she was up in her room self-harming and stuff like that.”

“It’s more relaxing with her not being here as she’s in a safer place, I trust they’re going to look after her better than we could.” [Sibling]

Hospital can provide well-needed respite for the family, with a sense of relief and feeling safer, but also guilt.

“It sounds awful but we cope better when she’s in there. It gives us the breathing space we need.” [Parent]

Many felt that supporting the family at home was desperately needed, but not happening. So, respite was seen as vital for the whole family’s wellbeing, but hospital, despite not being the most appropriate option, was frequently the only option to provide this.

“When she’s home it’s really difficult, now I can relax” [Sibling]

Many felt that an IP stay was unavoidable, and some people will always need it.

“No doubt about it she needed an IP admission. The illness was too strong, nothing could have happened in the community. In the hospital the illness has nowhere to go, it is being confronted on a minute to minute basis.” [Parent]
9. Important messages from siblings

Siblings can often be overlooked when children are receiving specialist support and families are in crisis. This process has allowed us to talk directly to some siblings and take time to explore their perspective and experience.

9.1. Siblings want more support

Siblings on the whole described being negatively impacted by their brother/sister struggling with mental illness, and the challenges that come with this for the YP and the family. It was acknowledged – by parents and siblings themselves - that there is very little support for siblings. Being part of the family in these cases can feel scary for siblings.

“Things have got worse but despite that there’s still no support for us. In terms of sibling care there’s been nothing at all.” [Brother, 11]

It can be difficult for siblings to express or even understand what’s going on for them, as one sibling described, it’s hard to say what might have helped [Brother, 13].

“I didn’t get any support. I wasn’t really talked to about how I felt. I didn’t really understand it at first, and seeing my sister in an institution upset me. It was all overwhelming” [Brother, 13]

Parents shared their concerns about how their other children are affected, for example It’s hard on the other two… they still need to be normal kids as well, and have time to do or not do things. [Parent]. In addition, they gave examples where siblings were being promised support which didn’t seem to happen.

9.2. Siblings don’t want to ‘steal spotlight’ or bother people

Siblings we spoke to wanted minimal fuss, and they shared some of the fears and concerns affecting different parts of their life, for example with the rest of the family …my parents asked how I was feeling, but I didn’t want to tell them as I didn’t want to upset them. [Sibling, M 13] and with friends and at school… there’s a few friends that know about it, but I don’t want to bother them with stuff like that [Sister, 14].

“None of my friends know, I decided to keep it private as I don’t want any of them to worry about me more” [Brother, 11]

9.3. Siblings want to be more included and informed

Siblings themselves expressed wanting to be included in the discussions about the care of their brother or sister, and the care of the whole family. They also wanted to be informed better about what was going on, for example, these days I don’t know what [my sister’s] up to anymore, other than the anorexia. They described how sometimes parents try to shield them from information so as not to upset them, but this was seen as unhelpful because when siblings are not informed, they
can begin to worry, for example one sibling wondered, *is there something going on behind my back?* [Brother, 11]

“There was quite a few times my sister was in hospital and I didn’t know why, I feel like it would have been easier if I had known as the not knowing made it harder, it was a mystery I didn’t know if she’d tried to take her life again or if it was an eating disorder or…” [Sister, 11]

9.4. **Siblings want support that suits their needs**

Siblings wanted the opportunity to access support of their own if they needed it, including non-talking therapies. They had some ideas about what support for them might look like, and it wasn’t clear cut, but options about the environment, confidentiality and who they spoke to were all important to them.

“I’d want different options really for talking, as there’s stuff more personal that affects me than my brother, so that’s not really something that he could understand but sometimes I do want to include him.” [Sister, 14]

“I don’t think I would have wanted to talk to anyone else, like from CAMHS, as I thought it would be fed back to my parents. But if I knew it was going to stay between me and that person it would have helped.” [Sister 14]

They also spoke about being an important part of family therapy, seeing that as something that *could be something that helps.* Two siblings made a suggestion to have additional family therapy without their sibling.

“Other than my parents no one else asked me how I was or if I wanted to talk, other than family therapy, but I only went to that once as my sister didn’t want me going as I don’t think she wanted me talking about her. Maybe some family therapy with just me and my parents would have been helpful.” [Brother, 13]

Siblings and parents also recognised the value of peer support because talking to someone similar would be good, as you can both understand and it’s not something you can get with any friend, you can just vent to each other.

“A sibling support group would be amazing, as siblings often get overlooked. I think there’s nothing like being able to talk to other people in the same boat. Something that she could access regularly would be great.” [Parent]

10. **How does intensive community support need to work well for everyone?**

Parents want a robust and proactive plan of joined up care in the community, a plan centred around the whole family’s needs, clarity about what’s happening and strong links between those involved. This is essential to give a sense of hope and confidence in the support team. Parents had good ideas about what this might look like, for example *A package of care which is a treatment programme, including social skills, education, addressing every aspect, for family –*
guidance, what can I do to help, dietician, psychiatrist, fine tuning the approach, meal plans, transparency about the package of care, why it’s happening and a joined up approach between all different staff”.

“If we’d had mental health support here, I think if [A] could have stayed in school, keep her eating at home and had days out for therapy and support, but still had the security of knowing I’m going home at the end of the day… this looks like intensive support in the community.” [Parent]

10.1. The need for more robust and intensive community support, choice, clarity and more joined-up care

Many families voiced a sense of total confusion at what was on offer in terms of community support, and a frustration about a lack of a concrete plan. It’s important to have a proper plan in place, written down… how regular appointments will be, who’s involved, how is the school going to be reintroduced etc. Families wanted the plan to be purposeful, something that is reviewed regularly and clearly communicated, so they know what’s happening and why. This is vital for effective community care, but particularly following discharge or preadmission, which families felt should always be planned rather than the approach of let’s just see how you do. This approach gave families a sense of hopelessness. Families actually wanted strong boundaries… clearer messages, like this is what’s going to happen, we are the experts, we know what we’re doing. Rather than families continually asking for it, they want regular updates and to know when things arise in real time, not just at review meetings, when it suits the professionals.

“I found the CPA helpful to gather things together from different professionals and their point of view, and to agree the plan to go forward. Now [since discharge] I am not sure what the plan is, I feel I am asking a lot.” [Parent]

10.2. Parents want more collaboration and better links between services, schools and families

Parents want services to link up with them and their YP, to be inclusive, so everyone feels informed, clear and confident about what’s happening, and able to contribute to the plan too. For example, more connection between your child’s key worker and you. Parents felt they had a broader knowledge of their child, compared to the professionals’ limited view through illness. Parents want more joined up thinking across services to enable consistent delivery of a person-centred approach. The value of a family’s experience is discussed further under the theme Person Centred Approach.

Collaboration both within and between services are equally important. There were criticisms about there being no link between general and psychiatric services, with psychiatric services feeling like a very separate entity being not linked at all and very disparate. There’s a strong need for more liaison and awareness between a range of services, including support in the community and local authorities. Parents questioned how a constructive plan can be effective, for example when local community CAMHS failed to notify the local authorities that [D] was in hospital. It transpires that the local ED team never told the local authority about [D] Families described losing confidence in the services and in the professionals when communication broke down.
It was felt strongly that more links between the unit and third sector could strengthen support networks for young people and also parents and to deliver a robust plan. Parents described how *arguing between departments* felt counterproductive. Without collaboration, it didn’t feel like the promises of community care could be fulfilled.

### 10.3. Families sometimes have a lack of confidence in staff and teams

Families expressed the need to be able to trust the teams involved in their YP’s care. It was deemed to be fundamental to effective community care, and the NCM working.

“A team that instils sense of hope, a consistent narrative of recovery” [Parent]

There was a shared sense of being *fobbed off*, and services not understanding families’ experience. *I feel like [our child has] been let down, not just one incident or one member of staff.* Some parents told us that CAMHS are *under resourced, they don’t listen, they don’t react to things… even the doctors say they’re appalling.* Issues were not only apparent to parents, *sometimes staff acknowledge problems or shortfalls within the system to us*, which reduced further parents’ confidence in the likelihood of successful treatment. Teams must perform well consistently to gain families’ and YP’s confidence, as often, parents said they’ve *lost faith in CAMHS* after being let down. Team members need to be highly trained and experienced, work proactively and collaboratively in delivering the promised plan. In reality though for some, it felt like agreed actions can *just go into the ether*, indicating a lack of cohesive teamwork and/or relevant expertise. Rather than chasing up care as previously mentioned, parents want to feel confident in staff’s word.

### 10.4. Parents would like better continuation of care

Keeping the YP connected to the community whilst in hospital can help them feel prepared to come home. An IP family therapist advised one family before discharge, *we need to prepare you to support [J] with your family and friends, because CAMHS won’t be there.*

A consistent theme throughout our conversations was about links and good communication between services being essential, particularly during transitions between IP and community. An effective handover was not the experience for many families we spoke to. Parents were not sure staff always got all the information they needed and felt as parents they were needing to fill in the information gaps. Parents told us it’s hard enough getting used to one staff member and then moving onto another, but that *the hardest thing is having to constantly retell the story*, which negatively impacts their child’s wellbeing.

Some families suggested a system that allows IP staff to be part of the transition into the community would have been invaluable. They would be able to share key information in a timely manner, whilst allowing bonds and trusting relationships to build with the community team.

“It would have been helpful to maintain a link with some of the nurses, key staff on the wards – who have got to know our daughter well – could they not form part of the outreach community offer?” [Parent]
This could also be useful for when IP care is interrupted for some reason. Parents feel as though they have to start again for readmissions.

“There’s no transition from IP to home. There’s no joined up thinking, the whole thing needs to be shaken up.” [Parent]

In addition, when an IP admission occurs, a continuing link with the CAHMS and community staff could be beneficial in maintaining trust and confidence for the YP and family. Continued contact from CAMHS could also help to keep them informed and prepared for receiving their child on discharge.

Geographical limitations can impact transitioning from IP to community, for example, if IP was nearer then maybe [B] could actually see people locally to integrate therapy. If families were closer and able to visit more easily this would reduce a lot of strain. This was echoed by siblings, wanting more eating disorder units more locally.

“YP need something before they go in and when they come out – our experience was that coming out of the unit wasn’t supported, there was no CPA, package of care, plan for her treatment. It was just back to local CAMHS.” [Parent]

Families felt that pre-admission worries and fears could be helped by more information and reassurance. For example, one YP felt frightened as they were told you will see people self-harming, whereas another YP felt less worried about IP after seeing pictures of it and a video made by the unit, she thought it looked nice, this was helpful in portraying the IP unit as more inviting, less scary and less clinical. It was generally felt that it would be useful to be given some realistic information beforehand about what to expect and to prepare everyone.

10.5. Suggestion of a day centre or outpatient facility

“What the consultant psychiatrist on the unit says should happen back in the community.” [Parent]

Families described the current services as binary - between either care in inpatient during periods of crisis OR within community CAMHS teams. Most parents we spoke to wanted something that’s in-between, that offers your child that support so they don’t have to be an IP, that would be a really big step forwards. This was suggested in the form of a day centre, to bridge the gap; a gentler place than hospital, more locally integrated, but a more intensive step up from community support.

“As we near her discharge date it’s becoming quite daunting that she will be coming back home, But I imagine it would not have felt as daunting if she’d been living at home and going somewhere on a daily basis.” [Parent]

This could also effectively support continuation of care through smoothing transitions between IP and community, a place where all staff could collaborate with families.
“In an ideal world there’d be more of a half-way house, a day care provision. An outpatient option in the unit with familiar staff who know [D] so well and how to help her manage. 10 months of close relationships – those are important and suddenly cutting that off could be very difficult. For us, being able to ring the unit for bits of advice after discharge, for a few months, telephone support from those specific staff because of their level of knowledge of our child. We probably wouldn’t use it that much but that would be reassuring.” [Parent]

Many described the transition of leaving IP and knowing as soon as they stepped out of the doors, the support and the things in place would stop. They wanted something which could offer a continuation of hospital therapies, to strengthen what was achieved as an IP and valuable relationships formed. It was suggested that maybe you get assigned a therapist for the duration of your care, working with the same therapist could continue at the day centre, such as IP family therapy, as families voiced the importance of having to connect well with a therapist. A stable place with consistent support, links between IP and community to ensure continuity of treatment, staff and shared knowledge of the individual YP would be extremely helpful for families. It could also be a comfort to have a point of contact that’s always there, who knows you and your YP.

“The massive extreme between the unit and home, this blew her confidence to pieces, in terms of what she was like when she came out. The institutionalising effect of it is really strong, and we can still see it.” [Parent]

10.6. Parents want to feel more supported and informed

“You treat the person with the disorder and give them support, but it’s only so far reaching, and we have to support her, we have no tools beyond whatever we’ve got ourselves.” [Parent]

Parents had various suggestions of support that would work for them. Many were trying to support each other within their own family, but parents felt they needed something separate to this. It was simply a sense of being able to offload to someone impartial, someone neutral outside of the family and support network.

“Not even necessarily a professional, but someone you can talk to and say the things you don’t want to say to [your child/sibling] but without saying it to those close to you, to offload. You just want someone independent in a non-clinical way.” [Parent]

Some parents were clear they wanted professional help, to fix ourselves [as parents] really, sort out the environment we have here and help out as much as we can. Some felt a more intensive approach would help, as trying to make the changes on their own felt quite hard to do.

Many parents told us they’ve had to be proactive in searching for family support themselves, usually online. However, parents who had accessed online groups told us they tended to be very negative and not supportive. They described how the internet can be unhelpful and confusing in terms of seeking support, particularly around ED.

Parents said they would like to know from services what is available for them specifically, as often families were left in the dark - we’ve not been told about anything, maybe they’ll be in touch and
say what there is, but I don’t think that will happen. The overriding message was simply wanting basic but personal support for themselves.

“They did ask me if there was any support I wanted, but never told me what was available e.g. was it an offer of informal chat, peer support, formal therapy. …It would have been nice to sit with the key worker in an informal way to chat through the plan, maybe half an hour before or after they meet your child.” [Parent]

Parents felt like most people don’t understand how challenging their situation is and the struggles that come with that. The majority were keen to have the option to access peer support. Those who had attended parent groups, such as Leeds CYP ED Parent Group, said they found it useful and helpful to meet other parents going through the same thing. Those with other children wanted the same support for them too.

“A peer support group for both siblings and parents, something the whole family could access would be great because everyone’s at different states, so you can get support from those further on in recovery and see what’s possible, and in turn you can offer support to people who are earlier on in their journey.” [Parent]

Some parents who had accessed groups at the IP unit said despite seeing the benefits, it was not well used as there was no designated parent space in the unit. It would be good to have a parent room, say with a vending machine, where you could gain some valuable parent support. Parents voiced a sense of wanting to engage with other parents, but questioned whether it’s appropriate and not wanting to intrude, when it would actually be really lovely just to chat… in a group specifically for this, rather than putting your foot in it. Parents said themselves there were times when it would have been too upsetting to talk to anyone, but would like to know there was peer support there for when needed.

10.7. Parents would like more practical advice and reassurance

The parents we spoke to were clear in wanting more practical information, helpful advice and positive reassurance. A common theme from parents was not knowing what support was available, and essentially just trying to get the best for [their child] in a system we don’t understand at all. Parents told us they kept trying to do what they could to inform themselves, reading lots online, looked at Healthwatch, the CQC but still feeling confused about who does what in the team.

Parents wanted there to be clearer about what help is available and what might happen. Many parents suggested an booklet or information pack, something to give to parents to inform and reassure them. Suggestions about what this could contain include

- Info on the professionals in the team, who does what [with photos] and how to contact them
- who to contact if X happens or someone else isn’t available
- what to do in X situation,
- what to say, what not to say to your child when they X
- tips and advice informed by parents and professionals.
what support is available in the community to compliment the specialist provision
- out of hours support

As an extra, some parents felt it would be good to have a contractual document between themselves and services which agrees responsibilities, manages their expectations, and spells out what can I expect of you, I'll do my bit and you do yours.

“As a parent I think sometimes it’s scary as we can’t make it better… but we do need something tangible, something we can go away and read, something meaningful and more positive.” [Parent]

The list above reflects parents wanting education and advice in the early stages about how to manage things, as often in not knowing what do, parents felt they were harmful, making it worse at home… we were triggering [B]. Parents feel they're providing most of their child’s community care, but also feel uncertain as it’s not like anyone has told me what I should be saying or doing, I’m making it up as I go along.

“I’m all for parents having the ability to look after our child because we can, but similarly I wouldn’t want to do all my own dental treatments.” [Parent]

Particularly with ED, parents felt there were many simple things that if CAMHS could teach or train parents, this would be the better way of dealing with your child. Many echoed not knowing they were playing to the anorexia by being flexible, why couldn’t they tell me this early on… it’s such a simple thing.

The information was lacking, they gave us a meal plan but didn’t emphasise how important it is… if it'd been explained better earlier, I think we’d have been able to handle mealtimes better ourselves.

Some parents told us how their YP’s IP unit were great because they felt able to ring or email at any time to ask about anything they wanted, and be given advice on a whole range of things, like how we should approach things when [B] gets home. They felt that with better information and advice, they might have been able to nip things in the bud easier without needing hospital. Many parents felt that the lack of helpful advice and clear guidance for them while YP are staying at home contributed to hospital admission or readmission.

For many without helpful advice, they turned to the internet to try fill in the gaps, which parents described as an awful strategy because it can feed all your fears and give you the wrong ideas. They wanted trusted information from services with balance and perspective, which was honest, for example, you might have to get used to this, these things take a long time.

“Be proactive, reassure us, make us feel like we're doing the right thing.” [Parent]

Parents felt reassurance was vital in helping them build confidence in their abilities, which they felt a real lack of since their child becoming ill, and to give them faith in services.

“I’ve lost all my confidence with everything. I’m quite capable of putting myself in a kitchen to cook, but I’ve lost confidence knowing what I should be feeding her and what she’ll eat.” [Parent]
Especially during crisis after diagnosis or IP admission, parents said they wanted professionals to reassure them that the situation is temporary and that there is hope. Parents felt that when they were unable to hold onto hope or following discharge they were unable to give the support their child needed and this is impacted the risk of readmission.
11. Thoughts on inpatient settings

There is no doubt that hospitalisation is necessary for some YP, but there were mixed feelings about the benefits it provided and how well the time was used.

11.1. Time spent as an inpatient should be more valuable

Not using time well was a common complaint. It was said that hospital felt like a holding place, where there was not enough time with psychiatrist or enough useful therapy. Many families had conflicted feelings that although hospital was needed to save their child’s life, they were left questioning whether any treatment in hospital made them better. Some wondered if their child came out worse. For some it was described as an awful time. For some it just kept her safe, there was no difference to staying in a Travelodge.

“A place… that was damaging, and traumatic” [Parent]

Some questioned whether there really needed to be an admission at all given the limited interventions on offer, for example a weekly weigh and a quick chat, and whether this could have been done in the community. Many complained of very little contact with their psychiatrist, seeing them only once or twice and sometimes no direct contact at all.

“The whole time [J] was there she didn’t ever have a 1:1 with the psychiatrist, they were making big decisions like putting her on ant-psychotic meds, and I was thinking ‘but you’ve never even met her’.” [Parent]

Hospital for many YP felt like endless time to kill where things seemed to take longer than they should and appointments were often postponed or cancelled. One parent described many long spells in hospital as 6 months initial admission without progress… I feel things could have moved on more quickly.
“I thought the unit would be intensive care around her mental health. I thought there was going to be intensive support, a therapist. Actually, it’s a holding unit, the function is to restore weight.” [Parent]

11.2. Good examples of inpatient care

“The IP unit are absolutely amazing. They keep us informed, they listen to what we have to say, they change what they’re doing based on what we’re saying and what [N]’s saying. They ring us after every MDT.” [Parent]

IP can be a time of valued support for some families, giving them all hope, where staff utilise a good plan, delivering the measures spoken about in the community section. The staff working on IP units and forming positive relationships with YP were often praised and very much appreciated.

“The staff have been outstanding” [Parent]

IP therapies were seen as rewarding and useful, for example a parent described how, some therapies did change the way [F] thinks. You can tell when she’s had the body image therapy, she’s chirpy and bright. There were examples where an IP unit supports a YP’s recovery with the whole family included, and the benefits were profound.

“Our family therapy sessions have been really useful and valuable, we’ve got such a lot from them.” [Parent]

“We’ve felt like part of the team. They’ve also kept us informed when she was really unwell, e.g. when things were at their worst, they said if you can’t sleep because you’re worrying just ring us. It was reassuring to know we could do that” [Parent]

We heard how peer support for inpatients can also play a valuable part, for example, other inpatients [P] met when she was staying there seemed to help her a lot – caring about each other but also seeing other people get better and going home. It did give [N] time and space to think. It gave her friends and the opportunity to meet people who understand. [N]) was hopeless before.

11.3. Parents would like more flexible pathways and less rigid models of treatment

Parents experienced very rigid pathways of treatment in IP for their YP. As in the community setting, a person-centred adaptive approach was seen as essential for supporting recovery in IP. For example, traditional ward round procedure were described as overwhelming for some and a widely shared view was that the inflexible hospital routines were institutionalising, potentially creating a compounding problem.

“I worry that she is institutionalised, it’s great that she feels it’s a safe space for her, but she’s got to step out of it at some point.” [Parent]
West Yorkshire CAMHS New Care Model: Conversations with parents and siblings.

Parents suggested that more variety of activities may help YP fixating less on routine which brings added challenges.

“Getting her home away from the rigid routine will be the problem.” [Parent]

Families explained how the rigidity of IP can affect homelife, and how they found it hard to make home a natural environment for their child following discharge. Long stays in hospital can result in families feeling institutionalised to an extent themselves too, as even though we’re not in the institution, that’s become our comfort and security, that she’s there and we’re here and we’re not doing the day to day things. Particularly where the YP has been in a unit far from home with little contact with their home environment, supported discharge becomes crucial.

11.4. Family time and more normality needed during hospital stays

Supporting relationships during IP stays and retaining some sense of normality was said to be helpful, in particular with regard to smoother transitions home. What this might look like in practical terms on the unit could be something as simple as nice visiting spaces, a bigger space for all of us would be great for visiting, places we can all go instead of just being trapped in one room, you can’t sit and relax as a family. Sibling relationships particularly can easily suffer, I don’t feel as connected to [my sister] … I do miss how it was with our 1:1s, but we just don’t get the chance to have them now as there’s no space for it. A space that nurtures more ‘normal’ behaviour was wanted, if the kids could access and play some [DVDS and Wii] games with [their sibling]… you think of teenagers at home, they don’t sit with all the family in the room and try find something to talk about. It was also noted that a private space would be a bonus, as currently it didn’t feel like there’s somewhere you can have just a quiet chat without it being outside the norm.

Another area where some sense of ‘normality’ could be retained is with routines to reflect home life. For example, parents described how sleep patterns were disturbed and school seemed optional. Parents suggested having activities to share with family during visiting to help when visits felt strained. We heard from a sibling how there wasn’t really any activities to do at hospital, we usually just spoke for a bit then left. I would like to do something, they do activities amongst the kids staying there, I think it might be nice for me to come in and do the activity with them.

It was noted how staff can go a long way to help YP feel more comfortable and in the process build trust and stronger relationships. For example, one unit took [L] on a trip to get new stuff for her room, and when the OT brought her on home leave they sorted out her room together. There’s all kinds of things like they played crazy golf the other week, they’re doing so much stuff. There was a strong sense that we must not lose sight of what’s healthy and normal for YP just because they are an IP, because having fun is a normal thing to do, and needs to be part of recovery.

“What she would like is a care support worker that could go out with her for a coffee or take her shopping, stuff like that, park the food bit and concentrate on the mental health.” [Parent]

Allowing time off the unit was, for one sibling, something that I found really good, [my sister] was allowed to be discharged for days at a time, to see her family, it was nice to see her outside of the intensive care unit. It felt normal for us all.
It was acknowledged how rules for each YP in the unit and for leave will vary, but sometimes this was noted by families and seen as unfair because it hadn’t been clearly explained to them why certain rules were being imposed. Parents wanted better communication and clarity about what specific rules were in place, for example one parent described how, *despite explaining about my shift work and other kids, being the only driver, they told us for leave we had to get her back within 24hrs of the time that we pick her up, this was so rigid but it’s what we were told. However, we’d see other people getting treated very differently getting early pickups and late drop-offs.*

We heard how issues with other patients and difficulties with their relationships created tensions. Several parents believed their child came out worse than before they were admitted, for example, *[S] learnt self-harm behaviour from other girls in the unit and hasn’t ever done this, I feel like the whole experience of being in an inpatient unit…damaged her mentally.* Parents described how their child was susceptible to being triggered by other patients, with a toxic competitiveness in some cases.

“She became institutionalised then as she was terrified of coming out. Being a high achiever, she had to be the best at being poorly” [Parent]

11.5. The need for a smoother and more supported discharge

A common challenge voiced by many families was dealing with the discharge from hospital back home and into community provision, and feeling terrified and daunted by this, especially when a robust exit plan was lacking. When it happens too quickly, as often was the case, it can be difficult to manage. Discharge often seem rushed, with insufficient preparation or support, for example, *we discussed a trial period of home visits… the next thing we know she’s discharged and we have no idea what the plan is.* Parents argue that the transition plan is critical but that it didn’t seem there was sufficient planning time in the form of home visits or day leave. Some parents said they would prefer professionals to exercise more caution regarding discharge.

YP need a lot of continued support to help transition to the community and minimise risk of readmission, and families said they need to be involved in this process too. Good communication of a thorough plan is needed, so everyone feels confident, safe and supported in what’s going to happen.

“When they come out it’s important to have a proper plan in place, written down… how regular appointments will be, who’s involved, how is school going to be reintroduced. We’ve got no support whatsoever since she came out. It can actually be a very scary time for everyone. My wife is going to care for [K], but she’s absolutely terrified of it spiraling like it did before. I do feel like we’re going to be on our own with it.” [Parent]

It seemed to some parents that some units were resolved that a readmission was inevitable, for example, *We were told she might need to come out of the unit and fail to realise that she needed the support.* According to parents, some community teams and IP units seemed to have different agendas which meant they were unable to agree and work together.

“The units say that they no longer discharge patients based on height weight ratio, they discharge them based on mental attitude. So the community team had a big row with them in the CPA saying
they don’t want her released until she’s 100%... The community team want them as an IP for as long as possible, which doesn’t feel supportive or caring.” [Parent]

It felt damaging for families to see such disagreement between services, described by one as a passing off of care. Services need to communicate with each other, agree on certain policies and follow them with belief and commitment so that YP and families know what to expect, feel safe and have confidence it will work.

“She was discharged as they said there’s nothing more we can do, she was terrified of coming out. The support worker didn’t feel she should be discharged yet and I didn’t either at the time, but I could see that she was becoming institutionalised and needed to get back to reality.” [Parent]

Parents recognise that resources are limited but did expect more joined up support from services, with the impression that they would be working much more closely with each other. Parents described how they can become aware of some of the shortfalls of the services and lost confidence. One parent described here how the lack of planning for discharge had difficult consequences, …the exit plan was the most shocking part of it, her dad and I were shocked at the speed at which it happened, her thoughts were no different, it was still all in her head and she was just going through the motions. When she came out, she plummeted, it was impossible, we went on as a family, but it was a disaster, she was just the same no different, restricting food.
12. Safe Spaces – what is needed in times of crisis?

It’s important to note that discussions about Safe Spaces often involved explaining to the families what this might look like, giving examples and ideas without many suggestions or ideas. It felt like a concept which was hard to envisage to many people we spoke to.

Parents described many challenges in navigating a child’s crisis, one of them main ones being engagement and willingness, when their child didn’t want to accept support. Some felt that any crisis intervention drew attention to what they didn’t want to think about, making things worse and stiffening their resistance.

“It’s all very well developing these things, but what if someone doesn’t want to engage with these services.” [Parent]

An issue was also raised about under 16s, where parents were unsure as to the practicalities of getting to and from the Safe Space. One parent told us that people make their own safe spaces, meaning crisis support for some didn’t necessarily mean a formal place to visit, and could actually mean a variety of things.

“It doesn’t have to be somewhere different, to just exist would be nice, somewhere [our child] wanted to go. If things got stressful here a physical alternative it would have been nice.” [Parent]

Most parents did like the idea of having an alternative measure to keep their child safe, for example they suggested, how about a drop in, somewhere young people in crisis could just go if they weren’t great and there were staff there all the time, a friendly face, an informal setting looking ordinary like a café. Parents could take them, and you don’t need an appointment.

With crisis support it felt important to consider how the whole family is affected, because crisis for our child generally meant crisis for us parents. It gets very intense for everyone, sometimes just to have a break would be good.” It’s clear that respite is helpful for families in crisis, but it’s also important to bear in mind that for some families, hospital admission is their preferred option during periods of intense difficulty. Some acknowledge that safe spaces might give some short-term
respite, but that it can be a huge relief when your child is in IP because you know they’re being looked after, and being outside is frightening.

12.1. Parents would like extended hours to be able to contact services

Parents told us that in crisis, some more neutral support and advice, ideally in person, would have been great, rather than a phone call to someone that you didn’t particularly trust. It was felt that a clear point of contact 24/7 for out of hours care would be really helpful. A crisis phone number, but ideally more resources behind just a phone call too, someone who is contactable 24/7 on the phone, who could come to your house if necessary. An overriding wish from families was for services to have extended hours, over evenings, weekends and holidays.

“CAMHS Outreach need to be more 24/7 to reduce IP… note the impact on the family practically and emotionally… do more to support them and actually indicate what’s available.” [Parent]

Parents want crisis support to be there 7 days a week, and out of hours services that actually are out of hours and don’t close at a certain time. They were also clear that they want support which is robust, effective and take crises seriously. One parent explained, if someone calls and says it’s urgent, someone should get back to them asap, not in days. Basically you’re dealing with a very ill person at home, trying to stop them going into hospital… the support just can’t be absent.

Parents told us that weekends were predictably more difficult are generally when everything kicked off. Families described weekends as terrifying at times, when they are at their most tired point, and their child behaving in ways which undid the help they’d had during the week. They remembered counting down the hours until the community team were back open. To be met with an answerphone or someone advising A&E as their only options, many parents felt abandoned and frightened.
12.2. A&E isn’t helpful and should be avoided

Families really welcomed an alternative to A&E particularly on a weekend. Most who had used A&E when their child was in a mental health crisis had negative experiences, describing it as *hit and miss* to *absolutely useless* to *destroying us as a family*. Families felt frustrated at the lack of alternatives, not only because A&E felt unhelpful at best but at worst *you go once and then it becomes a triggering place*. It was felt that some staff in the general hospitals had very limited knowledge of mental health care and lacked sympathy, which not only made YP feel awkward but could also reinforce their belief that they aren’t ill and don’t need treatment.

“I rang 999 because [S] lost it and grabbed a knife. I didn’t know what to do. She didn’t need physically to have a bed, didn’t need to be in a hospital setting, it was hard for her, she felt guilty and it was distressing. It’s about having someone to speak to. If someone could have come out to speak to her at 10pm at home, she might not have gone to A&E.” [Parent]
Appendix 1. Notes on eating disorder services

Particularly in relation to ED cases, parents had a strong feeling that IP settings were doing something unique, and that the hospital offered things that the community couldn’t; tube feeding, a section, and it saved [J]’s life. Some parents felt that there’s too much emphasis was put on care in the community when it felt non-existent. CAMHS support for ED in the community was inadequate in many parents’ experience. One parent commented, we wanted real home support, not meal support… what is that even about? Someone comes out and watches you eat a yoghurt!

Without adequate community resources, parents described it feeling like a revolving door to IP. Parents added that sometimes community care is not what a YP needs, as there are certain bits of care that you can’t do in the community, certain people who, through no fault of their own, cause themselves more harm in the community. Parents felt it was vital for YP to receive treatment relevant to their illness in the right environment, and it was a worry that YP might not receive this due to services’ goals to reduce IP admissions, particularly when it came to ED and lack of specialist units.

Parents were particularly passionate about the need for earlier intervention in relation to ED cases. It was felt that if specialist services were easier to access earlier on, even more complex cases could be supported to shorten an IP stay, and ultimately aid recovery. For example, we were told, You’ve got to wait until things get bad enough to meet the threshold… just waiting for her BMI to drop – if we could have had some targeted intervention then this all might have been avoided.

“Is this a crisis led service? It feels like it.”

There was also an overwhelming feeling that ED criteria got in the way of a timely and helpful intervention, because by the time a YP fitted the criteria and help came, this was too late and the illness was too hard wired by then to make any difference. This demonstrates how rigid pathways make it difficult to access services and personal treatment, a strong theme throughout our discussions.

The need for more focus on psychological aspects in ED treatment

There was an overwhelming feeling that the emphasis on the physicality of the disorder was unhelpful in treatment, and there was a lack of focus on psychological recovery. Parents were passionate about this, wanting staff to stop focusing so much on the eating as that’s a symptom of other things…we were in constant arguments about when she needs feeding… but she needs
help… we felt like therapy was the way forward. This was a recurring message from many parents, for example, we felt like the root of the problem was a depression, that turned into an ED, but nobody seemed to be interested in looking behind the eating behaviour at the root problems.

Families understood that the ED was a symptom of wider mental health issues, but felt this wasn’t reflected in the response. This was confusing and frustrating. The medical side is compromising everything for weight gain… if you don’t gain weight then no therapy.

“We saw the psychiatrist at CAMHS, he said right away, it’s not about the food, it’s never about the food. But then after that, nothing relevant happened apart from the food” [Parent]

“People’s weight isn’t necessarily an indication of whether people have an ED or not. It’s a very crude threshold. What is needed is a more holistic criteria – e.g. how much is this affecting your life? And exploring thought processes” [Parent]

Parents did appreciate the complexity of the treatment, as one parent explained, you have to respect that, it’s probably one of the hardest tasks in mental health to try persuade an anorexic of what they don’t want to hear, if it’s even possible. But the general message from parents was that the approach was too rigid and limited. A parent explained, I’m not sure about the ‘tried and tested’ approach of feed and the mood will lift. What if it doesn’t? Where is the next stage?

“With CAMHS it’s just about the eating, but what about the rest of it? No in-depth to the mental side, like what has this person stopped doing for example? It’s not being treated like a mental illness. ‘Eating disorders’ need redefining, reclassify it and come at it from a completely different view. It’s like with cancer, not looking at the cancer but trying to put the wig on. Medicine has moved on, we used to have one road but now we have multiple options” [Parent]

It’s important to note, however, that this wasn’t every parents’ experience, for example we also heard, when L first became ill, community CAMHS just focused on her eating, they didn’t focus on any psychology or therapy or anything, they said there’s no point doing any of that until her brain is being fed and she’s a heavier weight. But all she was doing was declining. Whereas in an inpatient unit, they don’t subscribe to that, they give them everything together because everybody is in the same building, so they give them the therapy and get them to see psychology even though they’re not eating. She saw the psychologist pretty much straight away.
Appendix 2. Notes on specialist CAMHS

Families are reluctant about ending support with CAMHS, preempting difficulties getting back into services if their child becomes unwell again. It was felt that early intervention is crucial in the case of a relapse.

“We’d be happy with less than [a weekly visit from CAMHS] if there was a feeling we could get straight back in the system if we needed to, but we don’t like the idea of being signed off because it’s not case closed. We’d have to go back to the GP and go back on the waiting list etc. so we still have CAMHS visits.” [Parent]

Most parents we spoke to were underwhelmed by how helpful community support was. They felt they had to push for even basic therapy in the community. It was a shared view that the community didn’t put much value on psychoanalysis or psychotherapy. Parents voiced wanting more confidential therapeutic space available for some of the underlying difficulties to be thought about. This can take time… Some YP need time to get to know the therapist, build up a reliable relationship before the work can really start.

Often promises of psychological support in the community hadn’t been fulfilled, for example we were told by one parent, it turned out [our CAMHS] doesn’t have a clinical psychologist and has been trying to recruit for some time. This was 9 weeks ago and there has been no therapeutic input, meanwhile L’s health has gone downhill. Another parent echoed this with further examples, being told family therapy might help… to then wait 2 months to be told it would be a once a month appointment.

To keep things simple and clear, one point of contact may be more effective for families. It was suggested as helpful to have one person to coordinate, so you know things will be dealt with. Despite families wanting a minimal number of professionals involved in coordinating their child’s care so as to maintain continuity and clarity, there was a sense of things not working - for example, if that one key worker was off sick. Nothing got done, unless you ring and ask and nudge, someone else might take it on. Families recognised the importance of a balance between
staff within a team working together, with strategies in place to be able to pick up another's caseload if needed, alongside maintaining that personal continuity of care.

It was felt that offering impersonal treatment is ineffective and wasteful of resources. A more holistic approach that values the families’ experience would give the whole family more confidence and hope for a solution. Parents ideas of a holistic approach were things like support positive things in the community – family, schooling, anything that is nurturing. Look at the whole picture, it starts in the home, there needs to be home life support… normal activities and recovery. This idea of wanting more support around everyday activities in the community was a common one from parents, who felt that emphasis needed to shift from food with ED and focus more on the mental health aspects of the illness. See more about this in the ED section.

Many families voiced having to fight for a wider range of approaches, despite it being a written recommendation. More treatment options are needed, such as multiple therapy options, and different approaches on offer. When considering offering these options it is important to make them accessible by varying times and locations, to make it reasonable for families to be able to attend regularly. It’s difficult for us to get to everything consistently as [Dad] works shifts. It was felt that if the therapies are believed to be genuinely useful, then services need to find a way to work with families in a flexible manner. Location came up as a recurring problem for families, feeling like things just aren’t on offer in some areas.

“There’s not enough support locally, I couldn’t tell you what’s available.” [Parent]

“It was really helpful when (the community team) came they did things like blood tests at home.” [Parent]

Families felt that services should have the capacity to be person centred, to have a more flexible, tailored approach to the individual. It was felt that rigid treatment plans don’t help the YP feel understood or listened to. In trying to follow a set pathway, sight of the individual’s needs can be lost.

“Not everyone fits in the same mould, it never works. There’s a broad way of dealing with things, but you have to treat every kid individually at every single level for anything to be successful. As soon as you make things policy or statistic based it’s gone.” [Parent]

Parents also expressed feeling like their child was being talked at instead of asking them what they want. The YP needs to be involved as well, listening to what they’re actually saying, not talked over like we know better. This approach can disempower the YP, negatively affect their self-esteem and willingness to engage in treatment. Parents themselves also often felt their feedback was not required or valued. A hierarchy of professionals made some parents feel they had to comply with instructions and not question them. Services need to respect and utilise parents’ experience.

By listening closely it was felt that a well thought out treatment plan can be arrived at together with the YPs input, CAMHS need to focus on what’s really important, which can be different for everyone. Find out what it is that has led that young person to use that as their coping strategy and is there anything they can give them that is any less destructive.
“There were good people who were sensitive enough to pick things up without imposing their own thoughts, …actually what the child is doing rather than the model they had in their mind already.” [Parent]

Listening is vital but of limited use without being able to follow it up with an offer of choices to suit the individual. *We got offered online advice and phone calls, but my daughter won’t speak to anyone on the phone she’s not that outgoing and confident.*

“We were offered basic CBT for daughter, but told they didn’t think it was going to be effective, so we asked what else and they said nothing” [Parent]

“It’s so wrong that they shoe-horn you down that road, I want another option apart from CAMHS as I don’t think its fit for purpose. 6 sessions and you should be cured? No.” [Parent]
Appendix 3. Notes on schools and education

Families felt it very important to get school on board. Educational links are vital for a YP to feel supported and able to cope in the community and stay in school if that is appropriate. It’s key to have CAMHS practical support to help school understand, and maybe do an assessment at school about what they may have missed, so there’s a point of reference. When schools and CAMHS join up well it can be amazing, for example [school] totally stepped in, did supervised eating to help [M] stay in school, supported by CAMHS staff.

“The school therapist let F down. F had a suicide attempt before [date], we [parents] didn’t know but F told her school therapist and they didn’t do anything. This should have been escalated. If the therapist said something then this could have all been avoided. I’m sure it could have. Maybe the therapist was out of her depth though. There was no feedback for us parents, no school meeting. As a parent when you’re not hearing anything you just assume everything is okay. We hoped F or others would have people at school they’d feel able to confide in and be helped.” [Parent]

It was felt that links with schools were inconsistent across areas, meaning the parents had to sort it all without CAMHS. When this support is missing, school can become very difficult for YP and families to navigate. CAMHS hadn’t contacted school, so [our daughter] walked in on her first day, with no named person looking out for her at mealtimes, she lasted 2 weeks then crashed.

When school and IP liaised with each other, It was effective for supporting a YP’s care plan and continuity but this was found to be lacking for some families, with IP and school not communicating and doing separate things, so most parents were being proactive in mediating between the two. It is equally important to recognise that mainstream school may not be appropriate at some points in a YPs life too, for example when school was a major source of anxiety for a young person.

Siblings felt very strongly about mental health education in schools; They felt teachers need to be more knowledgeable and schools need to better educate the pupils, increase everyone’s awareness in how mental health can impact young lives and what role they can play.

“It would be the more ideal situation to have lessons with my peers, because they can talk to you without knowing your personal perspective on stuff, and that’s kind of what bothers me about talking to my friends.” [Sister, 14]

Siblings felt it was especially important that mental health topics are covered consistently in the regular curriculum for all students.

“I feel like in years 7/8 you’re more uneducated about [mental health] and quite a lot of people at that age don’t know what’s going on, so they need to be educated even from primary school age. Maybe not anything that might traumatize them, but talking about depression or anxiety might just help them understand that sometimes people are really sad because of certain things.” [Brother,13]

Siblings also spoke about how their experience impacted school life. They wanted better ways of handling things sensitively for students and staff in schools. They described how it can be hard to
balance support with confidentiality and sharing of information. We heard how school can be helpful, in that for a lot of people school is their escape and they don’t want to miss lessons. Time off school after traumas around mental health at home can be difficult to manage at school, for example one sibling explained, *when she first went in the amount of times we were up and down that motorway, the impact on our school work has been big.*

“I don’t want teachers or anyone to treat me differently because of it, but obviously, with a confidential thing like this you don’t want to tell every teacher about it, so it’s difficult for a teacher to be understanding about something they don’t know.” [Sister, 14]
## Appendix 4. Interview questions

### Parent interview

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<th>Question</th>
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<tbody>
<tr>
<td>Age, gender, your relationship to YP</td>
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<tr>
<td>Initial thoughts re NCM</td>
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<tr>
<td>How might this new approach address any difficulties for families or YP with the way the services operate currently?</td>
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<tr>
<td>Might it make anything harder or worse for families?</td>
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<tr>
<td>How do you think the Intensive Community Support service will need to work to help you support your YP e.g. to avoid long stays in hospital? What would need to be in place?</td>
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<tr>
<td>SAFE SPACE IN TIMES OF CRISIS. What would you want from this to help manage? How would you best access it?</td>
</tr>
<tr>
<td>Other comments re model and approach?</td>
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<tr>
<td>ARE THERE ANY OTHER FAMILY MEMBERS WHO MIGHT TALK TO US?</td>
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### Sibling interview

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<tr>
<td>Age, gender, your relationship to YP</td>
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<td>Initial thoughts re NCM</td>
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<tr>
<td>How do you think the services could work to support you as a sibling e.g. so you can be helpful and also keep well yourself? What would need to be in place?</td>
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<tr>
<td>Other comments re model and approach?</td>
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Appendix 5. Illustration of NCM