ALTERNATIVES TO ADMISSION

to CAMHS Inpatient Mental Health Services in Humber North Yorkshire

For Children and Young People with an Eating Disorder

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Yorkshire and Humber Involvement Service

CONTENTS:

Background

The Humber and North Yorkshire Specialised Mental Health Learning Disability and Autism Provider Collaborative (HNY PC) are responsible for commissioning Child and Adolescent Mental Health Services) CAMHS Inpatient Services in the Humber and North Yorkshire area. There are 2 CAMHS inpatient units; Mill Lodge which is situated in York, and Inspire which is situated in Hull. HNY PC work closely with these 2 units in relation to service development and delivery of quality services.

The Yorkshire and Humber Involvement Network have been commissioned to work closely with the Humber and North Yorkshire PC, and bring together service users, families, staff and commissioners to share they experiences and views and work together to improve the quality of services and support that people receive. The Yorkshire and Humber Involvement Network are commissioned to increase involvement opportunities within the 2 CAMHS inpatient units and ensure involvement of CYP and families within the HNY PC.

Aims of the Alternatives to Admission for Children Young People (CYP) with Eating Disorder (ED):

To reduce admissions to Mill Lodge and Inspire for CYP with an ED
To support earlier discharge and reduction in length of stay at Mill Lodge/Inspire for CYP with an ED

Plans are progressing in relation to service development for Alternatives to Admission for CYP with an eating disorder in Humber and North Yorkshire. The Network provided opportunities for CYP, their families and professionals to consider the plans that were suggested and share their thoughts about what could be in place to prevent admission for some of these Young People.

We hope this report will cover some themes and trends that are familiar to your own journey, but also allow conversations to start for you and for your experiences to be heard to improve quality of services and care delivery in the future.

Methodology

We started this project by attending the Alternatives to Admission for CYP with an ED Workstream meeting and gaining an understanding of where the plans were up to for both

LYPFT and Humber. We then developed some questions and themes that we took to this workstream in the form of a Power Point Presentation (appendix 1). We identified the main focus as being:

- Understanding people's experiences
- Thinking what works well and what could be done differently
- Finding out their views on what is being suggested

Our proposal to the Workstream was as follows:

- Consult with CYP, families and staff within Inspire and Mill Lodge
- Consult with CYP and families who are currently in the community at risk of admission, or who have previously experienced an inpatient stay
- Consult with CYP and families who are currently in an inpatient bed out of area

Who did we speak to?

Children and Young People

- We carried out 3 engagement sessions at Mill Lodge and spoke with 3 CYP
- We spoke with 3 CYP who have previously been an inpatient in HNY
- We have spoken with 1 YP who is in an OOA placement

Families

- We spoke with 1 family of a current inpatient (Mill Lodge)
- We spoke with 2 families of YP who has previously been an inpatient in HNY

Staff/professionals

- We had 16 responses to the staff survey/questionnaire. 2 have been from inpatient services, 7 from community services

	Mill Lodge	Inspire	Community (at risk)	Community (previous admission)	OOA	Total
CYP	3	3	0	3	1	10
Families	1	0	0	1	1	3
Staff	8		8			16

- Despite advertising the opportunity amongst the 4 community teams we didn't speak with any families or CYP who are currently in the community at risk of admission, or any families at Inspire.

How?

- Meetings were held with the Inpatient services Mill Lodge and Inspire to discuss the project and arrange to speak with the CYP and families about the project.
- We made contact in June/July with all four community teams. Introductory meetings took place where we introduced the Network and our involvement with the Alternatives to Admission Project. We shared our poster and information for them to share with appropriate CYP and families. We followed this up in August with the staff survey link and a reminder to get the word out among CYP and families about opportunities for involvement.
- We had regular meetings with Charlotte Piper the family Ambassador who passed on our poster and information to the families of people currently in Mill Lodge and Inspire.
- Contact was made with the 3 Specialist Eating Disorder Unit's where there were CYP Out of Area to offer the same involvement opportunities as to those within HNY. To do this we liaised with Case Managers and contacted the hospitals directly with information to share with the CYP and families about how to get involved.
- Staff were offered the opportunity to fill in a survey / questionnaire on Microsoft Forms. (Appendix 7) This was sent out via the two inpatient services as well as round the four community teams, and also advertised on the Humber Global.
- We shared information about the project with the Keyworker service, Community of Experience, Humber Global, Young People's Advisory Group and Humber Youth Action Group.

Alongside this we also had discussions with an independent Expert by Experience (EbyE) who has previous experience of being an inpatient in multiple services both in and out of area as well as working as an EbyE and with experience of Project Work. She helped us to think about our methodology, the questions posed, our poster and questionnaire, and some areas to be mindful of when speaking with CYP and their families. She has also continued to offer her thoughts and experience throughout the project including helping with the identification of themes.

We decided to go with the process of listening to people's experiences told in their own words and collating themes from the collection of narratives, keeping the spectrum broad.

We had areas to prompt discussion as follows:

- Tell us about your experiences
- Tell us about what could help
- Tell us about what could change
- Ideas of Alternatives
- Magic Wand – what would you change if you could

We offered a range of ways to get involved with the project via a poster (Appendix 2) that was sent out. These included:

- Face to face discussions
- Microsoft Teams /Virtual meetings
- Telephone discussions
- Workshop / Group discussions
- Completion of a questionnaire
- Email correspondence
- Any other way that individuals would prefer to contact us or engage.

We had an option of people filling out a questionnaire. For this we came up with 4 different questionnaires that were for the following groups of people:

- CYP Inpatient Questionnaire (Appendix 3)
- CYP Community Questionnaire (Appendix 4)
- Family/Carer Inpatient Questionnaire (Appendix 5)
- Family/Carer Community Questionnaire (Appendix 6)

We then spoke to people over a 3 month period mostly face to face or virtually via Teams. We also developed a Staff Survey on Microsoft Forms that was sent out towards the end of the project after the School holidays. This was carried out differently to the CYP and family/carer work due to time constraints and resource within the team. We were keen to get the views of staff in the project however we wanted to focus our main resource on the CYP and Families and were therefore able to offer less options for engagement to the staff.

Some feedback in the coproduction of our method of engagement for the project

"Asking people 'what could we be doing better' but then taking a long time to change it. This doesn't help people now which might not be fair to ask or might upset people. People are altruistic and empathetic but also in crisis people need help NOW and it might be hard to think like that in the middle of it all."

It is also worth highlighting that feedback was gained from CYP and families at different stages of their treatment pathways, and from CYP, families and staff from a variety of different geographical areas in HNY which is covered by 2 inpatient services as well as 5 different community teams that have different provision available. They have also changed what they deliver over recent months so feedback gained from CYP and families may at times reflect a provision that was not available at the time, but that is now available, or vice versa.

Findings

These findings will include key quotes that outline some of the voices that help capture the key themes that can be seen across people's experiences (Service users, Family and staff).

The colour of the highlighted text identifies the voice of the participant:

Children and Young People	Families and Carers	Staff

Experiences prior to admission

The people we spoke to generally felt that they received little support prior to admission, or that the support they received was not the right support, or enough of it. This was true of families as well as the YP.

"Received very little support other than being told to follow meal plan"

"I had concerns that the support was just not intense enough at the start of the pathway/disorder development"

When the support was provided it was mentioned that it was too close to the point of admission.

"Home support ended up being provided but was too late and lead to an inpatient as an emergency admission".

Experiences of services

It was identified that admission was a traumatic experience and families received little information about how things are on admission to an inpatient unit.

"It was an extremely traumatic experience as I got taken in a van for 40 minutes here. It felt like being kidnapped. It was better to be here 40 minutes away though than the 4 hours and being sent to London".

"She was the only inpatient with ED and lead to complexity, in which it was identified a lack of expertise to deal with this case at the time. This was a traumatic time in which she didn't eat for 9 days and she was transferred to Mill lodge"

The inpatient stays were expressed to lead to a reliance on these services and lack access to positive things in YP life i.e., school, friends, and family.

"I just miss my family and friends. This could have helped me stay at school"

"The transition out now is difficult as she could be going back to school but lost everything including her identity as it is now taken over by the eating disorder."

This made the transition difficult to move back into the community as inpatient units become the norm for the YP and for the family/carer.

"Shorter stay or alternative could help this as now every positive step isn't a positive step to her … she has become dependent on the service."

"The thought of the support she is currently receiving has led to us all finding the thought of her coming home scary – that we are all becoming reliant on the support she is receiving as that is her life, her identity. But we are grateful for the service."

"Inpatient life becoming the norm."

"Artificial environment of which the intensity of treatment cannot be replicated in the community, so increased chance of relapse."

The inpatient stay was identified as having negative impacts on the YP at times.

"There were drawbacks as she found it became a competition between the patients with ED in who can intake the least food"

"I feel young people with ED are staying as inpatients far too long, often picking up copycat behaviours alongside their ED diagnosis."

"Concern of YP making comparisons with other YP in the unit and increasing difficulties."

Alternatives to Admission Proposals

These proposals were met with optimism from YP and their families.

"Good to lay out all the options for people so they know what there is and can make an informed decision. This would have really helped me. Something like a day service would have helped me and my family massively"

"I really like the ideas they sound brilliant! I would have some concerns for the experiences of families throughout the night though depending on how they were. It would have to have been well risk assessed"

It was thought that these proposals could lead to a smoother step-up and step-down process.

"I think local day services would be very beneficial as a step-up approach to community support, it enables staff to be able to offer in the moment support and an increased level of observation. Furthermore, it makes physical monitoring much easier, as GPs will not always be agreeable to providing regular ECGS and blood tests."

"That there is less of a gap between inpatient and community services so young people can step down with intensive support which can slowly be decreased as they settle back into the community rather than having to go straight back to 1 or 2 appointments per week when they have had staff there 24/7 in hospital."

"Having a day service might enable those who are currently inpatients to be discharged in more of a timely way with a step down from the inpatient team into the community."

Nevertheless, it was expressed the need for more options and an individualised pathway, where treatment options are made based on individual need.

"The proposals are such a good idea especially for Autism patients / as they might struggle with the transition into hospital so might make things easier"

"Be wary of narrowing down options as actually the more options the better – everyone is an individual and they might all benefit from something different. People say 'well we can't do everything' - Well why not?"

"It is so important to base it around the individuals needs and not be set on what you will be providing"

"It needs to be adaptive around treatment dependant on individual rather than rigid to the services plans"

"It would be great to transition back into the community, or have options instead of admission for some people, but it needs to be run by the community teams so that the same people can continue to support you throughout your pathway and to gain other support and know more about other aspects of life – not just hospital".

There were concerns over the support that will be needed for families to make this an effective and sustainable process.

"It was so distressing for us to go back and forth and her being so unwell within these different services, it would need to be considered how difficult it might be to get the Young Person there every morning if they weren't willing."

Multiple diagnoses

We spoke to a number of YP and their families with a range of diagnoses such as PD, ASD and PDA as well as the eating disorder, and the themes that came out of that were around feeling like the only treatment on offer was for their ED rather than anything else.

"They couldn't treat me because wasn't aware of PDA" with no units offering PDA or having trained staff.

"Feels like there is a real challenge in dealing with multiple diagnosis as focus is just on ED without taking both into consideration"

"There is a real need for BPD training"

When identifying these needs, it is important to understand the different illness contributing and offer support and options that support with all these needs.

"They need to explore that there may be another illness contributing"

"More intensive support such as meal support at home. NG feeds being offered in an outpatient setting. Exploring different ways of treating ED not just FBT as this does not always work particularly for people with autism."

Regards to plans for A2A… "I think it could be useful to have one of the available options cater more towards neurodiversity."

"She has shown Autistic tendencies and although staff reassure me of staff training/qualification in this, I don't see it happening in practice and seems like a blanket process is being repeated, as they keep doing the same things. They need more options for staff that has influence in this department i.e., keyworker service."

"Treatment OOA was outstanding, none of them had training and they were scared but they were willing to try with considering all my diagnoses and that saved my life"

"It about building trust, I trusted an assistant psychologist that broke down my BPD to help me, but didn't get that from psychologist. She was the most helpful person I came across in my journey. Now I want to be a psychologist because I want to help people like she helped me"

Out of Area experiences

CYP and their families discussed the difficulties that they experienced when accessing services out of area.

'If, buts and coconuts' I don't know if it could have been prevented it is impossible to know, but it would have definitely helped to have the day service option for both me and family. It would have taken a lot of stress off my family, all that carting me about, travelling, costs etc

"It was very difficult to maintain contact in a meaningful way when so far from home – some families could only afford to visit once a month, someone was there from Ireland so family couldn't visit. Some hospitals restricted phone use also – only a brick phone – or half an hour call 2x a week – hopefully that is better now"

"Very hard for parent being out of area as lots of travel and accommodation and associated costs"

"It appears that often young children are sent out of area which makes it difficult for family to be a part of their recovery at times."

"In my experience the further the admission is from the YP's home the more distressing the YP and family find the admission."

While others where thankful for the help they received out of area and mentioned that it is necessary for the specialist support needed.

"Treatment OOA was outstanding, none of them had training and they were scared but they were willing to try with considering all my diagnoses and that saved my life"

"They are not an eating disorder specific unit so some young people go out of area as they need a more specialist approach"

Support

CYP and families did reflect on the positive support being received from inpatient provisions and community teams

"I heard a lot of bad stories about these different units, but my experience hasn't been bad…. The support has been good here so far. I came here not wanting any help with my self-harm and suicide attempts but now I am open to it and want it to change"

"When we eventually got her in to hospital the inpatient care was person centred with a holistic approach and it saved her life"

"The support offered from a team's approach in CAHMS was beneficial, although there was a lack of psychiatrist until later but had access to a psychologist"

"There are many positive in the unit including the rapport built with staff being more consistent and it happening naturally… this also offers her more agency and responsibility for her pathway"

“Inpatient care can work well for young people with an ED who have even a small amount of motivation to work with the team and move back to the community. When there are other factors however, inpatient care can become detrimental to a young person.”

Staff Themes

Lack of beds

Staff expressed how difficult it can be to find a bed that is local for the YP. This is a process that can see the health of the YP decline in the time of admission

“If we need an admission for our area it has been difficult to access a bed in HNY”

“We only look for an admission when we have exhausted all options - main challenges are actually finding a bed”

“Inpatient provisions appear limited and often children's physical and mental health can decline whilst they are waiting for a bed.”

Communication

When discussing the levels of communication between services it was generally determined to be less than desired.

“Generally, not great. Teams don't know each other and there are no real relationships between teams. Care planning often isn't collaborative.”

“I don’t believe there is much communication to the wider team at all.”

This was also dependant on the service that they were communicating with and the time the CYP has been involved.

“It varies dependant on the inpatient service.”

“I have limited experience with inspire but with out of area provisions this has been a real challenge for our community team”

This communication can be seen to create frustrations around care plans that are unrealistic for different teams, their contexts and the additional support for CYP.

“This could defiantly be better, prior to being admitted all seems to work well but there have been times when we have felt "left out" of the planning”

“Unrealistic care plans, suggestions of interventions of which the community team do not have access to.”

Differences in approaches/Interventions

The lack of continuity in approaches used between services can cause confusion. This is because of a use of different therapies and views on support applied in different services and trusts across the pathway.

“Our local access unit is in a different trust, which can make things complicated in terms of working together. Sometimes they have a very different view of what support a young person needs compared to our team.”

“I would like the inpatient unit to work more in line with national guidance in relation to the treatment of eating disorders like eating disorder specific units do. Then there would be less potential for confusion for families and the inpatient service and community team taking completely different approaches.”

Nevertheless, it was also discussed that there is a need for a broader range of interventions for the complex needs of individuals.

“Earlier acknowledgement that the formulation for the young person and family may be more complex than eating disorder and consideration to a broader range of interventions.”

“More flexibility for young people and families - many community teams use FBT which does not work for everyone and can become traumatic for some families.”

“More intensive support such as meal supports at home. NG feeds being offered in an outpatient setting. Exploring different ways of treating ED not just FBT as this does not always work particularly for people with autism.”

Family as part of the process

The inclusion of the family or carers was mentioned as an important part of this project. The inclusion of family will give them the support or confidence and capacity to manage the situation at home.

"I think a day service would only be helpful for young people with eating disorders if their parents were also there."

"Parents to be part of the work, guided and supported in meal and therapeutic support."

"Step up/ Step down from hospital … would enable family to step back into offering support at an earlier juncture increasing their confidence but equally allow time for physical stabilisation and parents to receive additional 1:1 support in preparation for the YP returning home."

Health inequalities

There was numerous inequalities and anticipated difficulties in regard to resources for CYP to access these services. These include the location and travel implications for access, possibly excluding some CYP from access and staffing implications.

"Location, spaces. Thresholds of care. Staff burnout"

"Anxiety-as it is a change"

"Parents ability to travel, lack of support to parents from Children's services"

"Language and cultural"

There were recommendations to help reduce these challenges and barriers to access.

"Creativity of care plan, bespoke packages of care, as YP could go to the day service on different days etc. good group, staff supervision as well as individual supervision"

"Systemic work to address the underlying factors of a young person's eating disorder interventions to optimise engagement in school and family life, limits disruption and alienation education or peer support groups???"

"Consideration would need to be given about refunding travel costs. Parents would also need to be supported to take time off work (without being financially affected) so they can support their child whilst accessing a day service"

Magic Wand Recommendations

The final question that we asked all stakeholders was 'if you had a magic wand, what would you change?' The answers produced a series of helpful recommendations as follows:

"A willingness to listen to the young people and their families, to really understand them and not dismiss them. To work with them in partnership"

"I would change the attitude and culture of services, so that people truly feel listened to and professionals follow through with actions"

"In the ideal world these would be the same service for the whole pathway or at least providing a person to help the transition throughout the process"

"…More support and understanding given at home with more home support, that is tailored for the individual"

"…A virtual meal support option so that you have someone to be there through the mealtimes at home… "

"More joined up work across teams including social care, more time with families spent on the unit."

"That all community teams follow the same model and have the same provisions so that the outcomes are consistent for the young people."

"If we needed access to a bed then we could get this without spending days and weeks ringing round the whole country"

"Clear admission pathways"

Key Recommendations

Here are some key recommendations taken from the above report that we feel would help support some of the concerns that have been raised through this project to ensure the best outcomes for the CYP in relation to alternatives to admission.

- Ensure that treatment plans for each YP within the day services are as individualised as possible, taking in to account all their diagnoses and treatment needs.
- Individualised care and treatment plans in place for the CYP that where possible is co-produced and in a format meaningful to them.
- Involve CYP and their families in each step of the process, providing a range of treatment options where possible, while listening to and understanding their experiences and needs.

- A family care plan in place that details how they would like to be involved and communicated with that is regularly reviewed with the families involvement.
- A plan for systemic work with the CYP and families to support their involvement.
- Working with CYP and their families in partnership, involving them in decisions.
- A key worker / professional who provides continuity and support across the whole pathway. Providing CYP and families with better support to help with transitions through the process.
- Community team working intensively with the CYP and families alongside/within the day service to ensure continuity of input and approach.
- Better communication between professionals, CYP and families at transition points to make the pathway less confusing for families and CYP.
- Support families through individually tailored home support (also consider virtual options for support).
- A shared understanding around different therapeutic interventions/models across the pathway in HNY that can be fully understood and outlined for CYP and families.
- Recruit and retain a skilled workforce that are trained regarding multiple diagnoses and specialist treatments.

Summary

We spoke to a number of CYP, families and staff over a 3 month period to gather themes and trends about their experiences and thoughts around the alternatives to admission project proposals. The majority of people that we spoke to felt that the proposals were positive on the whole and that they would be beneficial to many YP with an ED diagnosis. CYP and their families spoke about difficult experiences and how they could see things being improved with the proposals; as well as some caveats around the importance of tailoring any service to the individual themselves and a need for increased support at home before a crisis leads to an inpatient admission. Staff spoke about how improvements could be made around communication through the pathway, some local frustrations, health inequalities and a lack of resource. The importance of a holistic approach was key throughout, as well as having the specialist knowledge and workforce in place to manage the complexities around CYP with an eating disorder where this is often not the only diagnosis for that YP. These themes highlight some key recommendations to understand if the current proposals can be improved.

Next Steps

This report will be discussed in the Alternatives to Admission Workstream meeting to see how these recommendations can be incorporated into future plans around the alternatives to admission proposals. We will continue to work with the HNY PC and the CAMHS inpatient workstreams to ensure that the voices of CYP, families and staff can empower these recommendations and continue to improve the quality of care and experience for all. We will consider the development of Patient Reported Outcome Measures (PROM's) or Patient Reported Experience Measures (PREM's) for the day service proposals and ensure that anyone who goes on to experience these services are able to share their experiences and views in how the services develop. Consideration will be given to carrying out an annual follow up with CYP and families who go on to use the service to ensure that their views and experiences continue to shape the service going forward.

We would like to thank everyone who took part in this project.

Thank you

Yorkshire and Humber Involvement Network

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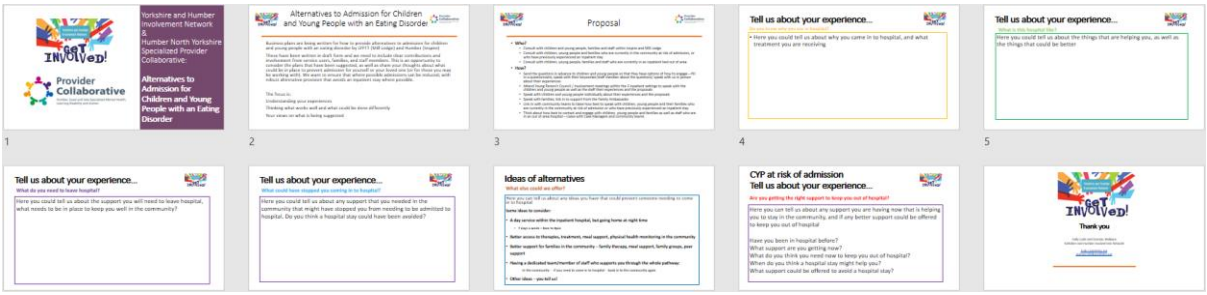
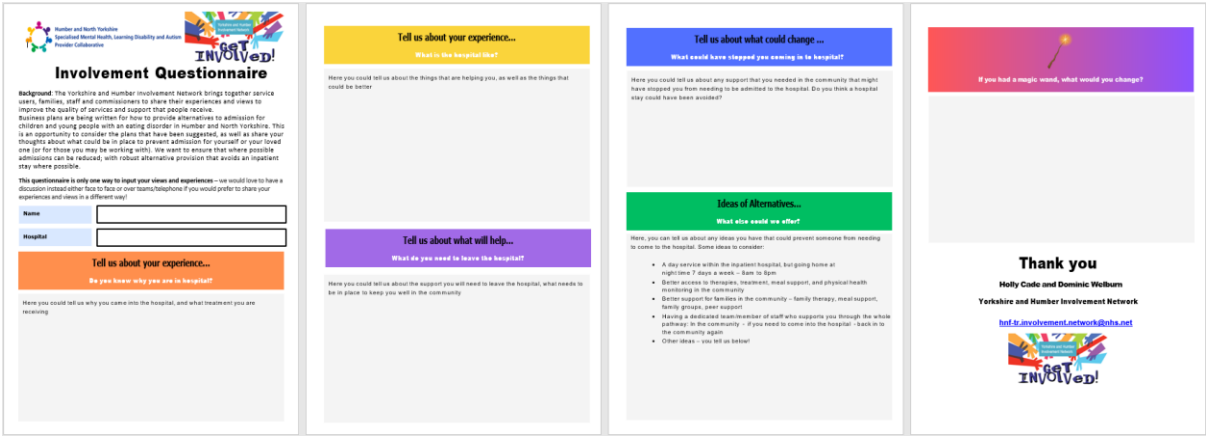
Appendices

Appendix 1 – PowerPoint used at workstream

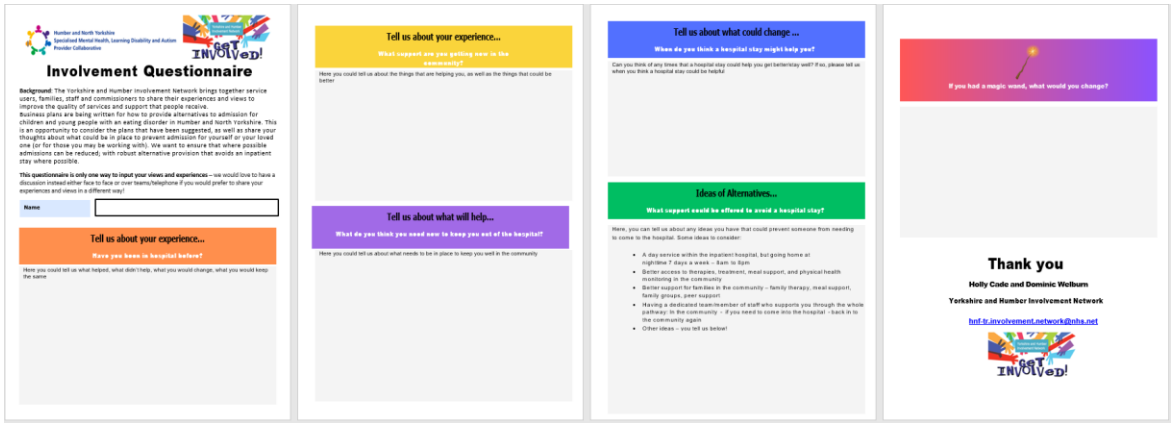


Appendix 2 – Poster

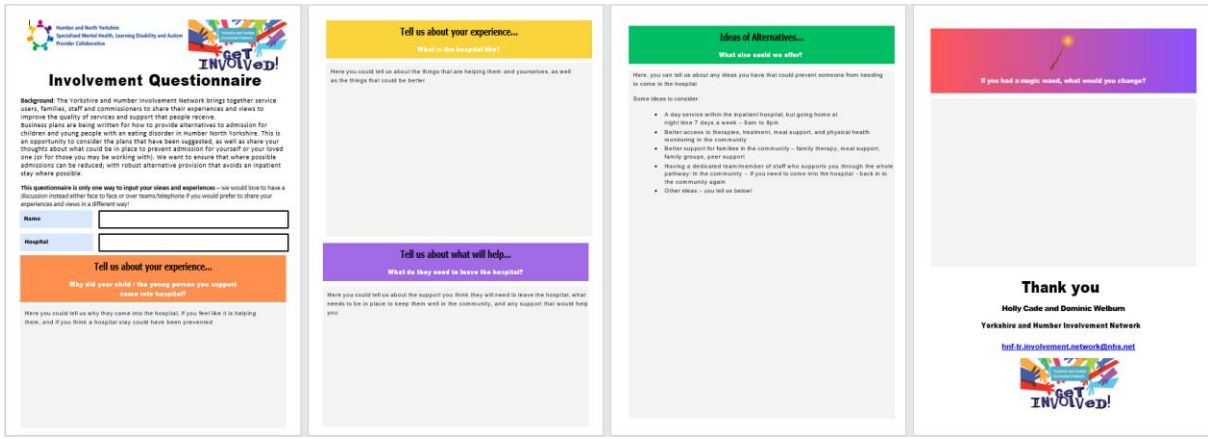
Appendix 3 – CYP Inpatient Questionnaire



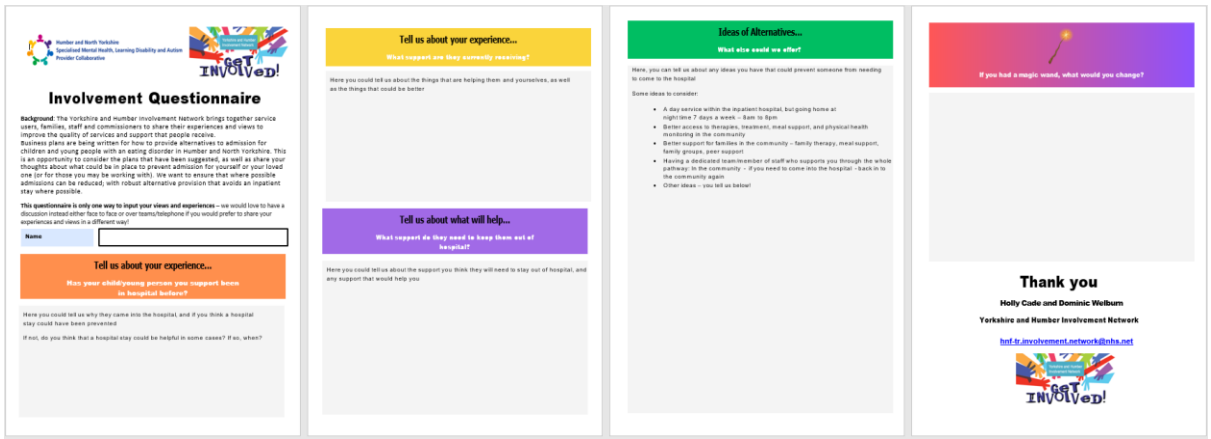
Appendix 4 – CYP Community Questionnaire



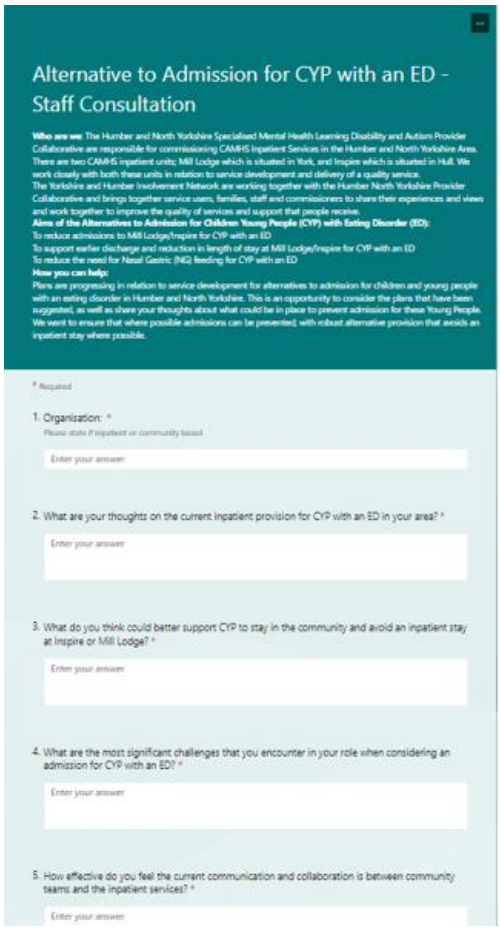
Appendix 5 – Family/Carer Inpatient Questionnaire



Appendix 6 – Family/Carer Community Questionnaire



Appendix 7 – Staff Survey



Alternative to Admission for CYP with an ED - Staff Consultation

Who are we: The Humber and North Yorkshire Specialised Mental Health Learning Disability and Autism Provider Collaborative are responsible for commissioning CAMHS Inpatient Services in the Humber and North Yorkshire Area. There are two CAMHS inpatient units; Mill Lodge which is situated in York, and Inspire which is situated in Hull. We work closely with both these units in relation to service development and delivery of a quality service.
The Yorkshire and Humber Involvement Network are working together with the Humber North Yorkshire Provider Collaborative and brings together service users, families, staff and commissioners to share their experiences and views and work together to improve the quality of services and support that people receive.
Aims of the Alternatives to Admission for Children Young People (CYP) with Eating Disorder (ED):
To reduce admissions to Mill Lodge/Inspire for CYP with an ED
To support earlier discharge and reduction in length of stay at Mill Lodge/Inspire for CYP with an ED
To reduce the need for Nasal Gastric (NG) feeding for CYP with an ED
How you can help:
Plans are progressing in relation to service development for alternatives to admission for children and young people with an eating disorder in Humber and North Yorkshire. This is an opportunity to consider the plans that have been suggested, as well as share your thoughts about what could be in place to prevent admission for these Young People. We want to ensure that where possible admissions can be prevented, with robust alternative provision that avoids an inpatient stay where possible.

* Required

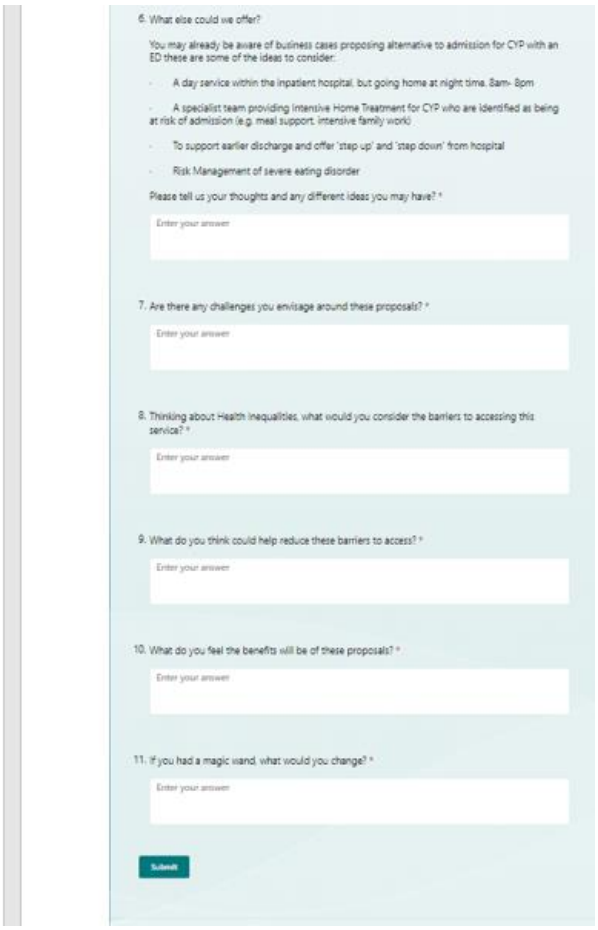
1. Organisation: *
Please state if inpatient or community based
Enter your answer

2. What are your thoughts on the current inpatient provision for CYP with an ED in your area? *
Enter your answer

3. What do you think could better support CYP to stay in the community and avoid an inpatient stay at Inspire or Mill Lodge? *
Enter your answer

4. What are the most significant challenges that you encounter in your role when considering an admission for CYP with an ED? *
Enter your answer

5. How effective do you feel the current communication and collaboration is between community teams and the inpatient services? *
Enter your answer



6. What else could we offer?

You may already be aware of business cases proposing alternative to admission for CYP with an ED these are some of the ideas to consider:

- A day service within the inpatient hospital, but going home at night time. 8am- 8pm
- A specialist team providing Intensive Home Treatment for CYP who are identified as being at risk of admission (e.g. meal support, intensive family work)
- To support earlier discharge and offer 'step up' and 'step down' from hospital
- Risk Management of severe eating disorder

Please tell us your thoughts and any different ideas you may have? *
Enter your answer

7. Are there any challenges you envisage around these proposals? *
Enter your answer

8. Thinking about Health Inequalities, what would you consider the barriers to accessing this service? *
Enter your answer

9. What do you think could help reduce these barriers to access? *
Enter your answer

10. What do you feel the benefits will be of these proposals? *
Enter your answer

11. If you had a magic wand, what would you change? *
Enter your answer

Submit

Appendix 8 – CYP & Family/Carer voices

Young Peoples and Family/Carers voices

I don't really know but I would have liked it because I just miss my family and friends. It could have also helped me stay at school.

I got told by both school and college that I can't attend due to my mental health, and this removed my basic right to education and affects my future career.

Support has been really good here so far. I can n not wanting any help with this self harm and suicide attempts but now I am open to it and want to change. I still do the same things but now I want to not want to do those things.

I heard a lot of bad stories about different units, but my experience hasn't been bad.

I have been self-harming since 12 and it didn't get any notice until 16/17. This was due to being under eating disorders and only taking measure for eating disorders. It was until I went to A5 and it was severe to the point of being sectioned.

Extremely traumatic experience as I got taken in a van for 45 minutes hes. It was like being kidnapped. It was better to be 45 minutes away than that of 4 hours and being sent to London.

I don't think it would have worked for me because of the self-harm on the night but I can see it helping others. So, it is dependent on the person.

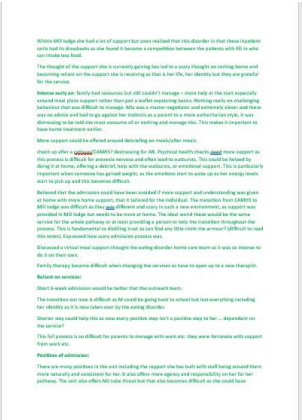
It explained that her daughter M is 16, currently at Mill Lodge with an eating disorder (ARI). She was admitted around January 2022. Through a referral from the GP. Trialled using her own meal plan.

It explained that she had no expectations on the CAHMS service and didn't know what to expect, and soon realised the unbelievable amount of stress this has on everyone's life as Mia's life suddenly thrust into the illness and impacted on the development of co-morbid symptoms of anxiety and depression due to the demand of the treatment. The support offered from a team approach in CAHMS was beneficial, although there was a lack of psychiatrist until later but had access to a psychologist.

From her experience she found that much of the feedback gained from professionals at the start was mixed and took lots of commitment from her and her partner, although she was fortunate as her work was supportive and Jason is self-employed so was able to be flexible. but at that time she read every book to inform herself on the condition but didn't realise the exculpation of the severity until later on when the psychiatrist informed her that Mia was severely Anorexic, cognitively as she was just getting on with and forcing her to intake food which meant her weight was stable but her behaviours was difficult to manage with a lack of support into how to manage this, leading to multiple calls to the crisis team. Rachel provided her concerns that the support was just not intense enough at the start of the pathway/disorder development.

She had a planned admission at Mill Lodge but fell through because an inpatient had covid. Rachel then expanded on the severity of covid to patients with an ED.

Home support ended up being provided but was too late and lead to an inpatient as an emergency admission was given to inspire where she was the only in patient with ED and lead to complaints, in which it was identified a lack of expertise to deal with this case at the time. This was a traumatic time in which Mia didn't eat for 9 days and she was transferred to Mill lodge.



Within Mill lodge she had a lot of support but soon realised that this disorder is that these inpatient units had to drastically as she found it became a competition between the patients with ED in who can intake less food.

The thought of the support she is currently gaining has led to a scary thought on coming home and becoming reliant on the support she is receiving as that is her life, her identity but they are grateful for the service.

Intense early on: family had resources but still couldn't manage – more help at the start especially around meal plans support rather than just a leaflet explaining basics. Nothing really on challenging behaviour that was difficult to manage. Mia was a master negotiator and extremely clever and there was no advice and had to go against her instincts as a parent to a more authoritarian style, it was distressing to be told she must consume all or eating and manage this. This makes it important to have home treatment earlier.

More support could be offered around debriefing on meals/after meals.

check up after a previous CAMHS? distressing for AN. Psychical health checks need more support as this process is difficult for anorexia nervosa and often lead to outbursts. This could be helped by doing it at home, offering a debrief, help with the outbursts, or emotional support. This is particularly important when someone has gained weight, as the emotions start to wake up as her energy levels start to pick up and this becomes difficult.

Believed that the admission could have been avoided if more support and understanding was given at home with more home support, that it tailored for the individual. The transition from CAMHS to Mill lodge was difficult as they was different and scary in such a new environment, as support was provided in Mill lodge but needs to be more at home. The ideal world these would be the same service for the whole pathway or at least providing a person to help the transition throughout the process. This is fundamental to distilling trust as can find any little crisis the arrows? (difficult to read this notes). Expressed how scary admission process was.

Discussed a virtual meal support thought the eating disorder home care team as it was so intense to do it on their own.

Family therapy become difficult when changing the services as have to open up to a new therapist.

Reliant on services:

Didn't 6 week admission would be better that the outreach team.

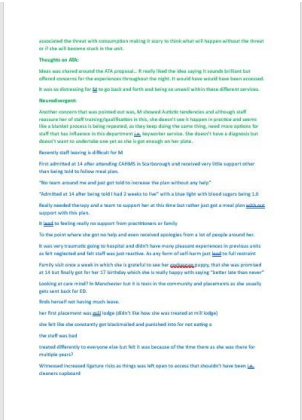
The transfers not now is difficult as A5 could be going back to school but lost everything including her identity as it is now taken over by the eating disorder.

Shorter stay could help this as now every positive step isn't a positive step to her… dependent on the service?

This full process is so difficult for parents to manage with work etc. they were fortunate with support from work etc.

Positives of admission:

There are many positives is the unit including the support she has built with staff being around them more naturally and consistent for her. It also offers more agency and responsibility on her for her pathway. The unit also offers MO take threat but that also becomes difficult as she could have



associated the threat with consumption making it scary to think what will happen without the threat or if she will become stuck in the unit.

Thoughts on ARs:

Ideas was shared around the ATA proposal… It really liked the idea saying it sounds brilliant but offered concerns for the experiences throughout the night. It would have would have been accessed.

It was so distressing for M to go back and forth and being so unwell within these different services.

Neurodivergent:

Another concern that was pointed out was, M showed Autistic tendencies and although staff reassure her of staff training/qualification in this, she doesn't see it happen in practice and seems like a blanket process is being requested, as they keep doing the same thing, need more options for staff that has influence in this department eg. keyworker service. She doesn't have a diagnosis but doesn't want to undertake one yet as she is got enough on her plate.

Recently staff leaving is difficult for M

First admitted at 14 after attending CAMHS in Scarborough and received very little support other than being told to follow meal plans.

"No team around me and just got told to increase the plan without any help"

"Admitted at 14 after being told I had 2 weeks to live" with a blue light with blood sugars being 1.6

Really needed therapy and a team to support her at this time but rather just got a meal plan without support with this plan.

It need to feeling really no support from practitioners or family

To the point where she got no help and even received apologies from a lot of people around her.

It was very traumatic going to hospital and didn't have many pleasant experiences in previous visits as felt neglected and felt staff was just reactive. As any form of self-harm just lead to full restraint

Family visit once a week in which she is grateful to see her [redacted] happy, that she was promised at 14 but finally got for her 17 birthday which she is really happy with saying "better late than never"

Looking at care in-mid? In Manchester but it is toxic in the community and placements as she usually gets sent back for ED.

finds herself not having much leave.

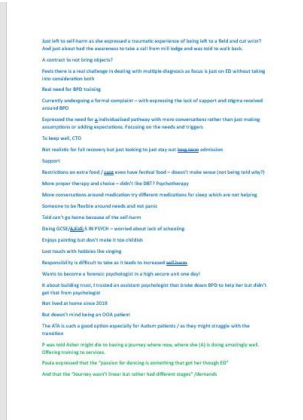
her first placement was mill lodge (didn't like how she was treated at mill lodge)

she felt like she constantly got blackmailed and punished into for not eating e

the staff was bad

treated differently to everyone else but felt it was because of the time there as she was there for multiple years?

Witnessed increased figiture rists as things was left open to assess that shouldn't have been i.e. cleaners cupboard



Just left to self-harm as she expressed a traumatic experience of being left to a field and cut wrist? And just about had the awareness to take a call then mill lodge and was told to wait back.

A contrast to not bring objects?

Feels there is a real challenge in dealing with multiple diagnosis as focus is just on ED without taking into consideration both

Real need for BPD training

Currently undergoing a formal complaint – with expressing the lack of support and stigma received around BPD

Expressed the need for a individualised pathway with more conversations rather than just making assumptions or adding expectations. Focusing on the needs and triggers.

To keep well, CTO

Not realistic for full recovery but just looking to just stay out long-term admission

Support

Restrictions on extra food / past even have festival food – doesn't make sense (not being told why?)

More proper therapy and choice – didn't like DBT? Psychotherapy

More conversations around medication try different medications for sleep which are not helping

Someone to be flexible around needs and not panic

Told can't go home because of the self-harm

Doing OCN A Level + AP PYCH – worried about lack of schooling

Enjoys painting but don't make it too childish

Lost touch with hobbies the singing

Responsibility is difficult to take as it leads to increased self-harm

Wants to become a forensic psychologist in a high secure unit one day!

It about building trust, I trusted ex-assistant psychologist that broke down BPD to help her but didn't get that from psychologist

Not lived at home since 2019

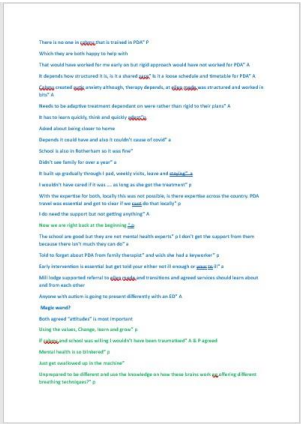
But doesn't mind being on OOA palces

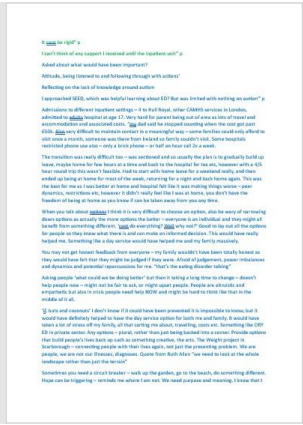
The ATA is such a good option especially for Autism patients / as they might struggle with the transition

P was told Asher might die to having a journey where now, where she (A) is doing amazingly well. Offering training to services.

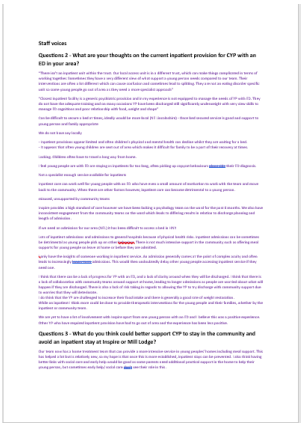
Paula expressed that the "passion for dancing is something that get her though ED"

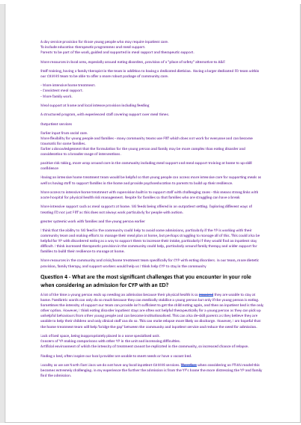
And that the "Journey wasn't linear but rather had different stages" /demands

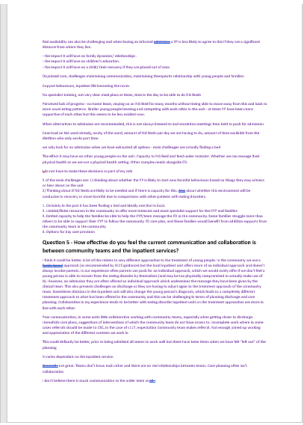


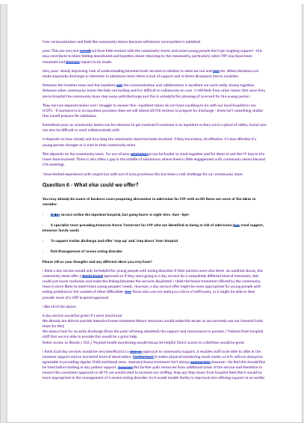


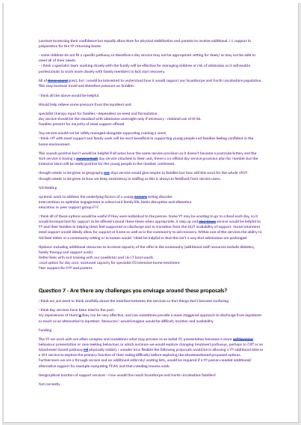
Appendix 9 – Staff voices

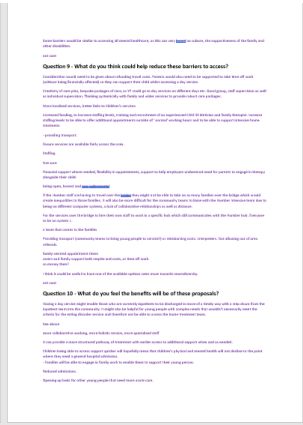












****We have not provided all the appendix documents in full due to the large size of these documents. Please email hnf-tr.involvement.network@nhs.net to request any additional documents from the appendix if you wish to read them in full****