Yorkshire and the Humber Clinical Networks

Adult Specialist Eating Disorder Engagement and Mapping Exercise

May 2021

Contents

Executive Summary

1. Introduction

Yorkshire and the Humber Clinical Networks identified a need to improve engagement with Specialist Adult Eating Disorder Services (SAEDS), and to map existing Eating Disorder Services/Pathways to identify any gaps and gain clarity around transitions between Children and Young People (CYP), Community Pathways and other SEDS. This need was aligned to the NHS England and NHS Improvement Long Term Plan ambitions for mental health. Where SEDS are referred to hereafter in the document it is in relation to adult services.

Yorkshire and the Humber Clinical Networks are centrally funded by NHS England and NHS Improvement to develop and improve mental health service provision. Clinical Networks provide system leadership, support and advice to health and social care systems in line with NHS England and NHS Improvement priorities. We bring people together across professional, organisational and geographical boundaries to share best practice, challenges and learning, and improve outcomes for patients and their families.

Two Clinical Leads were appointed on a fixed term secondment from December 2020 to 31st March 2021 to undertake a literature review, the mapping exercise, and support dissemination of its findings via this report, poster and a Learning and Sharing Event.

2. Methodology

A scoping exercise began with initial groundwork to identify the existence of local services with whom the mapping exercise should be undertaken. A literature review took place and an online questionnaire was then developed. The questionnaire underwent scrutiny from a representative from the National Eating Disorder Clinical Reference Group, an Expert by Experience, Older Peoples Mental Health professionals and piloted with a SEDS. The questionnaire was then adjusted based on comments and recommendations. SEDS were identified via the BEAT website (HelpFinder - Beat (beateatingdisorders.org.uk)) and/or signposted by SEDS. Challenges were indicated in this aspect of the Mapping Exercise:

1. Identifying contact details for respective service

2. Time and capacity to complete Mapping Exercise due to competing Service demands during the COVID-19 pandemic and ongoing associated pressures e.g. roll out of vaccines

Seventeen Services across Yorkshire and the Humber were contacted regarding the Mapping Exercise and asked to identify a named Lead and agree to complete the Mapping Exercise; thirteen Services responded and were sent the questionnaire to complete.
The questionnaire requested information on:

- Service Information; inpatient, outpatient, day patient
- Prevalence data of total and accepted referrals
- Gaps in service provision
- Treatment provision across different diagnoses, paying special attention to the provision of NICE recommended treatments.

Each service representative completing the questionnaire was asked the same questions, however appropriateness of questions varied based on service. Discrepancies in the level of detail in service summary (in the main body of this report) reflect that not all questions were necessarily appropriate for each service to answer. Key trends in the data and poignant themes are highlighted across services within the executive summary and a more detailed description of services is given in the main body. Time did not permit follow up interviews.

The final Adult Specialist Eating Disorder Engagement and Mapping Exercise Report (April 2021) includes information about the twelve Services who responded. A draft version of this report was shared with Experts by Experience for comment and recommendations.

3. Service Information

Inpatient
A total of four out of twelve service respondents reported providing an inpatient service. Two of these inpatient services use absolute weight measure and/or BMI threshold holds as part of inclusion/exclusion criteria with other measures used alongside to ensure that BMI is not the sole determinant of treatment provision. Two of the four services did not include BMI as an inclusion/exclusion criterion. None of the services accept self-referrals.

Day Patient
Again, a total of three out of twelve service respondents reported providing a day patient service. None of these services use absolute weight measures or BMI thresholds as an inclusion/exclusion criterion for treatment provision. One of these services accepts self-referrals, one does not, and one declined to answer.

Outpatient
A total of nine out of twelve service respondents reported providing an outpatient service. Seven out of nine reported using BMI thresholds alongside other measures as part of the inclusion/exclusion criteria, two reported using no BMI thresholds and one declined to answer. Four out of nine of the outpatient services accept self-referrals and five do not.

All services
Across all service levels four out of twelve reported accepting referrals for weight management where weight gain/obesity is the primary presentation. Seven out of twelve services do not accept referrals with this presentation.

4. **Prevalence Across the Region**

Prevalence was assessed by asking services for referral rates, specifically in terms of total and accepted referrals. Five out of twelve services declined to provide complete prevalence data, one service provided for their day patient service but not for outpatient as the information was unavailable to them. Across a total of four inpatient, three-day patient and nine outpatient pathways, 57% identified as having an increase in prevalence, with one service identified experiencing an increase of almost half. Exact rates are provided in the main body and in Appendices A-L.

Inpatient
Two out of four inpatient services have experienced an increase in referrals over the last two years and two services did not provide data.

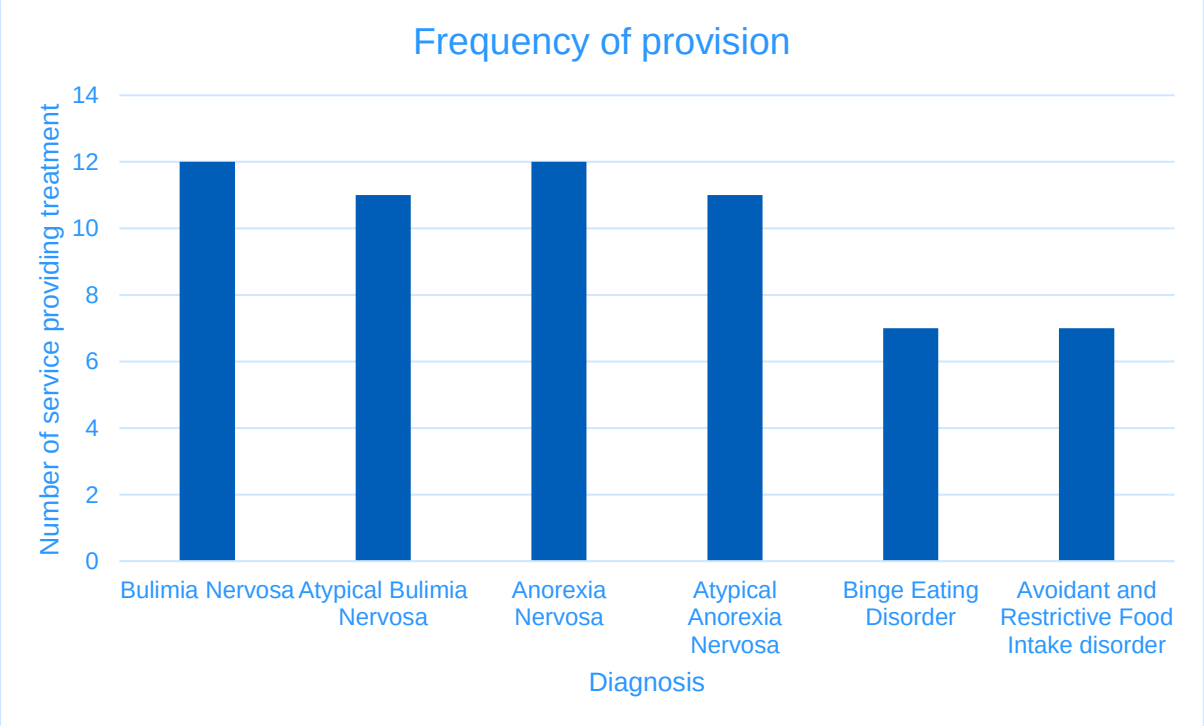
Day Patient
Two out of three of the day patient services have experienced an increase in referrals over the last two years and one service experience a decrease in referrals.

Outpatient
Five of the outpatient services provided prevalence data. Four of these services had experienced an increase in referrals and one service had experienced a decrease.

5. Treatment Provision

Treatment by diagnosis
Below is a table showing the frequencies of treatment provision across service in terms of diagnoses. This figure does not detail the modality of treatment or whether it is clinical or supportive. This will be discussed in the main body of the report.

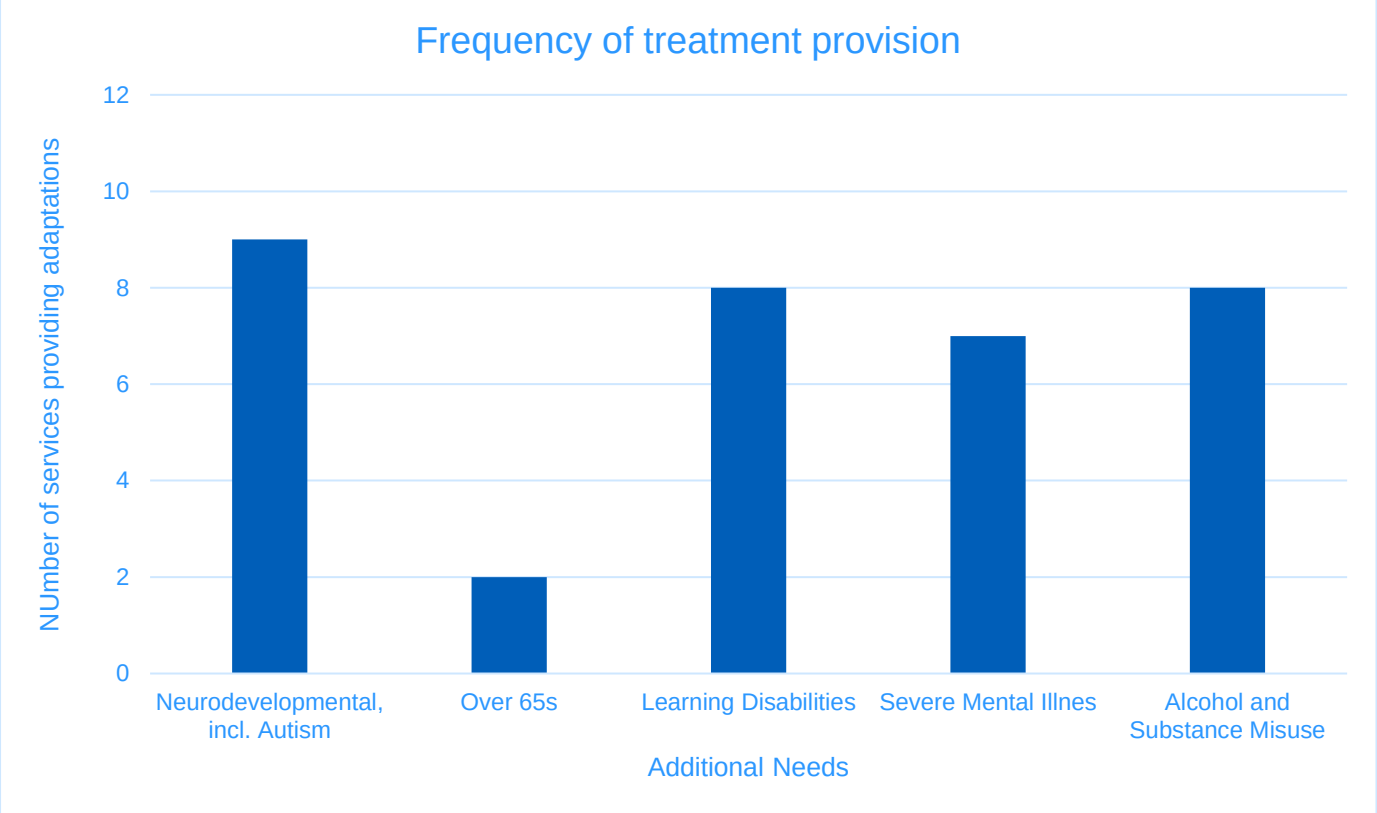
Figure 1. Showing the frequencies of treatment provision across services by diagnoses.



Additional treatment provision
Across all services, four reported providing nasogastric feeding. Eight out of twelve reported providing MARSIPAN groups, three were unsure and one did not. Out of twelve services, six reported providing treatment for someone detained under the Mental Health Act and four did not.

Adaptations for different groups
Services were asked to provide data on adaptations to treatment that will be provided for individuals with additional needs. Please see figure 2 for the frequency of treatment adaptations.

Figure 2. Showing Frequency of treatment adaptation across services



6. Gaps in Service Provision

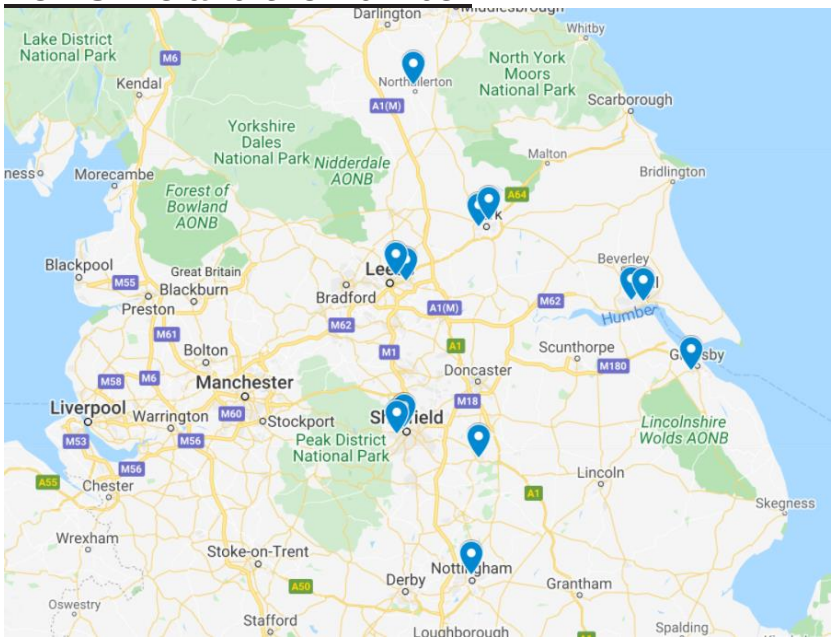
All services were asked to identify any gaps in service provision. A more detailed breakdown is given in the main body, but the following were identified as the main themes across services:

- Demand exceeding capacity
- Lack of funding
- Lack of community services within the locality to discharge patients to
- Lack of inpatient services
- Patients needing to travel outside of their locality

7. Summary

Twelve out of thirteen Services who were sent the Mapping Exercise questionnaire (92%) completed and agreed participation in stakeholder Webinar. An initial contacts list of each of these Services and geographical representation has been collated. This is the first engagement exercise by Yorkshire and the Humber Clinical Network for SEDS to share their pathways, identify gaps and training needs. This exercise will enable further opportunities for collaborative working, sharing of good practice/needs with other SEDS and also identifying good practice and support needs with transitioning SED CYPs.

Figure 3. Showing services and geographical representation across Yorkshire and the Humber



"*I think the mapping exercise is important as it provides transparency about services available in the area and the different referral criteria. As a patient this should make it easier to access services more quickly. This will hopefully avoid some of the stress and deterioration in health that I experienced as I struggled to get help and support*."
Sarah, Expert by Experience

"I read through the Executive Summary. I'm a little surprised that so many services are saying they use other measures alongside BMI. I never saw any evidence of that in my experience with XXXXX and wasn't asked about my other symptoms or behaviours in the referral process. Their website still states your BMI must be under a certain limit to be referred. Anyway, I'm sure the mapping exercise will start to

identify some of the issues that are important to people accessing these services and will do a lot of good. I'm really pleased you have done it during the Pandemic as this was when I found getting help the hardest time."

Jane, Expert by Experience

8. Recommendations:

1. Specialist training sessions should be offered to all applicable specialist services (Autism, ARFID, Diabetes, etc) wherever possible, to address the identified training needs.

   Further mapping is required with a focus on CYP to identify any possible transitional themes or issues across the age span. This is a focus in the CYP benchmarking survey taking place in April 2021.

2. Establish an Adult Specialist Eating Disorder Learning Collaborative to enable sharing of good practice, training, merging pathways for developing new pathways across ICSs, etc. Future consideration to be given to an All-Age group.

3. Identify where there are gaps across the geographical footprint and clinical footprint e.g. accessing Assessment /treatment for ARFID /BEDS etc.

4. Yorkshire and the Humber Clinical Networks to engage with all Primary Care and Community Services in the region in the establishment of an Adult Eating Disorder Learning Collaborative, to enable sharing of good practice, training, merging pathways for developing new pathways across ICSs, etc.

5. There are differences in the evidence-based treatments currently available at the SEDS. Benchmark current provision against National Guidance, which will provide further information around gaps, unmet need and training opportunities.

6. There is a limited availability of Eating Disorder prevalence data. Prevalence data collected during the exercise should be used to inform development of a national data set.

Key Contributors:

Dr Suzanne Heywood-Everett, Consultant Clinical Psychologist Bradford District Care NHS Foundation Trust & Clinical Lead Adult Eating Disorders, Clinical Network (Yorkshire and the Humber) ***Main Author***

Laura Ansboro, Clinical Network Manager - Mental Health, Clinical Networks (Yorkshire and the Humber)

Natalie Fox, Quality Improvement Lead – Mental Health, Clinical Networks (Yorkshire and the Humber)

Denise Friend, Quality Improvement Manager – Mental Health, Clinical Networks (Yorkshire and the Humber)

Jane, Expert by Experience

Katherine Haley, Assistant Psychologist, Bradford District Care NHS Foundation Trust

Ursula Philpot, Dietitian; Clinical Reference Group

Sarah, Expert by Experience

Naomi Turgoose, Clinical Lead, Rotherham, Doncaster and South Humber NHS Foundation Trust & Clinical Lead Adult Eating Disorders, Clinical Network (Yorkshire and the Humber)

Jenna Wallhead, Quality Improvement Manager – Children and Young People's Mental Health, Clinical Networks (Yorkshire and the Humber)

Dr Anne Worrall-Davies, Clinical Lead for Eating Disorders (Children and Young People)

ACKNOWLEDGEMENTS

This paper is the result of collaborative working and consultation with experts through experience, partnership organisations and All Age Eating Disorder Working Group. Appreciation, thanks and recognition is especially given to the main authors and contributors who are listed in alphabetical order above. Sincere thanks are additionally extended to the experts by experience and finally to all the Services who have spent valuable time contributing to this Mapping Exercise.

NHS England and NHS Improvement
Oak House
Moorhead Way
Bramley
Rotherham
S66 1YY

This publication can be made available in a number of other formats on request from Natalie Fox, Quality Improvement Lead natalie.fox2@nhs.net or Denise Friend, Quality Improvement Manager denise.friend@nhs.net.

Publication approval reference: