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Cumbria County Council

4 May 2018

To: The Chair and Members of the Cumbria Health Scrutiny Committee

Dear Member

Cumbria Health Scrutiny Committee – Monday 14 May 2018

Further to the agenda for the above meeting please find attached agenda item 8 – Eating Disorders in Cumbria which was marked 'to follow'.

Yours sincerely

L Harker

LYNN HARKER
Senior Democratic Services Officer

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Cumbria Partnership NHS
NHS Foundation Trust

Community Eating Disorder Services in Cumbria (CEDS)

Barry Chipchase

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Cumbria Partnership NHS Foundation Trust

8th May 2018

Strategic Context

Eating disorders (ED) are severe mental illnesses with serious psychological, physical and social consequences. Anorexia nervosa (AN) has the highest mortality amongst all psychiatric disorders[1]. People with ED commonly experience additional mental health problems, particularly depression[2], physical illness, difficulties in intimate relationships and the interruption of educational/occupational goals.

Approximately, 1.6 million people in the UK are affected by Eating Disorders[3]. This equates to 2.46% of the UK population (65,140,000). Eating Disorders typically emerge during teenage years and often last well into adulthood. Within Cumbria prevalence of eating disorders affect 1,374 of the population aged between 15 and 24. However research from Beat (2015) suggests that roughly only 50% of the known population, will access timely treatment for eating disorders.

Access to treatment is of particular concern, as the speed at which help is sought appears to the most important factor materially impacting on the likelihood of relapse. The outcome of a survey by Beat (2015) found that those who sought early help have a relapse rate of only 33% compared to an average level of 63% for those who sought help later.

The delay in seeking help is often coupled with a year long period of waiting for diagnosis followed by periods of waiting for treatment often over 6 months. Respondents in the Beat (2015) survey identified personal experiences of waiting 15 months between recognising symptoms and starting treatment. The outcome of such survey concluded that access to treatment is inconsistent and arguably inequitable.

Tulloch et al., (2008)[4] also found that eating disorders account for nearly a quarter of all psychiatric child and adolescent inpatient admissions. Admissions of 13 to 19 year olds have almost doubled since 2011, increasing from 959 to 1,815 in 2014 (Royal College of Psychiatrists, 2012)[5]. An analysis of tier 4 data in Cumbria also supports this research, as the number of occupied bed days in Cumbria has increased from 469 to 1542 days in September 2016.

The Kings Fund Report, Paying the Price; The cost of mental health care in England to 2026[6], states that service costs for eating disorders in 2007, were estimated at £15.7 million, with 95 per cent of this related to anorexia nervosa. Costs are projected to increase to 23.8 million by 2026, if services

[1] Herzog Nielsen S, Moller-Madsen S, Isager T, Jorgensen J, Pagsberg K, Theander S. Standardized mortality in eating disorders--a quantitative summary of previously published and new evidence. J Psychosom Res 1998; 44(3-4):413-434.

[2] Herzog DB, Keller MB, Sacks NR, Yeh CJ, Lavori PW. Psychiatric comorbidity in treatment-seeking anorexics and bulimics. J Am Acad Child Adolesc Psychiatry 1992; 31(5):810-818.

[3] Beat, The costs of eating disorders (2015)

[4] Tulloch S, Lelliott P, Bannister D, Andiappan M, O'Herlihy A, Beecham J, et al. The costs, outcomes and satisfaction for inpatient child and adolescent psychiatric services (COSI-CAPS) study. Report for the National Co-ordinating Centre for NHS Service Delivery and Organisation R&D. London: Royal College of Psychiatrists 2008

[5] Royal College of Psychiatrists (2012) Eating Disorders in the UK: service distribution, service development and training, London: Royal College of Psychiatrists.

[6] Kings Fund Report, Paying the Price: The costs of mental health care in England to 2026 (2008)

are not commissioned effectively. Early identification and intervention with access to effective evidence based, outcome focused services are of paramount importance to improve clinical outcome and increase cost-effectiveness and reduce inpatient admissions.

Based on this projection, the Future in Mind[7] report recognises that improvements are required across the UK in the provision of eating disorder services. This report represents the Government's commitment to driving improvements in the quality and consistency of eating disorder services. Additional national investment of £30million is being provided as part of the government's strategic drive to improve children and young people's emotional health and wellbeing.

Following the publication of the Future in Mind report, NHS England instructed local Clinical Commissioning Groups (CCGs) to produce transformation plans that aligned their local priorities of service improvement to the national priorities. Transformation plans detail the reforming of available treatment, improving access to appropriate community evidence based eating disorder care, alongside the introduction of the waiting time standards.

The refreshed local transformation plan for Cumbria has identified the initiation and development of an eating disorder service for CYP as a key priority work stream. The transformation plan clearly stipulated that by the end of March 2018, an Eating Disorder service will have been established across North and South Cumbria CCG boundaries. The establishment of such service will provide a platform to initiate movement towards the THRIVE, CAMHS redesign programme.

2.0 Current State-children

Across the UK, it is well publicised that there is variability in the arrangement of eating disorder services for CYP. Some Community CAMHS across the UK have invested in developing eating disorder expertise and established eating disorder 'mini teams' which are able to offer a level of specialist assessment and treatment. They are however limited as to the number of cases they can support (NHS Access and Waiting Times Standards for CYP with and Eating Disorder)[8].
Across Cumbria, the present eating disorder expertise for CYP comes from within the CAMHS Tier 3 service. The specialism for eating disorders is in the form of psychiatry and psychology input. A breakdown of the current workforce is provided in table one below.

Table 1 Existing Eating Disorder Workforce in CAMHS across Cumbria

Role	Band	WTE
Psychiatrist (adult)		0.4
Psychologist	8A	0.4
Psychologist	7	0.5
Practitioner	6	1.2
Psychology Assistant	4	0.9
Total		3.4

[7] Future in Mind, Department of Health, (2015)
[8] NHS Access and Waiting Time Standards for CYP with an Eating Disorder, Commissioning Guidance (2015)

2.1 Local Demand -children

Local population health data from public health indicates that the capacity required for eating disorders across Cumbria for the 0-19 years population is approximately 50 referrals per year. From a North and South Cumbria perspective this can be divided as follows:

- 31 referrals for North Cumbria
- 19 referrals for South Cumbria

An audit completed by CAMHS during spring 2017, identified the following response times to referrals received for eating disorder support and intervention:

Routine referrals waited on average 3.7 weeks for their first appointment, and 6.6 weeks for treatment (second appointment). Longest first appointment wait was 9.5 weeks, and longest treatment wait was 13.7 weeks. Shortest first appointment wait was 0.7 weeks and shortest treatment wait was 0.8 weeks.

Urgent referrals waited on average 3.2 weeks for first appointment and 5.5 weeks for treatment. Longest first appointment wait was 5.1 weeks, and longest treatment wait was 5.1 weeks. Shortest first appointment wait was 0.3 weeks and shortest treatment wait was 0.8 weeks.

The total amount of referrals received for eating disorders across Cumbria equates to 3.5% of the total number of cases open to CAMHS. Whilst this may appear to be a relatively small percentage of the cases, the intensity of work required with eating disorders cases is great and takes approximately 30% of available time from the existing workforce in Tier 3 CAMHS. It is expected that if the service is open to self referral then the number of referrals will rise rapidly.

2.2 Limitations of current state service provision-children

The limitations of the current service offer across Cumbria correlate with the outcomes of research nationally, that improvements are required for eating disorder services. Specific limitations of the service offer in Cumbria at present are:

- Small workforce across a large geographical area
- Limited data collection and analysis to evidence outcomes
- Variability in access times to treatment for routine appointments
- Urgent cases are waiting on average 3.2 weeks for first appointment which is not compliant with waiting time standards.
- Limited assurance that the quality of service provided is compliant with NICE 2017 Guidelines

The NHS Access and Waiting Times Guidance[9] stipulate that whilst small teams can be effective, they are more likely to encounter difficulties in achieving the requirements of a dedicated eating disorder service. They are also vulnerable to variation in the level of service user needs as well as staff absence

[9] NHS Access and Waiting Time Standards for CYP with an Eating Disorder, Commissioning Guidance (2015)

or loss of team members. This adds strength to the case that change is required to the current eating disorder provision across Cumbria for CYP.

2.0 Current State-adult

Across the UK, it is well publicised that there is variability in the commissioning of eating disorder services for adults
Across Cumbria, the only commissioned specialist eating disorder service for adults (ANIS) is for adults with the most severe Anorexia Nervosa who would otherwise need to go out of area to Specialist Eating Disorder Units (SEDU). A breakdown of the current workforce is provided in the table below.

Table 2: Existing ANIS Workforce Expertise

Role	Band	WTE
Consultant Psychologist	8C	0.6
Psychologist	8A/7	0.5
Senior Dietician	7	0.7
Practitioners	6	1.5
Total		3.3

The ANIS team works intensively alongside Community Mental health Assessment and Recovery Teams (CMHART) with this group of patients: a maximum of 15 patients across Cumbria at a time.

ANIS clients are seen within a week of referral: within 48 hours if urgent.

Other adults with severe eating disorders may be seen by non-eating disorder specialists in CMHART.

Adults with mild to moderate bulimia nervosa may be seen in first step for cognitive therapy, but such referrals are rarely received there.

The ANIS team also provides training sessions for families of people with eating disorders (any age and any eating disorder).

2.1 Demand –adult

Recent studies suggest that as many as 8% of women have bulimia at some stage in their life. The condition can occur at any age, but mainly affects women aged between 16 and 40 (on average, it starts around the age of 18 or 19).
Reports estimate that up to 25% of Britons struggling with eating disorders may be male.
In 2007 the NHS information centre stated that up to 6.4% of adults displayed signs of an eating disorder.

The number of people diagnosed with eating disorders has increased by 15 per cent since 2000

Figures for 2007 found 1.9% of women and 0.2% of men experience anorexia in any year. Between 0.5% and 1% of young women experience bulimia at any one time. (7)

About 40% of people referred to eating disorder clinics are classified 'Eating Disorder Not Otherwise Specified' (8) with symptoms that don't fit neatly into either the anorexia or bulimia classifications.

Estimates place the incidence of anorexia nervosa at 8.1 new cases per 100,000 total population, per year. **This means that Cumbria can expect to see approximately 30 new adult cases each year**

2.2 Limitations of current state service provision-adult

The limitations of the current service offer across Cumbria correlate with the outcomes of research nationally, that improvements are required for eating disorder services. Specific limitations of the adult service offer in Cumbria at present are:

- Small workforce across a large geographical area for severe anorexia nervosa
- Specialists only available for adults with very severe anorexia, despite evidence that early intervention is preferable, leading to better outcomes.
- Issue re monitoring and management of physical health risks

3.0 Preferred Service Model for 0-24-year-olds

The development of an eating disorder service in Cumbria has been subject to many workshop consultations with key professionals and involved site visits to other eating disorder services actually in practice across in the North East and Lancashire. Combining both pieces of work together, the preferred service modeldeveloped for Cumbria was one that will operate as a community eating disorder service, Cumbria wide, as opposed to a generic CAMHS, encompassing adult provision up to the age of 25 years.

The advantages of implementing this specific model were seen as:

- Providing greater economies of scale through pooling of existing CYP and adult resource with new investment monies
- Delivering a clinical pathway compliant with waiting time standards
- Increasing the diversity of existing expertise working across CYP and adults which will increase attraction and retention of staff
- Improving the transition process of CYP into adults
- Continuity and consistency of care

The team's collective membership will provide the following expertise:

- Psychiatric assessment for children and young people
- Medical assessment and monitoring
- Rapid response to referrals as outlined in the care pathway
- Staff trained to the supervisory level for evidence based psychological interventions for eating disorders (to include CBT/CBT-E and targeted family interventions)
- Community care: the team should have the experience to be able to provide home treatment and family support
- Acute service and paediatric support:

- Delivery of care: services should consider how they can provide care and response over a 7 day week
- Administration: the team should have sufficient staff to provide administrative and management support: It is important to ensure that support staff are experienced and have adequate training in relevant areas including data entry.

It was proposed that the existing resource from ANIS would transfer into the community eating disorder service.

The adult resource would be able to take 25 referrals a year for assessment. (Not all of these will be ready to engage with treatment) with priorities for intervention as:

- Anorexia Nervosa
- Transition
- Severe Bulimia/EDNOS

The adult ED specialists would also, for over 24s: provide training, supervision & consultation to CMHART as well as brief input to the over 24s discharged from SEDU.

CPFT would also be utilising our Children's Community Nursing specialism into the model to support with the ongoing physical health monitoring.

South Cumbria and Lancashire commissioners have recently decided not to proceed with the proposed Cumbria wide model. It is unclear at this point what will be provided for young people with eating disorder in the future in South Cumbria other than the current "treatment as usual" but this is expected to become clearer as commissioners make decisions on this. This pathway therefore describes what is to be proceeded with in North Cumbria CAMHS in line with the developed model.

Further discussions are to take place with commissioners with regard to the best use of the adult specialist eating disorder resource, in the light of changes to the commissioning intentions in South Cumbria, which have implications for the whole ANIS resource.

3.1 Operating Details and proposed Clinical Pathway (children)

The aim of the team is to provide specialised multi-disciplinary assessment, treatment and evaluation of care for these young people and their families / carers.

- This will include: evidence based interventions, supporting parents with the management of their eating disorder, and helping young people to deal with difficult thoughts and emotions that maintain the eating disorder.
- Treatment will be collaboratively formulated, evaluated and delivered to those young people and families who consent, in a way that is appropriate to the stage of the illness and recovery, placing their rights, wishes and preferences at the centre of all we do
- Evidence based interventions will be implemented in accordance with NICE guidance to best facilitate recovery and guard against possible relapse. These interventions will be offered in a manner which allows the complex needs of these young people to be

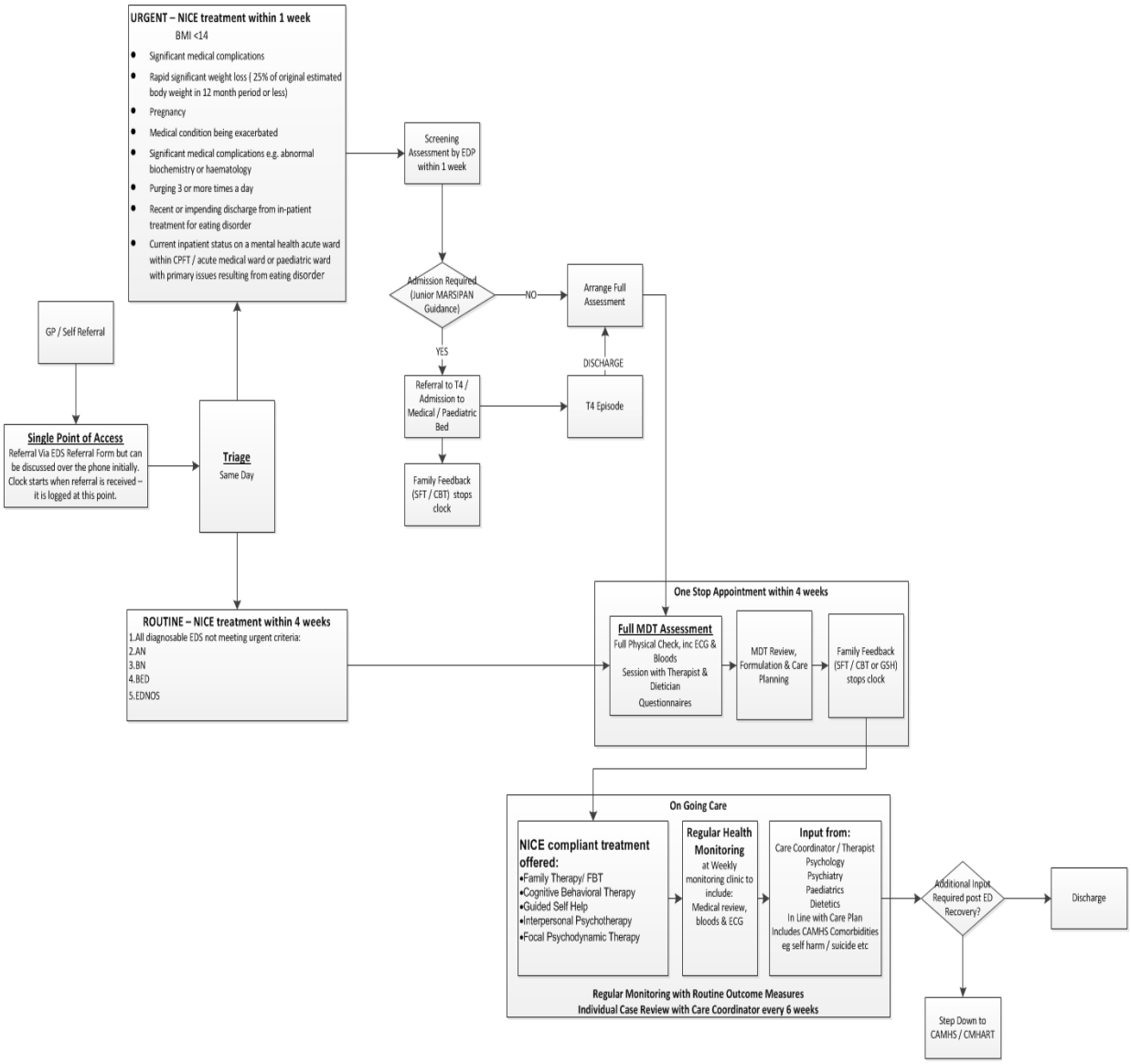
met in a co-ordinated and seamless fashion, providing specialist and intensive support at key stages in their care pathway.

The service will operate in North Cumbria CCG area Monday to Friday 9am to 5pm. The team will offer late appointments to suit CYP and their families and fit around schools, colleges and family work commitments where possible. The team will also offer home treatment and appointments in other locations such as schools to fit around the needs of the CYP as much as practicable.

3.2 Access(Children)

Referrals will come through to the service either from GPs or self referral, via a single point of access and will be triaged the same day. Referrals will be screened based on information presented as either fitting the criteria for routine or urgent screening/assessment.

Figure 1 shows the pathway into and through the service depending on presentation



3.3 Assessment for Routine Referrals (Children)

Assessment for referrals screened as routine will take place within four weeks of referral. The assessment process will be a one stop appointment and will involve:

- Detailed History and Background
- Young people will complete a questionnaire about eating and other aspects of their difficulties.
- Physical monitoring appointment – for weight, height, blood pressure, pulse and any other necessary physical assessment. (Blood Test pre assessment with results available at assessment clinic)
- Team formulation and initial thoughts on required intervention.
- Feedback session – Conclusions of the assessment and discussion re: next steps – consent to be sought and collaborative care planning to be carried out.

The access and waiting time clock will stop on the day of assessment.

3.4 Assessment for Urgent Referrals (Children)

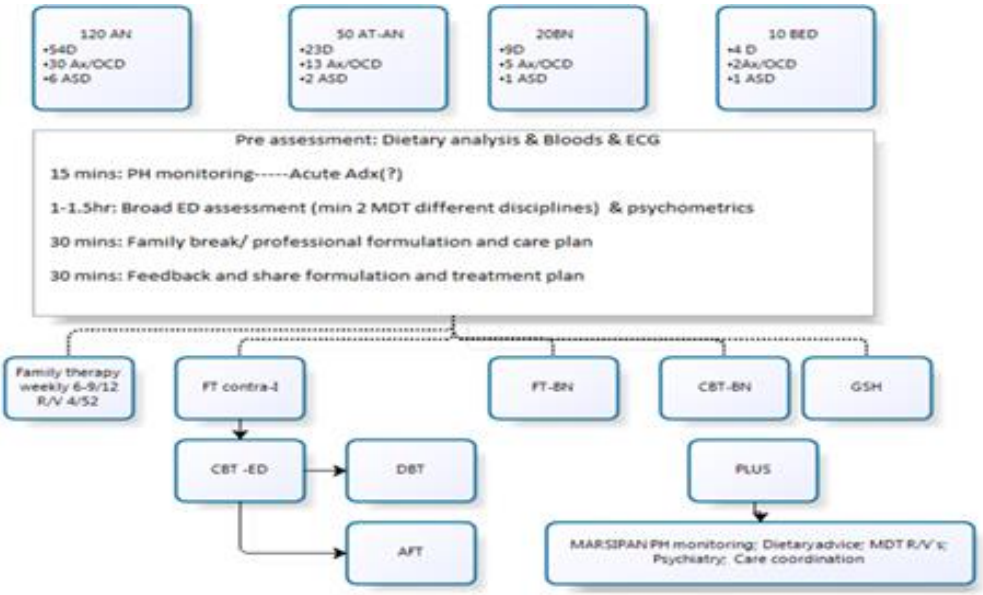
Referrals that require an urgent response will be screened against the below criteria to be deemed urgent:

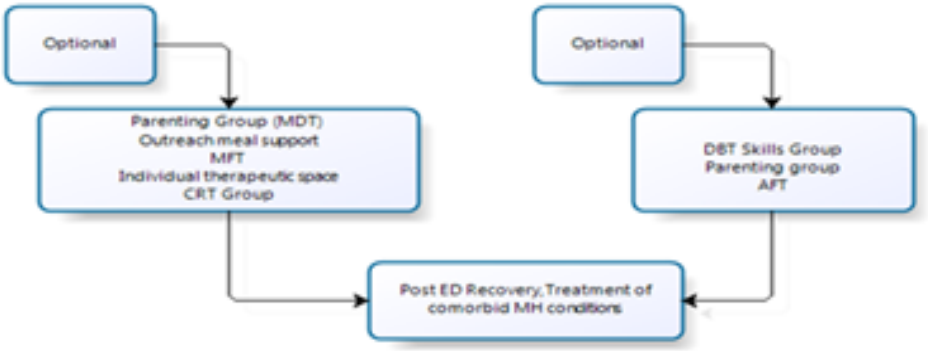
- Very low body weight eg BMI <14
- Serious Medical complications
- Pregnant
- Rapid significant weight loss (24% of original weight over last 12 months)
- Medical condition being exacerbated
- Purging 3 or more times a day
- Recent or impending discharge from inpatient with recent treatment for eating disorder
- Current inpatient on CPFT Adult Mental Health Ward/Acute/Paediatric ward with primary issue relating to eating disorder

Assessment of the referral will take place within 1 week of referral. Initial screening may result in admission to stabilise physical health. The assessment will conclude with feedback (Family Therapy or CBT) based on the day of assessment and results in full assessment as part of the discharge plan. The access and waiting time clock will stop on the day of assessment.

3.5 Ongoing Care (Children)

- Individual Care Plans will be developed appropriate to age and maturity of young person.
- Close working of Adult and Children Teams will deliver a blended team over time


120 AN
•54D
•30 Ax/OCD
•6 ASD
50 AT-AN
•23D
•13 Ax/OCD
•2 ASD
20BN
•9D
•5 Ax/OCD
•1 ASD
10 BED
•4 D
•2Ax/OCD
•1 ASD
Pre assessment: Dietary analysis & Bloods & ECG
15 mins: PH monitoring-----Acute Adx(?)
1-1.5hr: Broad ED assessment (min 2 MDT different disciplines) & psychometrics
30 mins: Family break/ professional formulation and care plan
30 mins: Feedback and share formulation and treatment plan
Family therapy weekly 6-9/12 R/V 4/52
FT contra-I
FT-BN
CBT-BN
GSH
CBT -ED
DBT
AFT
PLUS
MARSIPAN PH monitoring: Dietaryadvice; MDT R/V's; Psychiatry: Care coordination


Optional
Parenting Group (MDT)
Outreach meal support
MFT
Individual therapeutic space
CRT Group
Optional
DBT Skills Group
Parenting group
AFT
Post ED Recovery, Treatment of comorbid MH conditions

6.0 Benefits Realisation of the preferred CYPED (0-24) model

The benefits of implementing the preferred Community Eating Disorder Service model in North Cumbria from a quality, people, service and efficiency perspective are:

Quality; consistently deliver the highest possible quality of service we can achieve	
Clinical outcomes	• Service principles are aligned to the national access and waiting time targets/standards • Clinical interventions are compliant with NICE 2017 guidelines • Improved physical health monitoring • Improved data collection systems which will enable greater control over caseload monitoring, capacity and demand. • Focus on early intervention • Development and availability of family therapy • Delivery of Maudsley Model to carers of people with ED
Clinical Effectiveness	• Compliant with NICE 2017 guidelines • Greater assurance of clinical competency and standards of treatment through more clinical audit capacity.
Workforce planning and staff	• Fit for purpose clinical leadership and succession planning • Increased multi-disciplinary skill mix across adults and CYP services • Provision of appropriate clinical supervision for specialist roles • Development of family therapy at required level of training and expertise • Adults and Children staff working as a blended team will increase attractiveness of service for recruitment and retention of staff
Financial sustainability	• Pooling of resource between adults and CYP enables greater economies of scale across North Cumbria • Reduction in out of county expenditure as service will be locally available to prevent admission to hospital
Equality impact	• Improved access to service for CYP and adults up to the age of 25 across North Cumbria

At which stage of this work was the impact assessment updated? (✓)	Pre-implementation?	Pilot testing?	Review of implementation?	Other? (please specify)
	✓			
Estimated date of next update	Review at implementation– Summer 2018			

APPENDIX

Development Context of the 0-24 Community Eating Disorder Service (CEDS) Model

The need to develop a CEDS was prompted by the introduction of Access and Waiting Time Standards for children and young people up to the age of 19. In addition discrepancies between the existing ANIS, adult facing specialist service, and the more prevalent community offer prompted a review of this service.

In the light of these two factors Cumbria CCG began a process of developing options for CEDS.

Phase 1 of which was to determine the most appropriate service model for Cumbria that takes account of the needs of the population, the geographical challenge and the practicalities of providing a small specialist service across a large area. Options considered at this stage included:

- A stand-alone 0-18 CEDS
- A 0-18 CEDS embedded in a wider Tier 3 CAMHS team
- A stand-alone all age CEDS

Following a series of workshops it was determined that a Cumbria wide 0-24 service that incorporated the existing ANIS workforce that will provide NICE concordant treatment is the most appropriate for Cumbria. Reasons for this include:

- The existing ANIS workforce brings high levels of Eating Disorder expertise
- The extension of the age range enables the service to reach a wider population flattening out some of the peaks and troughs of expected demand in each of the three areas (West, North and South)
- The model enables the provision of consistent treatment across transition at age 18, a time of high risk for this patient group.

Having determined the service scope Phase 2 required further work that was undertaken by CPFT to develop a specific service model. In order to do this extensive learning from both LCFT (that currently provides an ‘all age’ CEDS in Lancashire) and TEWV (that currently provide a well-established CYP CEDS that meets the A & WT standards) was undertaken by the CAMHS CSM.

Planning Service Scale

The calculation of the required investment has been determined by;

- Use of the NHSE workforce planning tool
- Reallocation of existing CAMHS resource based upon an analysis of current caseloads and working practices
- Learning from existing services in neighbouring areas that are currently meeting the Access and Waiting times

Implementation

Funds have been allocated by North Cumbria CCG and implementation by CPFT is underway.

Greg Everatt
Senior Commissioning Manager, Children & Families, North Cumbria CCG

2 May 2018