CYP community eating disorder services national update

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Eating disorders: Prevalence

**Anorexia Nervosa**
- NICE estimates a prevalence of 1 in 250 females and 1 in 2000 males
- Clinical incidence rate of 165 per 100,000 of girls aged 15 and 19 years, about 8,000 new female cases of full-blown AN presenting per year (Micali et al., 2013; 2015) → about 35/CCG
- Admissions for ED are rising – reporting an 8% rise between 2011/12 and 2012/13; (HSCIC) biggest rise in YP aged 15 to 19 age
- About 5%-10% of all cases occur in males
- The gender difference is becoming smaller
- Overrepresentation of higher social classes now less evident

**Bulimia Nervosa**
- Lifetime prevalence 1%
- 1-year incidence 0.75%
- 1%-5% of adolescent girls in the US
- Far fewer clinically referred than AN
- Age of onset between 15.73 and 18.1 years old

Since the beginning of the 90s, more information about detrimental effects of dieting seem to influence a tendency to prevalence reduction
Eating Disorders: Natural History

1-33 years follow-up

- **Mortality** in anorexia range from 0% to 11% with a mean of 2.16%
- **Severity** of illness and duration of illness predict poorer outcome
- **Core symptoms** (weight, menstruation) have better outcome than residual symptoms
- Around 8% of adolescents with anorexia can become bulimic
- **Bad outcome** is predicted by premorbid weight, early onset (<11 years old), family dysfunction, later onset of treatment (Treasure and Russell, 2011 → first 3 years or outcome is poor)
- It implies higher levels of psychopathology, less empathy, less ability to interact socially
- Persistence of **preoccupations** about food and weight are **predictors of relapse**
Many anorectic patients present further psychopathology at outcome.

- Affective disorders: 20.90%
- Neurotic disorders: 26%
- OCD: 12%
- Schizophrenia: 6.50%
- Personality disorders: 19.90%
- Substance misuse: 18.90%

Cost of illness:
- Inpatient: 72%-90%
- Outpatient: 19%
- Medical monitoring: 9%

Total: US$ 36,200 p/patient
Anorexia: Physical Treatments

- Restoration of weight is primary goal

**Inpatient programmes**
- Indicated for **less than 70%** of body weight
- It must be within age-appropriate, **specialist wards**
- It can foster **therapeutic alliance**

**Outpatient settings**
- When **no purging and vomiting** as part of clinical picture
- When the **family** is very **supportive**
- Patient is **motivated** and cooperative (unusual)
- **Day programmes** with parents’ involvement are effective

**Medication**
- Reserved only for **co-occurring** conditions

- A liaison between **paediatrician** and child **psychiatrist** is needed
Anorexia: Psychosocial Treatments

- **Individual Psychotherapy**
  - Based on adult treatments
  - Only effective with intact cognition and motivation
  - CBT in combination with parental counseling, dietary therapy and multimodal feedback contribute to prevent relapses

- **Family-Based Treatment (FBT)**
  - Superior to individual therapy and supportive therapy
  - More effective when added CBT and parent-to-parent consultation

- **Behavioural Family Systems Therapy (BFST)**
  - Superior to Ego-Oriented Individual Therapy, but both are effective

- **Separated vs. Conjoint Family Therapy**
  - Separated is superior when there are high levels of maternal criticism
  - Separated is also superior in symptomatic changes
Bulimia: Treatment

- Few (< 5%) need hospital admission

- **Fluoxetine** has **limited** evidence
  - It could reduce the frequency of **binge and purge** symptoms

- **Manualised CBT vs. Manualised Family Therapy**
  - **Both** are efficacious
  - **Conflicting evidence** whether which one is superior
  - **Family therapy** seems to be **superior in adolescents**
Understanding the experience of care

Current care pathway (variable across the country)

- Primary care
- Identification and referral
- Generic CAMHS
  - Varying levels of expertise and different EB treatments available
- ED “mini teams”
  - Specialist-level treatment
- CYP-ED service
  - Specialist-level outpatient community treatment
- Inpatient treatment
  - Specialist ED inpatient service (mostly from private sector)
  - Some offer day treatment

Current challenges

Barriers to early intervention
- Problems in early identification
- Inadequate understanding of eating disorders
- Poor recognition of risks
- Delay in referral to appropriate services
- Poor awareness of local care pathways or eating disorder services
- Lack of capacity to respond by existing CAMHS or eating disorder services creating delays
- Lack of local eating disorder services
- Lack of capacity within the service to provide the intensity of treatment needed
- Lack of training of CAMHS professionals.

Barriers to identification and engagement
- AN does not seek out help. Difficult engagement
- People with ED see their health professionals for physical (gastrointestinal) symptoms, and not for mental health

Inadequate liaison
- Among healthcare providers
  - Significant national variability in the effectiveness of collaboration
- Often, systems for collaboration with education or other local agencies are not in place

Transition difficulties between services
- Age issues: 18 years old is a peak period for ED difficulties, however transition from child to adult services imply a break in treatment
- Geography issues: this age also imply high numbers of patients moving out of home: lost of familial support and difficult healthcare service transition
Evidence for cost-effectiveness of the CEDS-CYP model

The most cost-effective treatment of AN in CYP is reported to be delivered by a community-based eating disorder service as opposed to generic CAMHS

- Not uniformly available throughout the country.

Delaying access to specialist eating disorder treatment may increase long-term health costs:

- Children and young people starting treatment in non-eating disorder CAMHS settings have higher rates of inpatient admission in the next 12 months
- The majority of CYP managed in specialist eating disorder settings receive continuous care for their eating disorder without the need for further referrals
- In areas with direct access from primary care to CEDS-CYP there is significantly better case identification and therefore early referral for treatment

More studies underway

- CostED study (a study of the costs and effects of different types of community-based care for anorexia nervosa).
- Multicentre RCT of the outcome, acceptability and cost-effectiveness of family therapy and multi-family day treatment compared with inpatient care and outpatient family therapy for adolescent anorexia nervosa
- Multi-centre RCT of treatments for adolescent anorexia nervosa, including assessment of cost effectiveness and patient acceptability
- RCT of the cost effectiveness of cognitive-behavioural guided self-care versus family therapy for adolescent bulimia nervosa in a catchment area-based population.

Byford et al., 2007; House et al. (2012)
Eating Disorders (CYP)
The access and waiting time standard and commissioning guide for children and young people with an eating disorder was published July 2015

NCCMH Expert Reference Group developed:

- **Access** and **waiting time** standard
- Referral to **treatment pathways**
- **Model for delivery** of dedicated community eating disorder services for children and young people (CEDS-CYP).

- **Commissioning guide with workforce calculator** published to support local commissioners with transformation.

  - **Clinical lead**: Rachel Byrant-Waugh
  - **Commissioning lead**: Andrew Roberts
A new service to meet this challenges

A Community Eating Disorder Service for Children and Young People (CEDS-CYP)

- An **appropriately trained, supported and supervised** team
- Use of information **technology for teamwork** from different geographical locations
  - Eg. Following a “hub and spoke” model

**Requirements**

- Receive a minimum of **50 new** eating disorder referrals a year
- Cover a minimum general population of **500,000** (all ages)
- Use **up-to-date evidence-based interventions** to treat the most common types of coexisting mental health problems (for example, depression and anxiety disorders) alongside the eating disorder
- Enable **direct access** to community eating disorder treatment through self-referral or from primary care services (for example, GPs, schools, colleges and voluntary sector services)
- Include **medical and non-medical staff** with significant eating disorder experience
Eating Disorders (CYP)

Access and waiting time standard

Those referred for assessment or treatment for an eating disorder should receive **NICE concordant treatment within one week for urgent cases and within 4 weeks for every other case.**

**CCQI** will be launching a **Quality Network for Community Eating Disorder Services** (QNCC-CEDS) on 2 March 2016.

Aim is **for 95%** of those referred for assessment or treatment receive NICE concordant treatment with the ED standard RTT by **2020**

The Role of Education

**Eating disorder curricula group** being convened in partnership with HEE (first meeting October 2015) **building on:**

- **Systemic family practice** curriculum for eating disorder
- **Existing whole team** training packages for multi-disciplinary community eating disorder services/teams
- **Modality specific evidence based interventions** anticipated to be in line with updated eating disorder NICE guideline to be published in 2017
## Community Eating Disorder Services: Staff calculator

<table>
<thead>
<tr>
<th>Number of referrals per annum</th>
<th>150</th>
<th>100</th>
<th>50</th>
</tr>
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<tbody>
<tr>
<td><strong>Whole time equivalents</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Head of service (psychiatry/psychology)</td>
<td>1.9</td>
<td>1.3</td>
<td>0.6</td>
</tr>
<tr>
<td>Clinical psychologists</td>
<td>2.8</td>
<td>1.9</td>
<td>0.9</td>
</tr>
<tr>
<td>Eating disorder therapists (SFT-ED/MSFP-ED/CBT-ED)</td>
<td>4.9</td>
<td>3.3</td>
<td>1.7</td>
</tr>
<tr>
<td>Nursing staff (nursing/home treatment)</td>
<td>2.2</td>
<td>1.5</td>
<td>0.8</td>
</tr>
<tr>
<td>Speciality doctors (psychiatry)</td>
<td>1.2</td>
<td>0.8</td>
<td>0.4</td>
</tr>
<tr>
<td>Assistant psychologists (SFP-ED/ MSFP-ED/CBT-ED support)</td>
<td>2.7</td>
<td>1.8</td>
<td>0.9</td>
</tr>
<tr>
<td>Paediatricians (physical health)</td>
<td>1.9</td>
<td>1.3</td>
<td>0.6</td>
</tr>
<tr>
<td>Dieticians</td>
<td>1.9</td>
<td>1.3</td>
<td>0.6</td>
</tr>
<tr>
<td>Administrative staff</td>
<td>2.0</td>
<td>1.4</td>
<td>0.7</td>
</tr>
</tbody>
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Whole time equivalent staff broken down by profession.
Staffing of team for a service receiving 100 referrals

- Therapists, 47%
- Other, 66%
- Supervisors, 19%
- Dietician, 10%
- Admin, 11%
- Medical, 13%
- Other, 66%

Whole time equivalents by grade for 100 referrals

- Grade 9: 4.33
- Grade 8: 4.47
- Grade 7: 0.83
- Grade 6: 0.64
- Grade 5: 0.80
- Grade 4: 3.20
- Consultant: 1.3
- Specialty doctor: 3.20
Recommended training for CEDS-CYP teams

<table>
<thead>
<tr>
<th>Training goal</th>
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<tbody>
<tr>
<td>Develop multidisciplinary eating disorder teams</td>
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<tr>
<td>Understand the complex nature of eating disorders</td>
</tr>
<tr>
<td>Develop a strong team culture</td>
</tr>
<tr>
<td>Develop early intensive skills training and ongoing support and supervision</td>
</tr>
<tr>
<td>Adopt core CYP-IAPT principles</td>
</tr>
<tr>
<td>Evaluate the impact of training on transformation of services</td>
</tr>
</tbody>
</table>

Also, CEDS-CYP will have a role in training for other professionals

- Raising awareness
  - Primary care
  - Education
  - Other children services

- **CCQI will be launching a Quality Network for Community Eating Disorder Services (QNCC-CEDS) on 2 March 2016.**
  - The QNCC standards have been amended for CEDS to align with the standard and commissioning guidance

The relationships developed through the training will be used to provide regular support to the teams involved in improving early identification of children and young people at risk of developing an eating disorder.
## Benefits for users: children, young people, their families and carers

| Improved access and reduction in waiting times | Children, young people, their families and carers know how to ask for help in their local areas |
| Better knowledge of how to recognise eating disorders and how to access appropriate care when needed | Every person receiving appropriate evidence-based eating disorder treatment, based on their needs |
| Receiving treatments for eating disorders and coexisting mental health problems from 1 team | Improved outcomes, sustained recovery, reduction in relapse, and reduced inpatient admissions |
| Continued transformation of CAMHS evidence-based, outcome-focused, working collaboratively with children, young people and families | Less need for transfer to adult services and long periods of treatment |
| Less need for inpatient admission with the disruption to school and family life | CYP and families have more involvement in commissioning services that meet their needs. |