Children and Young People’s Mental Health Transformation: Eating Disorders

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Children and young people’s mental health transformation: an overview

• The current situation: key issues

• Policy overview: Future in Mind and the FYFVMH

• CYPMH Transformation programme: timetable for delivery

• Making it happen: levers and incentives
Key issues

Access

Waiting times

Vulnerable groups

Transition

Economics of investment

Infrastructure/resources

Systems

Not enough is being spent

£78

Average spend per child 0-17 yrs

6.6%

CYPMH as proportion of MH spend (2012/13)

The high cost of getting it wrong

YP with a MH problem are...

• 8x more likely to have contact with YJS
• Twice as likely to be claiming benefits

The low cost of investing early

£229

Group CBT

£7,252

Unit cost

Total lifetime benefit

Low workforce capacity

0.7

Number of WTE CYPMH clinical workforce per 1,000 0-17 yr olds in England.

102

Number of 5-16 yr olds with a diagnosable MH condition per 1,000 in England.

High numbers of referrals

270k

Aprox annual total CYPMH referrals 14/15

Long waiting times

26 weeks

Average maximum wait for first appointment (NHS benchmarking)

0-25s

Tiered system

Thrive

Varied approaches

Stepcare models

Integrated pathways

Various commissioners

CCGs

LAs

NHSE

MoJ

Schools
Future In Mind and the FYFV for Mental Health

By 2020, for people of all ages we want to see:

- **Improved crisis care** for all ages: right place, right time, close to home
- **Improved transparency, leadership, and accountability** across whole system
- **More visible and accessible support**
- **Improved public awareness** less fear, stigma and discrimination
- **Timely access to clinically effective support**
- **More evidence based, outcome-focused treatments**
- **Better use of data and information** across the network

And for children and young people specifically:

- Professionals who work with children and young people trained in child development and mental health
- Model built around the needs of children and young people, and a move away from the ‘tiers’ model
- Improved access for parents to evidence-based programmes of intervention and support
- A better offer for the most vulnerable children and young people
By 2020 there will be system-wide transformation of the local offer to children and young people underway, with LTPs embedding *Future in Mind* principles and fully integrated into STPs across the country.
Measuring the change...

<table>
<thead>
<tr>
<th>By 2020 there will be:</th>
<th>We will know if this has been achieved by:</th>
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<tbody>
<tr>
<td>System wide transformation of the local offer to children and young people underway with LTPs embedding key Future in Mind principles fully integrated into STPs across the country</td>
<td>CCG assurance process</td>
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<td>A suite evidence based treatment pathways with high level metrics that measure access, spend and progress towards delivery of agreed components in the transformation programme</td>
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<td>At least 70,000 more CYP receiving swift and appropriate access to care each year</td>
<td>Monitoring of new national data returns</td>
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<td>Completed national roll-out of CYP IAPT programme with at least 3,400 more staff in existing services trained to improve access to evidence based treatments</td>
<td>Assurance of Mandate requirements with HEE</td>
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<tr>
<td>1,700 additional new staff to support improved access to evidence based treatments</td>
<td>Assurance of Mandate requirements with HEE</td>
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<tr>
<td>Evidence based community Eating Disorder services for CYP across the country - 95% of those in need of Eating Disorder services seen within 1 week for urgent cases &amp; 4 weeks for routine cases by 2020</td>
<td>Mental Health Services Dataset</td>
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<td>The baseline will be set in 2017 enabling a trajectory to be set</td>
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<td>Improved access to and use of inpatient care, having the right number and geographical distribution of beds to match local demand with capacity, and leading to an overall reduction in bed usage.</td>
<td>Data from new national bed management system for Tier 4 will enable monitoring of occupancy and out-of-area placements</td>
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<td>Plans to improve crisis care for all ages, including investing in places of safety</td>
<td>Reduction in the numbers of CYP admitted to inpatient beds or police cells</td>
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<td>Number of CYP receiving NICE concordant care</td>
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CYPMH Transformation: making it happen

• Cross-system responsibilities
• Data: central collections and outcomes monitoring
• NHS Operational Planning Guidance
• CCG Improvement and Assessment Framework
• Local Transformation Plans: local planning, local scrutiny
• NHS England regional support: clinical networks and intensive support teams
Progress so far

CYP-IAPT
- 1371 therapists, 348 supervisors and 309 service leads trained
- 5 new curricula developed 2015/16
- CYP-IAPT covers 87% of 0-19 population
- Audit shows time between referral and assessment decreased by 73%
- Audit shows days between assessment and discharge decreased by 21%

Eating disorders
- LTPS identified 61 CED teams
- CED team training tendered for delivery
- Quality Network for CED teams launched
- Audit shows time between referral and assessment decreased by 73%
- Audit shows days between assessment and discharge decreased by 21%

Learning Disability
- CYP-IAPT covers 87% of 0-19 population
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- Audit shows days between assessment and discharge decreased by 21%

National support
- MH Improvement Teams established
- RTT development for crisis and generic CAMHS underway
- Commissioning support programme inc updating service specifications + system modelling tool.

Funding
- £149m released by NHSE in 2015/16

CCG plans
- 123 LTPS published and assured

Health & Justice
- Improving commissioning across Health & Justice

Vulnerable groups
- Personal budgets scoped

Tier 4
- Now 1,442 Tier 4 beds in England, higher than ever before
- £10m committed to improving joint inpatient - community commissioning in 2015/16
- Case managers in place
- Since December 2014, average distance travelled by CYP in England has decreased by 10%

DfE joint work
- Schools Single Point of Contact Pilots 22 sites 255 schools

Data
- MHSDS now includes CYP MH data

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Eating Disorders: an overview

• CYP ED Access and Wait Time Standard and curriculum development

• National overview: LTP analysis and population-level context

• CED teams: the rationale, service development, building the right team, and training

• Making it happen: data
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.

Introduced and **monitored** in 2016-17 via MHSDS and UNIFY data collection;
**NEW extension for day- and inpatient care**-to be published Spring 2017

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** convened in partnership with HEE (October 2015) **building on**:

- **Systemic family practice** curriculum for eating disorder
- **Existing whole team** training **packages** for multi-disciplinary community eating disorder services/teams – to be delivered 2016-17
- Modality specific **evidence based interventions** anticipated to be in line with updated eating disorder NICE guideline to be published in 2017
The majority of the focus for eating disorders is on **waiting times** and improving **access** with 35% of the KPIs relating to eating disorders covering these two topics.

Most areas reported to be making plans around developing a **community eating disorders service** with a trajectory towards achieving a fully compliant service by 2020.

**Early detection** and delivery of **intervention** was a primary focus for eating disorders.

Increasing **workforce capacity** and **training** was noted as important in achieving a compliant service.

Where services are already compliant, the funds are being spent on both **enhancing** the existing eating disorders service and on **crisis** and **self-harm**.

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**Key facts**

- **16%** of LTP areas are compliant with the new eating disorders guidance.
- **84%** of LTP areas are making plans on how to become compliant.
- **93%** of LTP areas are delivering eating disorder services with other areas.
England: population-level context

HSCIC (NHS Digital) data estimated that admissions for ED are rising – reporting an 8% rise between 2011/12 and 2012/13; biggest rise in YP aged 15 to 19 age group (HSCIC, 2014)

Incidence study showed that the number of people directly affected by ED increased significantly between 2000 and 2009 with an annual clinical incidence rate of 164.5 per 100,000 of girls aged 15 and 19 years, more than double the rate for other ages (Micali et al., 2013; 2015)

Treasure and Russell (2011) found that unless intervention is delivered in the first 3 years the outcome is poor
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 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)
Community Eating Disorder Services

Population-based

- Recommend minimum 500K (all ages) so may span more than one CCG

Should take referrals for ED and related disorders

- Anorexia nervosa, bulimia nervosa, binge eating disorders and co-existing problems (e.g. anxiety and depression)
- Multidisciplinary ED team able to respond to range of varying levels of need and severity

Minimum of 50 referrals per year to support viability

Enable direct access to community

- Eating disorder treatment via self-referral, GPs, schools, colleges and voluntary sector
- Support early identification through improved awareness, liaison and consultation

Maintain clinical oversight throughout the care path

- Including inpatient admissions or day-patient care
Recommendations for structuring a CEDS-CYP

When commissioning an eating disorder team or ensuring an existing service meets the Access and Waiting Time Standard requirements, commissioners need to know:

- Size of the population served by the team
- Local incidence of eating disorders in children and young people drawn from the JSNA in Mental Health
- General level of coexisting mental health problems and how these will be managed
- Capacity and effectiveness of current services
- Anticipated impact of new or proposed services in meeting the need
- A model that will be able to achieve the waiting times for the anticipated level of need.

All members of the team should have experience in:

- Treatment or assessment of eating disorders
- The mental health sector.

The team’s collective membership needs to provide the following expertise:

- Formulation of mental health problems and assessment for CYP
- Assessment and monitoring of physical health needs
- Rapid response to referrals as outlined in the care pathway
- Trained to supervisory level for evidence-based psychological interventions for EDs (family therapy, CBT and)
- Trained in the delivery of evidence-based psychological interventions for Eds and co-existing mental health problems
- Community care: the team should be resourced and experienced to be able to provide home treatment and family support
- Acute service and paediatric support: support should be provided to these services 7 days a week
- Delivery of care: Services should consider how they can provide care and response over a 7-day week and respond to emergency presentations
- 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.
Staffing of team for a service receiving 100 referrals

Whole time equivalents by grade for 100 referrals

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

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<td>Develop multidisciplinary eating disorder teams</td>
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<td>Understand the complex nature of eating disorders and co-existing MH problems</td>
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<td>Develop a strong team culture</td>
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<td>Develop early intensive skills training and regular support and supervision</td>
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<td>Adopt core CYP-IAPT principles</td>
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<td>Evaluate the impact of training on team functioning and service</td>
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Also, CEDS-CYP will have a role in training for other professionals

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

The relationships developed through the training can 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.
Why collecting data?

— Feedback is essential to the success of the ED treatment pathway programme, both nationally and locally

The data collected can:

— enhance collaborative therapy experience of children and young people and their families or carers—empower CYP and/family in guiding their own treatment
— support the development of each practitioner’s clinical skills and development
— support the development of teams/services.

Commissioners can use the data to:

— inform future needs assessments
— review service provision through benchmarking and volume of service required including demand and use of inpatient beds
— inform priorities in terms of the most effective services for the identified need
— inform the design of services that will provide the most effective use of resources to achieve the best outcomes
— manage contract performance
— receive children and young people’s feedback on service provision, which will enhance their choices.

Embedding change: why is data key?

Eating disorder services can use the data to inform and support the continuous improvement of services.
Recommended approaches for data collection

• **How collecting data?**
  - At every stage of the care pathway
  - Must incorporate perspectives of CYP and their family/carers
    • Patient Reported Outcome Measures (PROMs)
    • Patient Reported Experience Measures (PREMs)
    • Monitoring of goals and symptoms

• **Challenges in data collection:**
  - Clinicians to understand the benefits of using data as part of treatment
  - Many times implies training professionals and address resistance
  - Establishment of IT tools to comply with the Mental Health Services Data Set (MHSDS) requirements

• **What to collect?**
  - From the illness:
    • Severity of ED
    • General mental health problems
    • General functioning and well-being
    • Physical health
    • Coexisting MH problems
  - Attitudes and experiences of CYP and carers toward the provision of treatment
  - Care pathway
    • Clinical practice and service development
    • Design and usage information
    • ED treatment pathway Clock Start-Stops
    • Referral pathways
    • Specific information about treatment provided
    • Attendance
Data: the national picture

• MHSDS flowing from Jan 16, CCG IAF and MH Dashboard

• UNIFY data collection on ED RTT – Data to be published on national and regional performance (Jan 17)

• Technical Guidance published Mar 16 - to be reviewed for inclusion of admissions and day patient care
  https://www.england.nhs.uk/mentalhealth/resources/

• Prevalence Survey commissioned by DH – due to report in 2018

• HEE CYP MH workforce mapping with NHS Benchmarking to report shortly (CYP MH across NHS and non-NHS providers)

• QNCC-ED launched improvement and accreditation network - – hosting CED-CYP service directory to support a peer-reviewed peer network and whole team training.
Community Eating Disorder Services: what are we driving towards?

For every child and young person with an eating disorder and family/carers

- **Swift access** to appropriate evidence-based eating disorder treatment from first and *early identification* of eating disorder; offering treatment to meet *varying levels of presenting need*
- Improved access and *reduction in waiting times*
- Treatments for eating disorder and *co-existing MH problems delivered by one eating disorder team throughout pathway*
- **Improved outcomes** as indicated by sustained recovery, reduction in relapse, and reduced need for admission

- **Clear access to help** and advice when first concerned
- **Better collaboration** in treatment and parents’ and carers’ being able to support and better understand the eating disorder and treatment
- **Reduction** in need for *long periods of treatment*
- **Reduce disruption** to school and family life
- **Increased involvement** in commissioning of services that meet their needs
Resources

MindEd is a free educational resource on children and young people’s mental health for all adults.

Follow @MindEdUK

Resource for all adults to increase awareness and understanding
Includes free e-learning sessions for all those working with CYP (incl. ED sessions)
MindEd for Families
https://www.minded.org.uk/

GIFT
Sign up for www.myapt.org.uk;
see video clips
https://www.youtube.com/user/CernisLimited/videos

DATA:
Chimat and CAMHS ebulletin –
http://www.chimat.org.uk/camhs
CORC: http://www.corc.uk.net/
NHS Benchmarking Report 2015
MHSDS-flowing from Jan 2016
My Mental Health Services Passport

www.england.nhs.uk/mentalhealth/2015/10/15/passport-brief-yp-mh

Developed by young people and parents/carers with NHS England as part of the CYP IAPT programme

The aim of the passport is to help young people using services **to own and communicate their story** when moving between different services.

The passport provides a summary of young person’s **time in a service**, for the information will be **owned by the young person**, and for it to be shared with any future services **if the young person wishes**
Parents Say...

- **New online resource** created for and with parents and carers to help improve mental health care for children and young people.

- **Over 900 parents/carers** identified 5 key areas:
  - access, equality and diversity
  - communication
  - service leadership and delivery
  - methods of engagement
  - workforce development

- **Best practice case studies, videos, resource directory**

  [www.youngminds.org.uk](http://www.youngminds.org.uk)
Participation across whole CYP MH system (national, regional, and local level)

1. Co produce products and resources
   - where are the gaps?
   - what would be helpful?

2. National core and wider interest groups
   Diverse representation of CYP and parent and carers using services (incl. youth justice, those that tend not to use statutory services)

3. Embed across system
   - through support clinical networks, CYP IAPT collabora partnerships, workshops and masterclasses, monitoring impact at all levels

4. Best practice case studies, videos, resource website, directory [www.youngminds.org.uk](http://www.youngminds.org.uk)
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