MANCHESTER JOINT STRATEGIC NEEDS ASSESSMENT 2015/16

CHILDREN AND YOUNG PEOPLE
(STARTING WELL AND DEVELOPING WELL)

CHAPTER: Mental Health and Emotional Health & Wellbeing

TOPIC: Eating Disorders

Why is this important?

Eating disorders are serious mental health problems. They can have severe psychological, physical and social consequences. Children and young people with eating disorders often have other mental health problems (for example, anxiety or depression), which also need to be treated in order to get the best outcomes.

The number of people directly affected by eating disorders in the UK increased significantly between 2000 and 2009 (Micali et al., 2013). The King's Fund report, Paying the Price: The cost of mental health care in England to 2026 stated that 'service costs for eating disorders in 2007 were estimated to be £15.7 million, with 95 per cent of this related to anorexia nervosa. Costs are projected to increase to £23.8 million by 2026. Including lost employment costs brings the total to £50.6 million in 2007 and £76.4 million in 2026. Lost employment is estimated to account for 69 per cent of total costs' (McCrone et al., 2008).

NHS England's Access and Waiting Standard for Children and Young People with Eating Disorders (2015) suggests that individuals with anorexia nervosa are often misperceived as being responsible for their disorder (Crisp, 2005; Roehrig & McLean, 2010). Stereotypes and myths about eating disorders and perceived stigma can contribute to social isolation and reduced quality of life for children, young people and their families or carers. In turn, this can negatively affect the health and wellbeing of those with the condition, as well as of their family members (Crisafulli et al., 2008). Stigma-induced shame may act as a barrier to seeking treatment for anorexia and bulimia nervosa, and fear of being stigmatised may cause additional distress (Stewart et al., 2006).

Children and young people admitted to hospital because of eating disorders incur the highest costs and longest lengths of stay in in-patient services of all mental health disorders in Child and Adolescent Mental Health Services (CAMHS) (COSI-CAPS, 2008). Despite these high costs and long admissions eating disorders, especially anorexia nervosa, have the highest mortality and morbidity of all adolescent psychiatric disorders.

According to NHS England's Access and Waiting Standards for Children and Young People with Mental Health Problems (2015) there are currently a number of problem areas relating to the care and treatment of children and young people with an eating disorder. There are difficulties inherent to the conditions themselves, as well as to the delivery of treatment. As a result, many families and carers struggle to access appropriate care in a timely manner.

The standard identifies the following barriers

1. Reluctance of Child/ Young Person to Engage
2. Research indicates early intervention results in a better prognosis for recovery and can reduce risk of relapse from an eating disorder. This research suggests that unless intervention is delivered in the first 3 years, the outcome is poor (Treasure & Russell, 2011). NHS England's Access and Waiting Standard highlights that early intervention is hampered by; inadequate understanding of eating disorders, poor recognition of risks, poor awareness of local care pathways or eating disorder services, delay in referral to appropriate services, delay in treatment, caused by a lack of local eating disorder services, capacity in existing CAMHS or eating disorder services, suitable treatment and appropriately trained professionals.
3. Inadequate liaison among healthcare providers
4. Inadequate liaison with local authorities and schools or higher education
5. Transition difficulties between services
6. Geographical variability in distribution of services
7. Commissioning for severity
8. Eating disorder myths and stigma
9. External messages about healthy eating
10. Difficulties in outcome monitoring

The Manchester Picture

Estimates and definitions of the disorder lack consistency, the reality of the morbidity, fatality and the human and financial cost are clear (Gower's et al, 2010). Furthermore, young people with core anorexia nervosa and Eating Disorders Not Otherwise Specified (ED-Nos) are presenting with increasing frequency and at increasingly young ages. Prevalence estimates vary but assumptions suggest that 0.1% of young people under the age of 16 years and 1.0% of young people between 16-18 years old suffer from a significant eating disorder (Goodman and Scott, 1999). However, Beat's review (2009) of the literature would suggest a doubling of the prevalence of eating disorders between 1995 and 2005 (derived from Hay et al 2008).

The Greater Manchester area has a population of 2.7 million of which 20% are under 18 years, approximately 540,000. This roughly translates as 540 under 18s across the conurbation who will be suffering from an eating disorder which is serious enough to warrant intervention. Based on the prevalence estimate referred to in the previous paragraph, the Manchester equivalent figure for 2014 is 281 under 18s. Estimates of the prevalence of Bulimia Nervosa (BN) and Binge Eating Disorder (BED) are even more variable than those of anorexia and restrictive ED-NOS probably because sufferers of BN and BED are usually very secretive about their difficulties and relatively less likely to seek treatment.

The National Service Specification 2013 (Appendix for CAMHS Eating Disorders) reports 22% of admissions to all CAMHS Tier 4 beds for 13-18 years old and 5% of all beds for 12 and under are for eating disorders, and 90% of these children and

young people are girls. It also indicates that there are no specialist eating disorder units in the NHS sector in the North West of England. Gowers cites the 2003 O'Herlihy et al paper, which found that Anorexia Nervosa was the most common diagnosis represented on in-patient units. It is of note that these are conservative figures (i.e. 0.1% from 0-18) and probably an under-estimate.

The table below provides a comparison of the number of young people aged 16-24 years estimated to have an eating disorder. These figures are based on prevalence rates drawn from the Adult Psychiatric Morbidity Survey (APMS) (2007) applied to the number of young people 16-24 resident in the area. Based on these figures, it is estimated that there are likely to be around 12,785 young people aged 16-24 years with potential eating disorders living in Manchester - the highest in the North West Region.

Prevalence of potential eating disorders among young people: Estimated number of 16 - 24 year olds 2013

Count - population

Area	Count	Value	Lower CI	Upper CI
England	813,128	*	-	-
North West region	-	-	-	-
Blackburn with Darwen	2,249	2,249*	-	-
Blackpool	2,060	2,060*	-	-
Bolton	4,181	4,181*	-	-
Bury	2,539	2,539*	-	-
Cheshire East	4,624	4,624*	-	-
Cheshire West and Chester	4,705	4,705*	-	-
Cumbria	6,365	6,365*	-	-
Halton	1,800	1,800*	-	-
Knowsley	2,337	2,337*	-	-
Lancashire	18,427	18,427*	-	-
Liverpool	10,519	10,519*	-	-
Manchester	12,785	12,785*	-	-
Oldham	3,433	3,433*	-	-
Rochdale	3,218	3,218*	-	-
Salford	4,030	4,030*	-	-
Sefton	3,702	3,702*	-	-
St. Helens	2,471	2,471*	-	-
Stockport	3,658	3,658*	-	-
Tameside	3,183	3,183*	-	-
Trafford	2,854	2,854*	-	-
Warrington	2,767	2,767*	-	-
Wigan	4,485	4,485*	-	-
Wirral	4,302	4,302*	-	-

Source: Estimated

Source: Adult Psychiatric Morbidity Survey (APMS) 2007
http://www.ic.nhs.uk/pubs/psychiatricmorbidity07

What would we like to achieve?

CAMHS services in Manchester are signified by a tiered system of interventions reflecting increasing input at each stage.

- Tier 1 CAMHS is provided by professionals whose main roles and training is not mental health. These include GPs, health visitors, school nurses, social services, voluntary agencies, teachers, residential social workers and juvenile justice workers.
- Tier 2 CAMHS is provided by specialist trained mental health professionals. They work on their own but may provide specialist input into multiagency teams Manchester City Council.

- Tier 3 CAMHS is aimed at young people with more complex mental health problems and the service will be provided by multiagency teams
- Tier 4 CAMHS are aimed at children and adolescents with severe and/or complex problems. These specialised services may be offered in residential, day patient or out-patient settings. The service requires a combination or intensity of interventions that cannot be provided by Tier 3 CAMHS. These services include adolescent in-patient units, secure forensic adolescent units, eating disorder units, specialist teams for sexual abuse and specialist teams for neuro-psychiatric problems.

Nationally the majority of community CAMHS services do not have the capacity or workforce configuration to support the development of specialised eating disorder services service. In the absence of such services the likelihood of admission, and therefore cost, increases. Additionally stepping down from in-patient care from some in-patient providers is difficult because community CAMHS cannot mobilise the resources within the team to manage more complex young people, especially those young people who are likely to have a chronic relapsing and remitting course. These young people may end up having more than one admission and multiple transitions between Tier 3 and Tier 4 resulting in repeated discontinuities in therapeutic experience which is an issue highlighted by user groups as particularly anti-therapeutic and is associated with a worse prognosis.

The most cost-effective treatment of anorexia nervosa in children and young people is reported to be delivered by a community-based eating disorder service as opposed to generic CAMHS (Byford et al., 2007). Current NICE guidelines are dated 2004. It is acknowledged that there is very little up to date guidance on the treatment of Eating Disorders and the guidelines are due to be updated in 2017. It is anticipated that they will factor in the efficacy of day care as opposed inpatient care. Current thinking being that day care may be equally as effective.

A five year Transformation Programme has been initiated by the Government to enhance access to evidence based mental health and wellbeing interventions. Additional investment has been aligned to this programme including an element to establish a community based children and young people's eating disorder service. The funding is intended to improve the consistency and quality of eating disorders services, provide new and enhanced community and day treatment care, ensure staff are adequately trained and supervised in evidence based treatment and effective service delivery, and ensure the best use of inpatient services.

New mandated access and waiting time standards have been published and the ability of CAMHS to meet this standard will be monitored in 2016. Compliance with the Access and Waiting Time Standard for Children and Young People with Eating Disorders will provide assurance that NICE-concordant treatment will start within a maximum of 4 weeks from first contact with a designated healthcare professional for routine cases and within 1 week for urgent cases.

Specific service recommendations are:

- most children and young people should be treated in the community
- inpatient admission should be considered where there is high or moderate physical risk - admission should be to appropriate facilities with access to

educational provision and related activities and this should be within reasonable travelling distance.
- improved early identification
- increase in the responsiveness and flexibility in intensity of community-based care to reduce the need for inpatient care.

The benefits expected from implementing this model include every child and young person with an eating disorder receiving:

- improved access and reduction in waiting times
- appropriate evidence-based eating disorder treatment, based on their needs
- treatments for eating disorders and coexisting mental health problems from 1 team
- improved outcomes as indicated by sustained recovery and reduction in relapse, and reduced need for inpatient admissions.

Children, young people and their families and carers will benefit from:

- clearer referral routes and a better understanding of how to ask for help in their local areas
- a reduction in the need for transfers to adult services, long periods of treatment and inpatient admissions with the disruption to school and family life
- more involvement in commissioning services that meet their needs
- improved knowledge and training for all those working with children and young people, including a better knowledge of how to recognise eating disorders and how to access appropriate care when needed.

What do we need to do to achieve this?

Plans are already in progress for the development and delivery of a city wide Children and Young Peoples Community Eating Disorder Service. A collaborative approach is being taken across Salford and the three Manchester Clinical Commissioning Groups with a view to the service being fully operational in 2016/17. A new multi-disciplinary team will be created for our CAMHS provider to deliver against the new standard.

The commissioners are mindful of the potential for a Greater Manchester response to Eating Disorders in light of Devolution Manchester.

What are we currently doing?

Service provision for children and young people with eating disorders is variable across England. Services that are deemed to have good practices offer a ‘stepped care’ model of treatment, based on need, with more intensive support offered to those who are more severely unwell. While most people receive treatment in community services, some (mainly those with anorexia nervosa) receive treatment as

day patients or inpatients. The range of service provision means that nationally access to appropriate treatment is inconsistent. Considerable variability exists in referral to treatment pathways for children and young people with an eating disorder. There are currently 4 main settings that provide access to eating disorder treatment for children and young people. These are generic community CAMHS, eating disorder mini-teams, child and adolescent eating disorder services, and inpatient settings.

In Manchester out-patient care for children, young people and their families is currently embedded in generic Tier 3 CAMHS services split across the 5 Tier 3 services (North, Central, South Manchester, Salford and Emerge for over 16-17 years olds). Within these there are greater or lesser degrees of dedicated time and clinician interest, but not the capacity to flex up or down to respond to periods of high intensity need. The CAMHS service supported 86 new eating disorder referrals within its core teams in 14/15 across this footprint without a dedicated resource.

Currently there are 3 NHS and one independent sector provider of inpatient care in the Greater Manchester (GM West/Pennine Care/CMFT and Priory) conurbation providing inpatient and limited out and day patient provision young people with eating disorders. Like most NHS Tier 4 units most of the eating disorder provision in these beds is on generic units and the number of patients with eating disorders in these units can vary.

The exceptions are Galaxy House at the Royal Manchester Children's Hospital (RMCH) in the NHS and the Rivendell Unit at the Priory with 14 in-patient beds for children and adolescents on its Altrincham site. Galaxy House currently provides approximately 6 beds (can vary) explicitly for patients with ED. These beds meet MARSIPAN and QED criteria for specialist eating disorder bed status. Galaxy House is located on a large paediatric hospital site and staffed by both mental health and paediatric trained nurses. In addition, robust links with specialist paediatric gastroenterology, metabolic and endocrinology, cardiology and clinical chemistry services means that even very physically unwell young people can be confidently managed on the unit, with minimal disruption to their therapeutic program. Galaxy House is the only unit in the North West that is co-located on a site with paediatric expertise can accommodate patients under 12 with eating disorder if a 7 day placement is required.

Community and Stakeholder Views

To improve access, commissioners first need to understand the experiences of children and young people and their families or carers. A parent engagement session took place in August 2015 to inform local transformation plans. The following key messages were vocalised and will inform the design and delivery of the Children and Young Peoples Community Eating Disorder Service

- Children and Young People should not have to get into a crisis before specialised services are available
- Time frames are important especially how quickly services accessed.

- The need for improved early identification in primary care
- The need for outreach teams to support children and young people their parents and carers in the home.
- Support for parents and carers is a critical element of recovery

References and Links

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