Specification for Eating Disorder Services in Gloucestershire

Summary

This document specifies broadly the nature of Eating Disorder Services that Gloucestershire Health Authority wishes to secure for residents of Gloucestershire.

Background

The specification outlined below, is the result of a programme of work, including a health needs assessment, undertaken with the support and advice of a multi-agency, multi-disciplinary project group. As a result of this work, a strategy has been developed.

The overall aim of the strategy is to improve the quality and effectiveness of services in Gloucestershire for people with eating disorders.

The strategy aims to:

- decrease the length of time between the onset of eating disorders and access to appropriate help
- limit the physical and psychiatric morbidity, social disability and mortality caused by eating disorders.

This will be achieved by:

- increasing and improving early identification and intervention in the community and primary care
- improving specialist clinical and resource management within mental health services.

Gloucestershire Health Authority intends to target limited resources to secure an integrated network of services that are flexible enough to meet the individual health needs of people with eating disorders in Gloucestershire. For the purpose of this document, eating disorders are defined as anorexia nervosa, bulimia nervosa and their atypical variants (e.g. binge eating disorder). The definition does not include obesity unless there is a current eating disorder as well.

Population to be served

The population of Gloucestershire is 549,090 (Public Health Common Data Set 1995). Eating disorders can affect women, men and children, but the group at most risk are adolescent girls and young women (ages 15-24), of which there are 32,117 in Gloucestershire (PHCDS 1995). Men make up only 5-10% of cases of Anorexia Nervosa and far fewer cases of Bulimia Nervosa. Sufferers come from all sections of society, including minority ethnic groups.

Prevalence

Statistics from community based studies and a large primary health care based study undertaken in the Netherlands, would suggest the following distribution of people with eating disorders at different levels of care within Gloucestershire at any one time.

Living in the community	1800-2200
Conspicuous in primary care	300-350
Receiving mental health care	180-220
Receiving in-patient care	5-15
Detained under the Mental Health Act	0-2

Incidence

Estimates based on studies in primary and secondary health care would suggest the following incidence of new cases in Gloucestershire each year.

Primary health care	***Secondary mental health care***
Anorexia Nervosa = 44	Anorexia Nervosa = 27
Bulimia Nervosa = 63	Bulimia Nervosa = 33
Atypical Eating Disorders = ?	Atypical Eating Disorders = 30

A local audit of referrals to secondary mental health services (April 1996-March 1997) recorded a total incidence of 112 eating disorder referrals, 50 Bulimia Nervosa, 40 Atypical Eating Disorders and 22 Anorexia Nervosa. It appears that most community mental health teams are currently receiving 5-15 referrals per year.

General description of service requirements and recommended interventions

Gloucestershire Health Authority wishes to see improvements in services for people with eating disorders within the community, primary care, secondary mental health care (child and adolescent and adult) and tertiary specialist care. We will support the development of eating disorder services within each of these settings by purchasing and supervising the services of a Clinical Co-ordinator for Eating Disorders.

The Clinical Co-ordinator will work with the project group to implement a programme of interventions that aim to co-ordinate and improve services currently provided by East Gloucestershire NHS Trust, Gloucestershire Royal Hospital Trust, Heath House Priory Hospital, Severn NHS Trust, Swindon and Marlborough NHS Trust and other specialist units that occasionally receive extra contractual referrals from Gloucestershire Health Authority.

There is a wide range of severity of eating disorder as well as co-morbid personality disorder, physical and psychiatric illness amongst sufferers. Consequently, no one discipline or therapy has all the resources required by the range of sufferers and their carers.

Gloucestershire Health Authority therefore believes that generic mental health teams (child and adolescent and adult) are best placed to offer the range of services required for clinical management of moderate to severe eating disorders within the community. However, we recognise the need for specialist skills, knowledge and experience, so we wish to ensure that each Community Mental Health Team has at least two team members who develop a special interest and are able to take regular referrals including one named professional who can take a lead responsibility for eating disorders.

Statements of expert clinical consensus have established the principles of clinical management for patients with eating disorders. Ideally, a multi-dimensional treatment approach should be offered on an out-patient basis. More intensive interventions (day hospital or in-patient) are reserved for patients who are severely ill. Some sufferers will require multi-disciplinary input to their care. Length of contact with mental health services will be determined on an individual basis according to the severity of need, but a course of therapy for bulimia nervosa is likely to be at least 16-20 sessions over 4-5 months. A course of therapy for anorexia nervosa is likely to be much longer.

Local specialist clinical management of someone with an eating disorder, within community mental health services should normally include at least five components:

Comprehensive assessment of the sufferer's mental, nutritional and physical health by a member of the team with knowledge and experience in eating disorders, including where possible an interview with close relatives.

Education regarding the effects of eating disorders and dietary advice.

Monitoring of the sufferer's dietary intake, weight, physical health, psychological problems and behaviour.

Psychotherapy, including the use of cognitive behaviour therapy techniques and especially for younger sufferers, family counselling/therapy. Life skills training and creative therapies may also be helpful.

Support, including encouragement to attend a support group (EDA) and long-term follow-up to help prevent relapse.

When *intensive intervention* is required, there should be sufficient skilled help available to ensure adequate nutritional intake and emotional support.

Drugs, especially anti-depressants are sometimes required to treat co-morbid psychiatric illness or to help gain control over bingeing, but they are not usually effective for treatment of the eating disorder and relapse is common even whilst still on the drug.

Volume of service

Mental Health Services recorded 112 referrals of people with eating disorders for the year April 1996-March 1997. For the year April 1997 - March 1998, Gloucestershire Health expect between 100 and 150 referrals. This figure is likely to increase each year as awareness of eating disorders and access to services is improved. At this point, it is impossible to predict how many more referrals are likely to be directed to CMHTs. Referral rates will be monitored on an annual basis.

A survey found that there were 121 people with eating disorders on the caseload of Mental Health Services on February 11th 1997. Whilst this number is possibly an underestimate due to under reporting, it represents the best information currently available. The total number of contacts with CMHT staff is not available, but the survey showed that within an average month, patients spent about 406 hours with Mental Health Service staff (average 3.5 hours per patient). If it is assumed that a contact usually lasts up to 1 hour and the caseload remains roughly stable over a year, the total number of contacts would be 4872 for the year. Therefore, for 1997-98 the total number of contacts is likely to be about 5000.

The Departments of Nutrition and Dietetics at Gloucestershire Royal Hospital (GRH) and Cheltenham General Hospital (CGH) received a total of 29 referrals for people with an eating disorder during 1996-97 (CGH: Anorexia Nervosa = 5, Bulimia Nervosa = 0. GRH: Anorexia Nervosa = 16, Bulimia Nervosa = 8).

7 people spent time in hospital within Gloucestershire during 1996-97. The total number of admissions within county was 12 (including people already in hospital on 1/4/96). The total number of bed days was 472 (average length of admission 47 days, range 1-141). The average length of time spent in hospital over the year per person was 67 days (range 1-141, <3 months = 10, 3-6 months = 2). It is difficult to predict what effect improvements in services will have on numbers of admissions and length of stay.

16 people spent time in units out of county during 1996-97. 8 went to Heath House Priory Hospital, 4 to Marlborough House, and 4 to other units as ECRs. The total number of admissions out of county was 25 which includes 7 second admissions (mostly follow on admissions, but including 1 change of unit) and 2 third follow on admissions. The total number of bed days was 2386. The average length of time spent in hospital over the year per person was 149 days (range 9-365, <3 months = 6 people, 3-6 months = 4 people, 6-12 months = 6 people).

Specific services required:

Gloucestershire Health Authority will purchase the services of a Clinical Co-ordinator for Eating Disorders. The Clinical Co-ordinator will work in collaboration with Health Promotion, Primary, Secondary and Tertiary health care services, as well as other relevant organisations, to develop and evaluate the following services that are required (see three year project plan in Appendix A).

In the community

- Education and awareness raising in schools, youth and community settings.
- Other preventative interventions supported by evidence of effectiveness.

- Easily available information regarding eating disorders and how to access help.
- Support for sufferers and carers who have not accessed help through their GP or who are no longer receiving help from mental health services.
- Early identification and appropriate intervention within schools, youth and community and other relevant organisations.

Gloucestershire Health Authority expects improvements in these services from June 1999 and will support schools, child health staff, youth and community and other organisations to develop services by instructing the Clinical Co-ordinator to ensure that:

- Consultation and collaborative work with Health Promotion Gloucestershire is progressing by January 1998.
- A public telephone helpline is advertised and available by January 1998.
- A basic information leaflet on eating disorders, self help and how to access help is produced and distributed to all relevant organisations by January 1998.
- Information leaflets on eating disorders and their effects are produced and distributed to relevant organisations by June 1998.
- A well publicised, open access Eating Disorders Association (EDA) support group meets regularly in Gloucestershire by January 1998.
- Training on awareness of eating disorders is available to relevant organisations by January 1999.
- Guidelines for dealing with children with eating disorders in school are agreed and distributed by June 1999.

In primary health care

- Assessment of the sufferer's physical health (including weight and height), eating pattern, purging behaviour, attitude and aims regarding weight, menstrual history, substance use and mental state.
- Initial treatment, including education and advice regarding healthy eating and the effects of eating disorders, and encouragement to use a self help book and attend a support group.
- When necessary, on going monitoring of physical health, eating disorder behaviours and mental state as required.
- Early referral to the appropriate CMHT for people with moderate to severe eating disorders.

Gloucestershire Health Authority expects improvements in these services from June 1998 and will support General Practitioners to develop services by instructing the Clinical Co-ordinator to ensure that:

- Guidance on clinical management in primary care is produced and distributed to all GP's by January 1998.
- Training on understanding eating disorders, early identification and intervention is available to all GP's and other relevant primary health care staff by June 1998.
- Primary health care staff have easy access to specialist advice from the Clinical Co-ordinator and their local CMHT's by January 1998.
- A well publicised, open access Eating Disorders Association (EDA) support group meets regularly in Gloucestershire by January 1998.
- A range of educational leaflets is produced and distributed for use in primary health care by June 1998.
- CMHT's provide specialist assessment and clinical management for people with moderate to severe eating disorders by June 1998.

In secondary community mental health care (child and adolescent and adult)

- Comprehensive assessment of the sufferer's physical health, eating pattern, purging behaviour, attitude and aims regarding weight, menstrual history, substance use, mental state, personal history, family and social relationships and motivation for change, undertaken by a professional experienced in the clinical management of eating disorders.
- Involvement of carers in the assessment process, including an assessment of their needs in relation to the sufferer's eating disorder.
- Referral to a dietician for nutritional assessment and advice when required.
- Education and advice regarding the consequences of eating disorders for sufferers and carers.
- Encouragement to use a self help book and attend the EDA support group.
- On going monitoring of physical health (including weight), eating disorder behaviours and mental state as required.
- Psychotherapy including the use of cognitive behaviour therapy and especially for younger sufferers, family counselling/therapy.
- Access to life skills training, physiotherapy and creative therapies when required.
- Multi-disciplinary involvement in clinical management when required.
- Support and social interventions for people with severe and chronic eating disorders.
- Measurement of outcome and long term follow up.

- Referral for intensive intervention in hospital when required.
- On going involvement and liaison in preparation for discharge from hospital.

Gloucestershire Health Authority expects improvements in these services from June 1998 and will support CMHTs and other relevant professions (e.g. Dieticians and Physiotherapists) to develop services by instructing the Clinical Co-ordinator to ensure that:

- Each CMHT has at least two team members who have experience of the assessment and clinical management of eating disorders, including a named professional (Link Worker) who takes lead responsibility for the development of eating disorder services within the team by January 1998.
- Link Workers from the CMHTs meet on a regular basis with the Clinical Co-ordinator for shared supervision, joint clinical work and training (at least one session per month) by January 1998.
- Specialist supervision and consultation is available from the Clinical Co-ordinator and others if required by January 1998.
- Training on understanding eating disorders and clinical management is available for all CMHT and other relevant staff by January 1998.
- CMHT staff are updated annually on developments in research and practice by June 1998.
- Guidance on clinical management is produced and distributed by January 1998.
- A range of educational leaflets are produced and distributed for use in secondary mental health care by June 1998.
- Specialist intensive intervention is easily available for people who require in patient care by January 1998.
- Training in outcome measurement and support with data collection and evaluation are available by June 1998.

In secondary in-patient health care

- Admission to a local general hospital for medical emergencies, or treatment of co-morbid physical illness relating to the sufferer's eating disorder.
- Admission to a local psychiatric hospital for treatment of co-morbid mental illness or clinical management of the eating disorder, where specialist intensive intervention is not required.

Gloucestershire Health Authority expects improvements in these services from June 1998 and will support hospital staff to develop services by instructing the Clinical Co-ordinator to ensure that:

- Staff in general and psychiatric hospitals have access to support and advice from the Clinical Co-ordinator and the relevant CMHT by January 1998.

- Staff in general and psychiatric hospitals have access to training on understanding eating disorders and in-patient clinical management by January 1998.

In tertiary specialist care

- Specialist Consultant Psychiatrist assessment and advice as required.
- Specialist multi-disciplinary assessment as required.
- Programmes of specialist intensive intervention, including in patient clinical management for people whose physical or mental health is at great risk or who require special help to initiate changes.
- Regular liaison with the local CMHT responsible for on going management.

Gloucestershire Health Authority expects improvements in these services from January 1998 and will support tertiary specialist staff to develop services by instructing the Clinical Co-ordinator to ensure that:

- Close working relationships are developed with tertiary treatment centres by January 1998.
- Protocols are agreed and written by January 1998 for admission, liaison and discharge and are reviewed by June 1998.
- Contracts with specialist treatment centres clearly state the treatment programmes required by Gloucestershire Health Authority by April 1998.
- Contracts with specialist treatment centres are clinically reviewed and monitored by the Clinical Co-ordinator with support from the appropriate Contracts Managers at Gloucestershire Health Authority by June 1997.

Quality

Gloucestershire Health Authority wishes to secure high quality services that are clinically effective, acceptable to service users and their carers, and which utilise the available resources efficiently. The quality of services for people with eating disorders will be measured by:

- Evaluation of clinical outcome data.
- Surveying the views of service users and their carers.
- Clinical audit of agreed standards of care.
- Eliciting the views of professionals within each relevant agency.

The desired outcomes resulting from developments in eating disorder services are listed in Appendix B.

Monitoring

Developments in eating disorder services will be monitored by the project group which will continue to meet 3 times each year (January, May and September) to receive and discuss a report from the Clinical Co-ordinator. The project group will review:

- Progress with the work programme
- The volume and quality of clinical work
- Developments in best practice
- Future developments in eating disorder services

Regular monitoring of the following will be undertaken:

- Referrals to CMHTs.
- Caseload numbers within CMHTs.
- Telephone calls to the eating disorders helpline.
- Attendance at the EDA support group.
- Admissions to local hospitals and specialist treatment centres

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Clinical Co-ordinator

Eating Disorders

August 1997

Appendix B

Desired Outcomes

The Clinical Co-ordinator will be responsible for ensuring that work is undertaken to achieve the following outcomes:

Principal desired outcomes

1. People living in Gloucestershire, who suffer from eating disorders will have easy access to appropriate help according to their individual needs.
2. People caring for eating disorder sufferers will also be offered help according to their needs.

In the community and primary health care

1. The general public and community agencies will have easy access to information and advice on eating disorders.
2. All relevant agencies in the community (education, youth services, voluntary agencies, social services, primary health care teams) will know how to access help for someone with an eating disorder.
3. Relevant staff within each agency will have been offered training on early identification and intervention.
4. Those staff will also have a basic understanding of the causes and consequences of eating disorders.
5. General Practitioners will have access to advice on clinical management within primary health care from the Clinical Co-ordinator and their local CMHT.
6. A well publicised Eating Disorders Association support group will be meeting regularly in Gloucestershire.
7. Guidelines for dealing with young people with eating disorders in school will have been established and reviewed.
8. The quality and effectiveness of these interventions will have been evaluated by eliciting the views of service users and relevant agencies.

In secondary mental health care

1. Staff within CMHTs will have received basic training, and will have a clear understanding of the causes and consequences of eating disorders, as well as knowledge of the principles of clinical management.
2. Referrals to CMHTs will be assessed by a member of staff who has experience and training in the care of people with eating disorders.
3. Each CMHT will have at least two team members who regularly assess and clinically manage referrals.
4. Each CMHT will have a named professional (Link Worker) who takes lead responsibility for eating disorders.

5. Link Workers from the CMHTs will have met regularly with each other and the Clinical Co-ordinator for supervision, joint clinical work and training.
6. CMHT staff will have access to specialist supervision and consultation.
7. CMHT staff will have been updated annually on developments in research and practice.
8. Clinicians specialising in eating disorders will have received on going training to develop knowledge and skills.
9. Referrals to CMHTs will have been monitored annually.
10. An annual caseload survey will have been undertaken.
11. The outcome of intervention will be evaluated by standardised measures of outcome.
12. Clinical standards will have been agreed, written and audited.
13. The quality and effectiveness of clinical management will have been evaluated by surveying the views of service users and their carers.

<u>In specialist tertiary mental health care</u>

1. There will be a close working relationship between specialist secondary mental health services and tertiary specialist treatment centres.
2. Data on all admissions will have been monitored and reviewed regularly.
3. A protocol for admission, liaison and discharge will have been agreed and audited.
4. Contracts with specialist treatment centres will clearly state the treatment programmes required by Gloucestershire Health.
5. The outcome of admissions will have been monitored, including the views of sufferers, carers and staff.
6. Options for the development of day care will have been explored and where ever appropriate and possible, day care will be provided in preference to in patient care.

Appendix C - List of documents supporting this strategy

1 The epidemiology of eating disorders in Gloucestershire

2 Services for people with eating disorders in Gloucestershire

3 Eating disorder services in Britain

4 Models of eating disorder services

5 Effective treatments for eating disorders

6 Principles of clinical management for patients with eating disorders

7 Admissions to hospital for people with eating disorders in Gloucestershire

8 Eating Disorders and Health Promotion