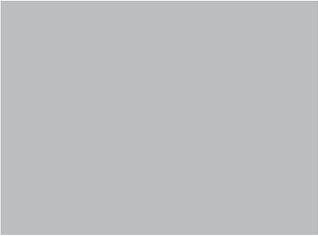
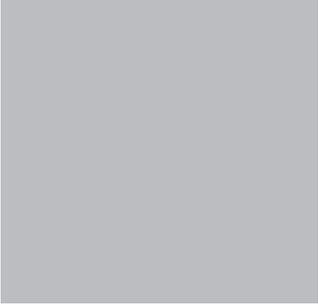


COMMUNITY TREATMENT OF EATING DISORDERS

Paul H. Robinson

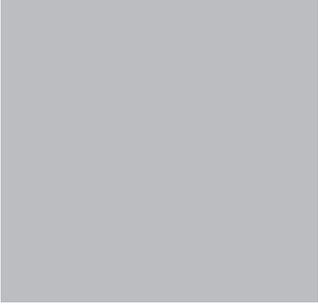


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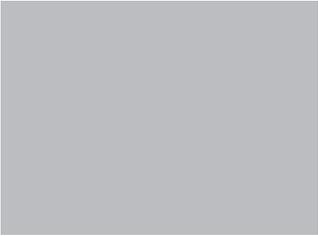
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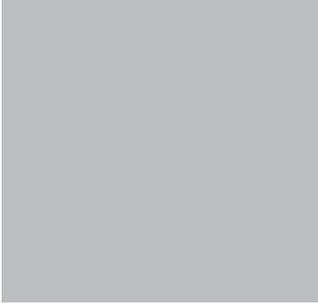
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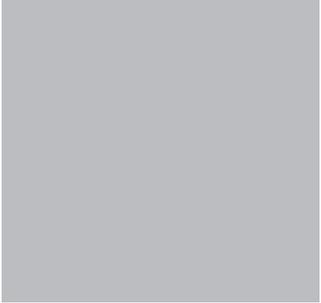
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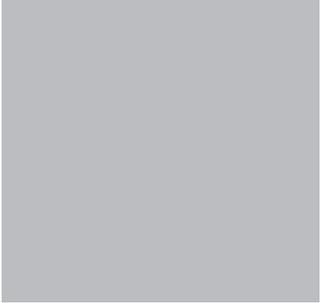
CONTENTS

About the Author	vii
Acknowledgements	ix
Introduction	xi
Chapter 1 Establishing a Home-oriented Service	1
Chapter 2 Staff	19
Chapter 3 Initial Outpatient Assessment	32
Chapter 4 Physical Assessment and Monitoring	57
Chapter 5 Psychological Interventions	80
Chapter 6 Day Care	103
Chapter 7 Liaison and Outreach	122
Chapter 8 Inpatient Care	141
Chapter 9 Rehabilitation: Dealing with SEED ..	165
Chapter 10 Technical and Academic Aspects	177
References	191
Index	193



ABOUT THE AUTHOR

Dr Paul Robinson is a consultant psychiatrist in eating disorders psychiatry at the Russell Unit, Royal Free Hospital, Camden and Islington Mental Health and Social Care Trust. After postgraduate training in general medicine he trained in psychiatry at the Maudsley Hospital, was a family therapist and conducted research into control of eating behaviour at the Institute of Psychiatry and Johns Hopkins Hospital, Baltimore. In the last eight years at the Royal Free he has built up a multidisciplinary team dedicated to the community approach to eating disorders, minimising use of inpatient care and developing safe and effective ways to provide treatment for these distressing, debilitating and at times life-threatening conditions. The team has twice been in the final of the Hospital Doctor Team of the Year Award. His present interests are the treatment of severe and enduring eating disorder (SEED), and the delivery of therapy via email, for which he reached the final of the Medical Innovations Award. He lives in North London.



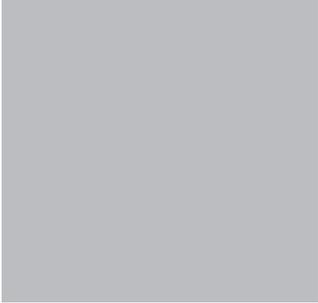
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Paul Robinson
London, November 2005



INTRODUCTION

This book is intended for all those who are concerned with and responsible for the provision of care for people with eating disorders in their locality. It is aimed in particular at those professionals in the field who are seeking a treatment approach that minimises the use of hospitalisation. It will also be of interest to sufferers from eating disorders and their families, who may find here some insights into the mind of a healthcare provider and be more aware of what they should expect from an eating disorders service.

With this in mind I have set out to make this book accessible to different types of reader in the hope that it can speak to as many people as possible. I have covered some medical topics but hope that I have made them comprehensible to non-medics. I believe that the majority of care for eating disorders is properly provided by non-medical professionals, and that they need to be informed about the sometimes dread physical complications of the disorders so that they can safely and confidently conduct treatment, and know when medical intervention is required.

Community treatment suggests that most interventions should take place while the person receiving those interventions resides either at home or in a place in which they have autonomy, such as a community hostel. Treatment location varies from the outpatient clinic, the day hospital, the patient's accommodation and the community mental health team base. Inpatient treatment is included in community treatment, perhaps surprisingly, but appropriately, because inpatient treatment represents one end of a continuum of intensity of care that extends from the outpatient clinic to the hospital bed. In the last 50 years psychiatry has seen a profound shift in emphasis from hospital to community care, and the closure of thousands of hospital beds has been accompanied by the establishment of a whole range of new approaches, namely community mental health teams, assertive outreach teams, crisis response teams, day hospitals and many new community workers in the fields of housing and occupation. Development of community approaches in eating disorders has been patchy, largely because expertise is available in only a few locations. This book will provide a model for localities to develop their own community-oriented eating disorders services.

It is my experience in building a community-based service that has led to my writing this book, in response to a demand for a handbook on 'How to do Community Eating Disorders'. It should be helpful for eating disorder services at all stages of development, from the glint in the eye of the mental health purchaser to the GP and the consultant in his or her empire. Surveys have repeatedly shown that specialist care for eating disorders is sparse in many parts of the United Kingdom, especially those parts away from the London–Oxford–Cambridge box in the south east. The rule appears to be that funding for eating disorders care, and perhaps funding for other specialist services, is inversely proportional to distance from the seat of government. People residing in those areas have either very little local service or a small unit that cannot cope with local demands. The most severely ill may be referred to a specialist centre, and then be discharged back to the same inadequate provision. This is not an acceptable state of affairs, and many local healthcare providers and purchasers are attempting to get funding together to establish local services. When committing funds, it is necessary to decide how much should go into inpatient care and how much into community care. It is our view that investment in the latter will reduce spending on the former, and evidence is presented in this book that a well-functioning community team can keep people out of hospital.

It has been suggested that a community team could be established for every million population so that in the UK's population of 60 million, 60 teams are required. It has also been suggested that each team should be funded to the level of around £1 million for staffing. This would provide adequate community care for the population, but not fund the beds required. We have estimated that four beds per million, of which half might be low dependency hostel beds, are required which would require one 20-bed unit per five million population.

Needless to say this book is written in an English context and, inevitably, much of the political landscape will be unfamiliar to those in other countries, with purchasers, providers, GPs, the Mental Health Act, the Care Programme Approach and other peculiarly English phenomena. It should, however, be useful to services outside England as a model of how to provide local services for eating disorders, however funded and managed. Conducting seminars in Northern Ireland, France, Spain and Finland has shown the author that the issues everywhere are similar, and invitations to provide workshops arise from a wish to enhance skills in providing community care while according inpatient care its proper place. In most settings it will be possible to recognise the following groups (English equivalents are in brackets): patients, families and carers; primary care teams (general practitioners); secondary care teams (psychiatric services, community mental health teams); and specialist teams (eating disorders, drug and alcohol, etc.), while on the management side there are the government

(Department of Health), local health commissioners (Primary Care Trusts), and local mental health provider organisations (Mental Health Trusts).

The idea for this book arose after a gratifyingly large number of clinics had called the Russell Unit and said 'Can we come and visit? We're developing eating disorders and heard you have an interesting model of care'. We are delighted to host visitors and welcome them to attend our team meeting. This volume represents the idea, 'You've met the team, now here's the book!'

The book is arranged in three sections, beginning with establishing a service and dealing with staff issues in Chapters 1 and 2. The main body of the book, from Chapters 3 to 9, deals with various aspects of care, from initial assessment and physical monitoring in Chapters 3 and 4, through management in different contexts including outpatients, day hospital, other units and inpatient care in Chapters 5 to 8, ending up with the treatment of the patient with long-term illness (SEED – severe and enduring eating disorder) in Chapter 9. The final section, Chapter 10, covers technical aspects such as database development, research, IT and teaching.

For brevity, patients are generally referred to using feminine pronouns, as females make up over 90 % of the clientele of a specialist eating disorders service.

It goes without saying therefore that this book could not have been written without the support of my team who have my admiration, affection and respect. In preparation for the writing I spent an hour with each team member, as well as some patients who had successfully navigated the system. All contributed in their unique way, and their contributions permeate the book. For all of them, past and present members, this is their book.

Chapter 1

ESTABLISHING A HOME-ORIENTED SERVICE

THE TASK

Providing first-class community care of eating disorders is a challenging task. The service must offer high-quality treatment, including therapies known to be effective, and provide safety so that patients who require admission can be identified and provided with timely and appropriate in-patient care. Systems are required to support staff dealing with difficult and demanding clinical situations, to supervise the provision of high-quality therapy and to make sure that patients are monitored for emergence of risk factors. Systems must be in place to deal with extreme physical and psychological difficulties, while staff continue supporting those in intensive day care and in less intensive outpatient care. When patients are admitted, they, their families and the teams looking after them require continuing support and advice. At the same time the team must be in a position to co-work with other community teams in primary care, general psychiatry, drug and alcohol and child and adolescent psychiatry, so that patients' needs are met and they do not slip through the gaps that can appear between services.

PREDICTING AND MEETING DEMAND

In order to receive health care the prospective patient has to negotiate a number of hurdles. If 100 people in a community suffer from a condition, only a proportion will consult anyone about it. Others will discuss it with family or friends, or consult printed or electronic sources of information. Of those who consult in person, many will go to a general practitioner (GP – family physician), who may or may not diagnose the problem, largely depending on how it is presented (e.g. weight loss or stomach pains) and how inclined the GP is to look for psychological problems. Once the condition is recognised, the GP will make a decision about referral to specialist services. This decision is based on many variables, including the expertise

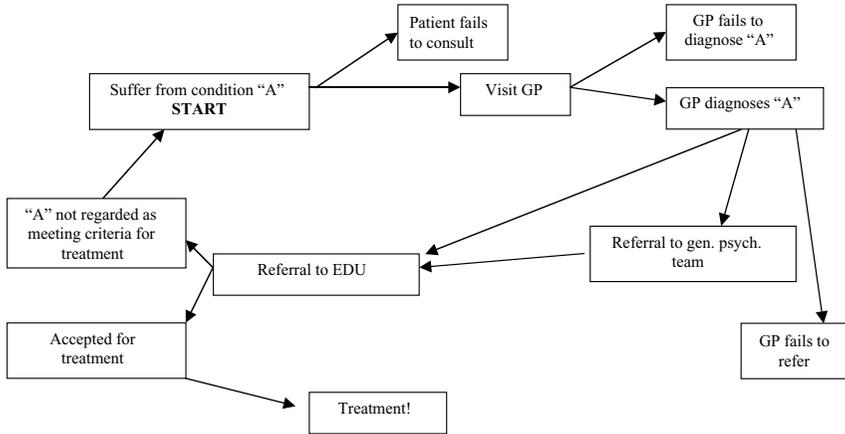


Figure 1.1 Pathways to care: Hurdles that the patient needs to negotiate before obtaining treatment. At every point onward progress may not be made if recognition and appropriate referral fail to occur.

of the GP and resources in primary care, and the availability and quality of specialist services. The sufferer may now have negotiated three of the hurdles (whether to visit the GP, whether the GP will diagnose the problem and refer to a specialist). Between the GP and an eating disorders specialist there may be an additional hurdle, sometimes imposed by the funding agency, in the form of a referral to a general psychiatrist who may or may not refer on to the eating disorders specialist (Figure 1.1). The intrepid patient has now leapt nimbly over three or four fences and arrives at the eating disorders specialist. There is a further hurdle. The specialist has to agree that the patient does have an eating disorder and that it is of sufficient severity to warrant treatment in the specialist unit. These hurdles in referral to specialist care are more substantial and numerous in a government-funded health service as in the UK. They are least in a private service funded by the patient or family and insurance funding tends to make intermediate demands.

Surveys of bulimia nervosa and related disorders in the community in the UK have found that eating disorders are very common, but that consulting a doctor in order to obtain help is relatively rare, generally under 10 % of cases. Reluctance to visit the GP has been attributed to patients' perception of their GPs as sometimes dismissive and uninformed (Newton, Robinson & Hartley, 1993). In a survey sponsored by the Eating Disorders Association and the Royal College of Psychiatrists respondents cited self-help groups, training for GPs and availability of specialist services as key priorities.

In a population of 1 million people, how many are likely to have eating disorders and of that group how many will arrive at the specialist service? Prevalence estimates suggest that 0.4 % and 1 % of young women will have anorexia and bulimia nervosa, respectively. Epidemiology is currently

inadequate but a conservative estimate suggests that an additional 3 % will fulfil criteria for clinically significant eating disorders (eating disorder not otherwise specified or binge eating disorder). The proportion of females aged 16–45 in the UK is 32.1 % (9.733 million). This gives an estimate for eating disorders of 450 000 people (adding 5 % males), or 7500 people per million population. Looked at from the other end of the telescope, the clinical eating disorders service at the Royal Free Hospital, the Russell Unit, receives 300–350 referrals per million population per year. This clearly demonstrates the powerful effect of the hurdles: around 4.6 % of the eating disordered population are referred in one year. In a research project described in Chapter 10, students and staff at a large college in the University of London were circulated by email and offered therapy online. Of 97 people accepted for treatment, only 21 had until then received any form of therapy. On the one hand the small proportion of people contacting healthcare services represents a serious failure to address a public health problem. On the other, GP and specialist services would quickly be overwhelmed if all potential patients turned up at once! Given that a unit providing care for 1 million people attracts, on average, five new referrals a week, how many will have bulimia nervosa (BN) and anorexia nervosa (AN)? Epidemiology suggests the proportion should be around 2:1. In practice those proportions are not too far off. At the Royal Free, over a year, the average proportions are 48 % BN and 19 % AN. The figures for binge eating disorder and eating disorder not otherwise specified (EDNOS) are more at variance with statistics, which suggests that they should be in the majority. In the clinic they form only 27 % of referrals, suggesting that ‘typical’ patients are being preferentially referred. Five new patients a week can be accommodated in an efficiently run new patient clinic. Length and intensity of treatment are needed in order to make an estimate of ongoing staffing requirements. With an average caseload of 10 and a duration of therapy averaging 1 year, and 150 patients eligible for individual psychotherapy, a staffing of 15 therapists would be required. In practice there will be fewer therapists, and therefore a waiting list is inevitable as assessed patients back up while awaiting therapy. If a day hospital is envisaged, staffing needs to take account of groups, meals and key working, while provision for liaison, outreach and emergencies adds further to the demands. The staff numbers in the Russell Unit are detailed in Table 1.1 (see p. 4). The figures are also given in whole-time equivalents per million population, so that they can be used in service configuration.

LOVE OF MONEY: THE ROOT OF ALL EVIL

In the 2001 report (Royal College of Psychiatrists, 2001) from the Eating Disorders Special Interest Group, we came up with a delightfully simple formula: £1 (€1.42) for each population member will give you enough to

Table 1.1 Staff members on the team serving an area containing 840 000 people

Staff members	Grade	Whole Time Equivalents	WTE per million
Management	Service Manager	1	1.19
Doctors	Consultant*	1	1.19
	Junior Trainee	0.5	0.6
	Senior Trainee	1	1.19
Nurses	Senior	2	2.38
	Junior	2	2.38
Psychologists	Consultant	0	0.0
	Non-consultant	2.1	2.5
Dietitian	Senior	1	1.19
Massage Therapist	Junior nurse	1	1.19
Art/Movement/Drama Therapists		0.4	0.48
Occupational Therapist	Senior	1	1.19
Family Therapist	Senior	0.8	0.95
Administrative (secretaries)	Senior	1.6	1.9
Total		15.4	18.33

* 0.9 Eating disorders psychiatrist

0.1 Consultant psychiatrist in psychotherapy

provide a good, community-based service for over 18s with eating disorders. In this section we assume that you are developing adult eating disorder services for 1 million people with a mixture of urban and rural populations. Almost all healthcare funding organisations are short of money. When there is a well-developed National Health Service (NHS), as in the UK, private funding agencies are able to limit access to private health care funding, especially for long-term conditions, knowing that the NHS will be there to provide ongoing care. Indeed, private insurers will sometimes demand that, as the time for their funding comes towards an end, the clinician has expressly indicated the NHS alternative treatment package that has been set up. Where access to high-quality free health care is restricted, as in the USA, private care has a real ethical dilemma in how to limit care in someone who very much needs treatment, but is unable to continue to pay for it after insurance or public funding has been withdrawn. In much of Western Europe, specialist care can be obtained and the state will pick up all or most of the bill.

Given that money is in short supply, what can a clinician or manager do to encourage a loosening of purse strings in favour of a specific need such as eating disorders? It is important to be aware that your favourite clinical area is in competition with many others, for example drug misuse, forensic services, early intervention and assertive outreach. In general, the money directed towards a particular area is dependent on a finite number of pressures. Broadly they comprise: (1) costs: both of funding new services and of not funding them; (2) profile: the level of interest in an area both locally and

nationally; (3) danger: how dangerous to the public and (less influentially) to themselves are your client group?

I will expand on these three essential areas, and provide information on how to maximise their effectiveness in obtaining funding for a new or developing service.

1. Costs

As far as can be discerned, funding bodies appear to be motivated by cost, safety, consumer opinion and effectiveness, probably in that order. While the cost of something may be high, funders may well provide the money if the cost of not providing it is higher, in other words, could the service save money? In order to argue this you need to find out what is happening to this patient group at present. It may be that other services, such as general medical or general psychiatric, are attempting to do the work. Find out from clinicians who have tried to treat severe eating disorders how it went. If the patient was in a psychiatric ward for weeks, ran rings round the staff and ended up not gaining weight, while the unit was so short of beds that an acutely ill manic patient needed to be admitted to a private unit, you have a case. The new service, you can argue, would work constructively with the patient and family, probably prevent the admission, and obtain a better outcome. The most telling argument is that the acutely ill general patient would have been accommodated without an expensive and inappropriate private admission elsewhere. If patients with severe eating disorders are being admitted to inpatient units, funded by the local health purchasers, find out how much has been spent in the past few years on these placements. It would not be unusual to find that £200 000, (€ 330 000) had been spent per year. Offer to develop a community service with that starting budget which would give you two nurses, a part-time consultant, manager and therapist. Discuss with great care the question of funding inpatient admissions. If the funding body ask you to pay for admissions out of your own budget remember that one admission could easily put your service in the red. The alternatives are: (a) to hold back a proportion of the budget (say £100 000) to cover admissions or (b) to accept a lower budget from the funding body while responsibility for funding admissions remains outside your eating disorders budget. Because admissions for eating disorders can be so expensive, no one wants to hold the hot potato of the financial risk for them.

2. Profile

Patients with eating disorders are not that popular (see Chapter 6) but that can work both ways in terms of the support you may or may not get from your colleagues. Some might see eating disorders as relatively trivial and definitely second rank to schizophrenia and depression, while very much wanting someone else to deal with the patients because they can be so difficult to manage especially on general psychiatric wards. Have there been any enquiries or surveys of eating disorders in the

area, and what were the recommendations? Is there a local branch of the Eating Disorders Association and what do they think of local services? Is it known that a local dignitary had a relative with an eating disorder, and might lend support to a campaign? (Occasionally a very high profile individual has a family connection with eating disorders, as occurred in France, but in that case, the idiosyncratic services that were set up did not meet with the approval of many eating disorder specialists.) On a national level, look at the guidelines available. In the UK NICE (www.nice.org.uk) has been successful in gathering together the evidence for effective treatments in a variety of areas. It is likely that, in the UK, hospitals will be rated and, perhaps, funded according to whether they comply with NICE recommendations. This will be a tremendous boost for service quality, although where the money will come from to fund the necessary improvements no one knows, as yet. For our clinical gold prospector looking for cash to start or improve a service, the promise of extra funding for a Trust which might come from complying with NICE could well encourage a Trust to 'Spend to Save'.

3. Danger

This is one of the most powerful influences on funding bodies. Serious incident enquiries following the death or serious disability of a patient can have profound effects on services. Risk to others is often even more influential. In England the murder, by a patient with schizophrenia, of a member of the public sparked off a wave of enquiries and reports that led to a fundamental change in the way discharged patients who might move to another area were managed. The enormous bureaucracy known as the Care Programme Approach in which care in clinical and social spheres is documented and the responsible person identified for each intervention, as well as for coordination of care, was a result of this wave. Obtain reports of any enquiries that have been held in cases of patients with eating disorders in the area and in all adjacent areas, and collate the recommendations. Many such reports conclude that specialist help was not available when it should have been or that it was not accessed or heeded at the appropriate time. These findings are strong arguments to persuade funding bodies to release more money.

WHICH STAFF?

Staff from differing professions are like travellers who reach a caravanserai having come from widely differing directions. They will each have a different and unique story to tell and be able to teach their co-travellers about their particular experience, while at the same time having much in common with the others. It is important to have certain skills in a team, but, as will be seen in the following chapters, a healthy team develops in such a way that people can overlap considerably in role, so that underlying