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Beginning the journey: mapping the route

Aim of the book: how to improve mental health care

The reform of mental health services is now proceeding in many countries throughout the world. Although the speed and the local details of these changes vary between countries, there is a clear need for an overall map, which can assist all those service-users, family members and staff involved in this transformation. In a sense this book acts as a guide, providing a compass to orientate the direction of travel.

The mental health care changes we shall discuss are reforms in two senses. On one hand they are a profound re-orientation of the principles which guide how treatment and care should be provided to people with mental illness. On the other hand they also refer to changes in the physical shape and pattern of health- and social-care services. In this book we shall provide a practical manual to help people who are involved in improving mental health services, and offering guidance in relation to three key cornerstones: the ethical foundation, the evidence base and the accumulation of experience which has been gathered in recent years.

First, the ethical foundation refers to establishing agreed fundamental principles which orientate how service planning, provision and evaluation should be conducted. For example, is it more important to emphasise continuity of care in a service, or to focus upon accessibility, or should both be local priorities? Second we shall highlight the importance of providing, wherever possible, interventions and services which are soundly evidence-based, for example those shown to be effective in routine clinical settings in systematic reviews, based on the results of randomised controlled trials. Third, we shall also draw upon a range of other types of evidence, such as knowledge stemming from the experience accrued from good clinical practice, especially in those areas of clinical practice which have not yet been subjected to formal evaluation. In our view the foremost of these guideposts is the ethical base, as this provides the foundation stone for deciding what types of evidence and experience should be valued most highly [1].

Table 1.1 The Matrix Model

Place Dimension	Time Dimension		
	(A) Input Phase	(B) Process Phase	(C) Outcome Phase
(1) Country /Regional Level	1A	1B	1C
(2) Local Level	2A	2B	2C
(3) Individual Level	3A	3B	3C

A clear limitation of this book is that it focuses upon our own experience in Western Europe, and so includes less information from other continents [2;3]. We shall try to balance this by including illustrations by colleagues in 25 countries worldwide, in which they describe their experiences (both positive and negative) in developing mental health care, so the lessons they have learned can also assist you.

Drawing the map: the 'matrix model'

We believe that a map is necessary to help shape service aims and the steps necessary for their implementation. To be useful such a map should be simple. We have therefore created a scheme with only two dimensions, which we call the *matrix model*.

Our aim is that this model will help you to assess the relative strengths and weaknesses of local services, and to formulate a clear plan of action to improve them. We also expect that the matrix model will assist you by offering a step-by-step approach that is clear, but is also flexible enough to be relevant to your local circumstances.

The two *dimensions* of this map are place and time (see Table 1.1). Place refers to three geographical levels: (1) country/regional; (2) local and (3) individual. The second dimension (time) refers to three phases: (A) inputs; (B) processes and (C) outcomes. Using these two dimensions we can make a 3×3 matrix to bring into focus critical issues for mental health care.

We have chosen to include the geographical dimension in the matrix because we believe that mental health services should be primarily organised locally, to be delivered to individuals in need. However, some of the key factors are decided regionally or nationally, for example overall financial allocations to the mental health sector. In this sense, therefore, the local level acts as a lens to focus policies and resources most effectively for the benefit of individual service-users.

We have selected time as the other organising dimension, as we see a clear sequence of events flowing from inputs to processes to outcomes. In our view

outcomes should be the most important element, and the mental health system as a whole should be judged on the outcomes it produces.

One of our aims is that this matrix model can assist, in a sense, the accurate diagnosis of dysfunctional mental health services so that corrective action can be applied at the right level(s) to improve care. At the same time, this model is not intended to be rigidly prescriptive. It can be taken as a tool to use in analysing problems, and then in deciding what action to take. We encourage you to adapt these ideas to maximise their relevance to your local situation.

Illustrations of using the matrix model

The practical use of the matrix model is the central theme of this book. One illustration of this is how the model can help us to understand which factors contribute to a good outcome for a person with an acute episode of severe mental illness who is treated at home. Such an outcome is often seen as a success for the practitioners who work at the *individual level*, but, in fact, also depends upon decisions made at the *local level* (e.g. to provide home treatment services), and in addition may be enabled by policies and resources decided at the *national level* (e.g. to develop community care).

How to use the resources and ideas in this book

To make this book as useful as possible for you we shall provide an array of resources from which you can choose. The main ideas will be presented in the text, accompanied by tables and figures to show them graphically. In addition we shall offer text-boxes, which include relevant quotations, by service-users, family members and staff, of their experiences, linked to the themes of each chapter. There will also be special feature-boxes, with examples of good practice on specific topics. Throughout the text you will also find references to the background literature, with full details provided at the end of each chapter, in case you want to go back to these primary sources. We shall try to keep the book free of jargon. Each chapter will end with a summary of the key points to reinforce the main issues addressed.

Although we shall attempt to make balanced and fair use of the available research evidence, at the same time we need to say that we are not neutral. We would like to make clear to you our own bias. We have both undergone a medical training, and we now place ourselves in the traditions of epidemiological psychiatry, and public-health medicine. From these traditions we attach a very high value to an evidence-based approach. In addition, we believe, from our own experience, in the importance of a direct interplay between research and clinical practice, which should be mutually beneficial. Indeed we consider

that the medical model alone (without taking into account social, psychological and economic factors) is insufficient to understand the full complexity of mental disorders, their causes and their consequences for people with these conditions and their family members.

This new book is written following our earlier volume, called *The Mental Health Matrix* [4]. Our approach remains consistent; how to offer ideas that will be practically useful to those of us who are trying to make mental health services better. Whereas the earlier book was written for a more research-orientated readership, here we intend to provide useful ideas for a wider range of people, including service-users, family members, practitioners and students of the mental health professions, and so the core ideas are presented directly in relation to examples from clinical practice. Second, we have substantially updated the evidence base, which has changed a great deal over the last decade. Third, having discussed the matrix model with many colleagues worldwide in recent years, it is clear that it should be considered as an approach which can be flexibly adopted according to local circumstances, in high-, medium- and low-resource countries. For this reason we shall include many real examples from colleagues who have tried to make changes for the better, sometimes succeeding and sometimes not.

Key points in this chapter

- The matrix model can be used as a map to guide decisions about how to improve mental health services.
- The matrix model includes two dimensions: time (inputs, processes and outcomes) and place (national, local and individual levels).
- Planning needs to consider knowledge from three domains: ethics, evidence and experience.

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2

Mental health of the population and care in the community

What does 'community' mean?

We shall discuss at the outset the key question: what is the meaning of '*community*'? Table 2.1 shows five definitions of 'community', selected from the *Concise Oxford Dictionary*. In relation to the focus of this book, the first two meanings ('all the people living in a specific locality', 'a specific locality, including its inhabitants'), are most important as they reflect our view that mental-health services are best organised for defined local areas, for *all* local residents who need treatment or care. Within any local population there are likely to be specific sub-groups who are at higher risk for mental disorders, or whose needs for services are distinct. Such groups include immigrants, people who are homeless, or those exposed to particular environmental or biological risk factors, such as disaster or bereavement.

The last two of these definitions shown in Table 2.1 also have important implications, namely when 'community' refers to the 'fellowship of interests of the general public' as a whole. This wider community of citizens in fact delegates responsibility for the care of mentally ill people to the mental health services. One aspect of this approach is that mental health staff are expected to provide a public service, not only by treating, but also by removing or containing, those who pose a risk to the public safety.

Defining 'community care' and 'community mental health'

In essence, 'community care' means services close to home. The term 'community care' was first officially used in Britain, for example, in 1957 [2;3;4], and its historical development has been interpreted in four ways to mean: (i) care outside large institutions; (ii) professional services provided outside hospitals; (iii) care by the community or (iv) normalisation in ordinary living [5]. Taking into account these roots of 'community', how can *community mental health*

Table 2.1 Definitions of 'Community'

Community
(1) All the people living in a specific locality
(2) A specific locality, including its inhabitants
(3) Body of people having a religion, a profession, etc., in common (*the immigrant community*)
(4) Fellowship of interests etc.; similarity (*community of intellect*)
(5) The public

Source: Concise Oxford Dictionary [1]

services be defined? Table 2.2 shows a selection of key definitions which have appeared over the last 35 years.

Integral to this most recent definition is our view that a modern mental health service is a balance between community-based and hospital-based care, which replaces the traditional, more custodial system dominated by large mental hospitals and out-patient clinics offering follow-up care, usually limiting treatment to medication [6].

The public health approach to mental health

What does the 'public health approach' mean? The origins of the public health approach lie in the concept of 'social medicine', which Virchow introduced into Germany in 1948 [7], proposing the reform of medicine on the basis of four principles:

(1) The health of the people is a matter of direct social concern.
(2) Social and economic conditions have an important effect on health and disease, and these relations must be the subject of scientific investigation.
(3) The measures taken to promote health and to contain disease must be social as well as medical.
(4) Medical statistics will be our standard of measurement.

Doctors are the natural advocates for the poor and the social questions fall for the most part in their jurisdiction. (Rudolf Virchow, *Medizinische Reform* (1948); Shepherd (1983) [8])

The public health approach is primarily concerned with the health of populations, not individuals. Although populations are clearly made up of individuals, the individual approach and the population approach are, in many ways, quite distinct. Measures of morbidity, explanations of possible causation, and the necessary interventions may be entirely different or require alternative strategies at these two levels.

Table 2.2 Changing definitions of community mental health services

G. F. Rehin and F. M. Martin (1963)
Any scheme directed to providing extra-mural care and treatment … to facilitate the early detection of mental health illness or relapse and its treatment on an informal basis, and to provide some social work service in the community for support or follow-up (quoted in Bennett and Freeman, 1991).

M. Sabshin (1966)
The utilisation of the techniques, methods, and theories of social psychiatry, as well as those of the other behavioural sciences, to investigate and meet the mental health needs of a functionally or geographically defined population over a significant period of time, and the feeding back of information to modify the central body of social mental health and other behavioural science and knowledge.

R. Freudenberg (1967)
Community psychiatry assumes that people with mental health disorders can be most effectively helped when links with family, friends, workmates and society generally are maintained, and aims to provide preventive, treatment, and rehabilitative services for a district which means that therapeutic measures go beyond the individual patient.

G. Serban (1977)
Community psychiatry has three aspects: first, a social movement; second, a service delivery strategy, emphasising the accessibility of services and acceptance of responsibility of mental health needs of a total population; and third, provision of best possible clinical care, with emphasis on the major mental health disorders and on treatment outside total institutions.

D. Bennett (1978)
Community psychiatry is concerned with the mental health needs not only of the individual patient, but of the district population, not only of those who are defined as sick, but those who may be contributing to that sickness and whose health or well-being may, in turn, be put at risk.

M. Tansella (1986)
A system of care devoted to a defined population and based on a comprehensive and integrated mental health service, which includes out-patient facilities, day and residential training centres, residential accommodation in hostels, sheltered workshops and in-patient units in general hospitals, and which ensures, with multi-disciplinary team-work, early diagnosis, prompt treatment, continuity of care, social support and a close liaison with other medical and social community services and, in particular, with general practitioners.

G. Strathdee and G. Thornicroft (1997)
The network of services which offer continuing treatment, accommodation, occupation and social support and which together help people with mental health problems to regain their normal social roles.

G. Thornicroft and M. Tansella (1999)
A community-based mental health service is one which provides a full range of effective mental health care to a defined population, and which is dedicated to treating and helping people with mental disorders, in proportion to their suffering or distress, in collaboration with other local agencies.

Table 2.3 Comparison of the public health and the individual health approaches

Public Health Approach	Individual Health Approach
(1) Whole population view	(1) Partial population view
(2) Patients seen in socio-economic context	(2) Tends to exclude contextual factors
(3) Interested in primary prevention	(3) Focus on treatment rather than prevention
(4) Individual as well as population-based interventions	(4) Individual level interventions only
(5) Service components seen in context of whole system	(5) Service components seen in isolation
(6) Favours open access to services on the basis of need	(6) Access to services on the basis of eligibility, e.g. by age, diagnosis or insurance cover
(7) Teamwork preferred	(7) Individual therapist preferred
(8) Long-term / life-course perspective	(8) Short-term and episodic perspective
(9) Cost-effectiveness seen in population terms	(9) Cost-effectiveness seen in individual terms

Psychiatrists, unlike sociologists, seem generally unaware of the existence and importance of mental health attributes of whole populations, their concern being only with sick individuals. (G. Rose, 1993 [9])

We wish to emphasise the need for mental-health practitioners to be able to understand, in addition to the individual-health approach, the public-health approach, and we compare the two in Table 2.3.

The needs of the mentally ill cannot safely be entrusted to the 'invisible hand' of market forces … mental health services should be based upon egalitarian principles, not simply as a moral imperative, but because a socially just system of provision is by far the most effective for a nation's health. (B. Cooper, 1995 [10])

The public health impact of mental disorders

The public health impact of mental disorders can be judged according to these criteria: (i) frequency; (ii) severity and consequences; (iii) availability of interventions and (iv) acceptability of interventions.

First, in terms of *frequency*, mental illnesses are common. Face-to-face household surveys of more than 60 000 adults in 2001–2003 in 40 countries worldwide, for example, showed that the prevalence of all mental disorders in the previous year varied, with most countries having rates between 9.1% and 16.1% [11;12]. More specifically, in the United States a national survey found that the prevalence rates of mental illness did not change between 1990 and 2003 [13]. By comparison, it is estimated that the total number of people with

schizophrenia in less economically developed countries has increased from 16.7 million in 1985 to 24.4 million in 2000 [14], with continuing high proportions of people who are not treated, even in high-resource countries [12;15;16].

Second, as far as *severity* is concerned, mental illnesses can substantially interfere with life expectancy and with normal personal and social life [17–19]. In terms of mortality, such conditions contribute 8.1% of all *avoidable life years lost*, compared, for example, with 9% from respiratory diseases, 5.8% from all forms of cancer, and 4.4% from heart diseases [14;20]. In relation to *combined mortality and disability*, the World Bank has calculated this in terms of the Global Burden of Disease for different disorders, measured in disability-adjusted life years (DALY). These are defined as the sum of years of life lost because of premature mortality, plus the years of life lived with disability, adjusted for the severity of disability. An estimated 12% of worldwide DALYs are caused by psychiatric and behavioural disorders, exceeding even the global burden of cardiovascular conditions (9.7%) and malignant neoplasms (5.1%) [18;21]. By comparison, the average global expenditure on mental disorders is only 2% of national health budgets [18].

Depression, the most common mental disorder, is the leading cause of such global burden among all the mental illnesses. The proportion of all DALYs which are attributable to depression is expected to increase from 3.7% to 5.7% between 1990 and 2020, moving from 4th to 2nd in the overall ranking [22–25].

Mental disorders may also have important *consequences*, both for individuals with mental illness and for their families. For the individuals concerned, the consequences include the suffering caused by symptoms, lower quality of life, the loss of independence and work capacity, and poorer social integration [26–28]. For family members there is an increased burden from caring, and lowered economic productivity [17].

Third, as far as the *availability* of interventions is concerned, the public health approach implies that help should be made available and accessible, in proportion to need [29]. Interestingly, research suggests that usually this is not the case. In the large survey of mental illness conducted in the USA referred to above [13], the proportion of mentally ill people who received treatment rose from 20.3% to 32.9% between 1990 and 2003 [13]. Further, by 2003 only about half the people who received treatment had conditions that met diagnostic criteria, and so ran the risks of harm from unnecessary treatments with no prospect of benefit. This means that the health system in the USA has the capacity to treat up to two thirds of the people with clear-cut mental illnesses, but in fact only treats about one third. In other words, even in a very high-income country, most people with mental illness received no professional care. There is a paradox here. While mental disorders are very common, most people affected receive no treatment. Yet many people receiving treatment for mental illness are not actually mentally ill!

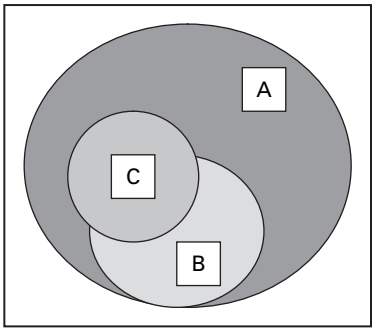

Figure 2.1 Relationship between true prevalence and treated prevalence. Key: A = total adult population, B = true prevalence, C = treated prevalence.

This raises the important issues of coverage and focusing. *Coverage* means the proportion of people that could benefit from treatment who actually receive it [30;31]. *Focusing* refers to how far those people actually receiving treatment in fact need it. In other words do they have any form of mental illness [32]? Even in the best resourced countries we find both low coverage and poor focusing. Within the European Region of the World Health Organisation an action plan calls on governments to provide effective care to people with mental illness [33–35]. Yet a comparative international study of depression found that 0% of depressed patients in St. Petersburg were treated with anti-depressants in primary care, and only 3% were referred on to specialist care. The inability of patients to afford out-of-pocket costs was the reason why 75% of the depressed Russian patients went untreated [36]. From the public health approach, therefore, the key issue is the appropriate use of resources, whatever the level of resources actually available, namely to increase both coverage and focus.

Figure 2.1 shows the relationship between true and treated prevalence. True prevalence means the total number of cases of a particular condition in a defined area. Treated prevalence, by contrast, refers to the fraction of this number of cases that are receiving care. In the National Comorbidity Survey Replication (NCS-R) study of 4319 participants representative of the general population in the USA (A, 100%), the true prevalence of all emotional disorders was 30.5% (B) of those surveyed, while 20.1% of all participants received treatment for any mental disorder (C) [13]. Among group C, half of these individuals did not have an emotional disorder at the time of treatment. Table 2.4 summarises this information numerically.

In a similar study in European countries (Belgium, France, Germany, Italy, Netherlands and Spain) using the same methods as the NCS-R, among 7731 participants, the true prevalence of all emotional disorders was 11.7%, and the