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Edited by Gavin Andrews and Scott Henderson

Excerpt

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**Part I**

## **Unmet need: defining the problem**

## Assessing needs for psychiatric services

Norman Sartorius

Life is becoming more complicated by the day. In times past, when asked how much should be invested in providing services for a particular mental or physical illness, we could provide an estimate of the number of people who had such an illness. Then we could state how many personnel, drugs and beds are necessary for appropriate care and how they should be used. It is still possible to do this today but, in many settings, it will no longer be correct.

There are several reasons for this. First, the needs of the patients, the needs of the community and the needs of the government only partially overlap. For example, governments are particularly interested in avoiding high costs for disease control, while the community places a high premium on diminishing or preventing disturbance to the normal ways of societal functioning. Patients and their families are more insistent that quality of life, before and during treatment, is an important criterion of treatment acceptability. Consultation between these three groups, therefore, emerges as a necessary part of the estimation of needs.

Second, it has gradually become accepted that the notion of calculating needs, outcomes or costs by using averages is misleading. Average (demographic) citizens, average reactions to treatment, and average outcomes are often not applicable in individual cases.

People are different whether well or ill. They belong to different cultures, have different personalities, physical constitutions and personal histories, all of which makes them perceive their diseases in a specific manner. They cope with the consequences of diseases in individual ways, and thus require different types of help. Some of them do not want anyone to help them; others want more help than could sensibly be expected given the impairment or suffering that their disease produces. Some of them do not want help from a health service; if convinced that their disease is a consequence of someone's magical influence they may prefer to seek the help of traditional healers, exorcists or others that deal with black magic.

Third, the needs of the health professions play a particularly important, yet neglected, role in planning health services and assessing and providing care for a sick population. Health workers, for example, will not take jobs in places where their children might not get acceptable schooling. In some countries,

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this keeps the density of health care agents in rural areas low and, in turn, affects the expression of demands for, and availability of, care in a rural population.

Fourth, it has become clear that plans made to cover long periods must be vague, addressing only overall objectives and goals. The notion that a five-year plan should be precise and include operational details, as was promoted in countries of Eastern Europe, lost much of its attraction when it became clear that services in those countries did not develop in accordance with the plans, and that the making and announcing of those plans had served mainly political purposes. These reasons and others – unforeseen political changes, methodological problems in the planning and evaluation process, incompetence of planners because of insufficient training – have led to an increasing recognition that the previous standardized ways of planning are not very useful. In many countries during the late 1970s and early 1980s this type of planning has resulted in the gradual disappearance of planning institutes, planning departments in the ministries of health, and planning courses in public health training programs.

More recently, planning and evaluation services have regained strength under the pressure of economic factors (expressed mainly as the wish of governments to reduce the costs of care) and the population's insistence that they receive more care of better quality.

This new wave of planning is, however, different from previous versions in that it has begun to define the three key elements of planning in a new way:

1. Investment is measured in terms of *total expenditure* – not only the money spent to build services or pay health personnel, but also implicit expenses such as the time that relatives spend looking after sick members of their family.
2. The main indicator of health care productivity is now assessment of *outcome* in terms of improved health, whereas it used to be assessment of improvement in the *process of providing health care*.
3. The definition of needs for health services are changing. Previously the best indicator was thought to be the total number of people in the population with the disease in question. There are now four parts to defining the needs for health care services: (1) the need for health care should consider the expressed demands of the community; (2) the needs of the health professionals' quality of life should be assessed and addressed; (3) the need for health care must consider the availability of effective and ethically acceptable solutions; and (4) the health sector's involvement must depend on how much the solution lies within the health sector's competence and responsibility.

The consideration of these four elements raises several unresolved issues:

1. *Whose need is the most relevant?* The demands expressed by people

affected by a disease are not necessarily the same as those of their families. As previously mentioned, planning for health services has become less popular because of disparities between the expressed needs of those who are sick, their families, and the community. It is imperative to consult all those concerned when needs are defined. In theory, this sounds reasonable; the difficulty lies in applying the process, which requires all concerned to learn new ways of behaving.

2. *Are demands linked to disease, illness or sickness?* The English language has the luxury of having three terms that can be used for the three aspects of a morbid condition: *disease* corresponds to a specific pathological substrate and a specific course and outcome of the condition; *illness* corresponds to the subjective experience of the morbid condition; and *sickness* corresponds to the societal recognition that the disease prevents an individual from contributing to society. Psychiatrists – and other health workers – have to deal with *diseases* and *illnesses* in their clinical practice and with *sicknesses* when they are acting as agents of society. Illnesses, diseases, and sicknesses are not exactly the same. People sometimes feel more ill than their disease warrants in terms of average values; sometimes people have diseases that do not make them feel ill; and sometimes the term sickness is used to describe individuals who do not feel ill and have no demonstrable pathological substrate for their condition. What then is a ‘true’ intervention? – the one that responds to a disease? or to an illness? or to a sickness? or to all three?

3. *What is an effective intervention?* A problem becomes a need when there is an effective and ethically acceptable intervention that can be performed by the health services. It is therefore necessary to define an effective intervention. There is a growing consensus that the value of interventions should be assessed on the basis of the results of scientific investigations. This does not resolve everything. Sometimes, interventions deal with the disease or its consequences in totality; sometimes, they can only deal with part of the problem caused by a disease. Different interventions may be effective for different parts of the disease problem. The question that arises is whether the gains of using the different interventions (each dealing with a different part of the disease problem) are equivalent – but equivalent from whose point of view? The population? The population in general, or the population affected by the disease? Alternatively should experts, for example experts on the social impact of disease, be invited to advise? For a long time, psychiatrists have valued interventions by how well they relieve symptoms. Their patients might have preferred a treatment with fewer side-effects, even if that meant a less complete relief of symptoms. The population might have been particularly keen to see the application of treatments or other interventions that reduce disability, diminish dependence on others, or eliminate public disturbance. The three groups have different agendas.

There is also confusion about who is responsible for the implementation of

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some interventions. When the intervention requires knowledge and skills unique to health service staff, the issue is easy to resolve; unfortunately, for many diseases the situation is not that clear-cut. For example, as science has not yet provided an answer to dementia, should health staff decline to be involved with the problems faced by people with this disorder? Yet families need help in dealing with, say, the symptom of fecal incontinence, which is a consequence of the dementia. Should health care staff become involved in the provision of incontinence pads and the education of carers as to how to persuade the demented person to wear them? At one level this can be seen as preventing decubitus ulcers, a proper concern of medicine, but at another level the supply of incontinence pads and education about their use could well be the responsibility of aged care services generally. Similarly, if a person with a chronic psychosis fails to take medication because they cannot live in settled accommodation, is it the responsibility of the health service to provide and pay for suitable accommodation? The boundaries between health and education, health and child-care services, between health and housing or health and the criminal justice services are often unclear in an individual case, and much negotiation is required to ensure that each service can apply the majority of their budget to their main task. In the case of medicine this is the intervention against disease, but a broad view is likely to prove more beneficial than a narrow one.

The second issue concerning the assignment of responsibility is of a more profound nature. It concerns the justification for any medical intervention intended to help people who have a disease. Recently this issue has become confused. It has been said that disease must be treated because it will save society money. By spending several thousand dollars to cure a disease, the argument goes, the individual, freed from disease, will be able to contribute financially to society for many years, which will amply repay the investments made. Of course, the argument is flawed: it is not certain that the person who had the disease will find or maintain a job and contribute to society. There is no guarantee that the same individual will stay free of disease and that the State will not have to spend more money on his/her health. It is not certain how long a person who has been cured of a disease will live and receive retirement benefits; and so forth.

However, even if the economic argument were not flawed, it should never become the main reason for providing health care. Care for the sick members of a society is an ethical imperative, even if significant amounts of money are spent and not recouped. This consideration is important because it moves the burden of deciding whether a particular person merits care from the health system to the political arena. The task of the health care specialist is to provide the best possible treatment or support for those members of society who are not well: the political structure of the country has to decide on the total amount of money that will be spent on health.

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With these considerations in mind it is possible to propose that needs for health care be defined as, *'the agglomerate of those demands of people having a health problem, their families and their communities to which the health care system can respond by an effective intervention. In this context, effective interventions are those that have a predictable and significant positive effect on the problem and are acceptable to the individuals who have the problem and to those who care for them.'* This definition would allow a pragmatic assessment of needs for care and is cast in the spirit of seeking an alliance between patients, their families, their communities and the health care system. Its acceptance would avoid the pitfall of deciding that illness without an organic substrate is not a legitimate reason for seeking and obtaining help. Similarly, it would avoid equating epidemiological estimates of the prevalence of mental disorders with needs, regardless of the capacity of the health sector to respond to it. It underlines the need to assess interventions scientifically and ensures that only those interventions that are effective are used. It also implies that it is the health sector's responsibility to decide which of the interventions should be applied on ethical and scientific grounds, while the decision not to provide the best treatment remains in the political domain.

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## Unmet need: a challenge for governments

Harvey Whiteford

Governments around the world are struggling to find ways to improve the health status of their populations. Priorities change within and between countries; however, modern public health programs and clinical medicine now offer more than can be bought by historically set health budgets. When this is combined with the considerable unmet need for health services, including mental health and substance-abuse services, the politicians and the government departments responsible for health have an unenviable challenge.

The general population, health professionals and consumer groups all routinely demand new or better health services. In my experience, politicians generally try to do what they believe the electorate wants and respond to these demands. At the same time, they are wary of the disproportionate influence of vested interests, but do acknowledge that these groups are often well organized and skillfully use the media to apply pressure to governments. So usually there are demands for more money, and for a greater slice of the available public or private payers' budget for health care. There has been little public debate on how much a country should spend on health versus, for example, education, law and order or defence. How do we know if the Organization for Economic Co-operation and Development (OECD) average of around eight percent of gross domestic product (GDP) is right? The most successful national example of expanding health expenditure is the USA. This experience clearly shows that doubling the proportion of the GDP a country spends on health services does not, by itself, fix that many problems. It shifts the cut-off point where funding is stopped, but does not change the fundamental problem of how governments allocate scarce resources and respond to unmet need.

Most western countries can point to their form of national health insurance as a safety net. Many of these are reasonably accessible to people with mental illness; even those that are not are slowly moving in that direction. For example, amendments to the US Public Health Service Act and the 1996 Mental Health Parity Act, passed at a time when the USA is trying to rein in its health expenditure, are steps toward requiring parity in insurance coverage for mental illness in that country.

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However, once the ability to purchase basic health services is removed as a barrier, funders such as governments and health insurance companies become more involved in deciding which services are to be paid for. Using price signals such as consumer copayments can limit demand, but the supply and consumption of health services notoriously fail to meet the criteria required for market forces to act as effective controls. People with chronic illness are especially vulnerable. Some countries such as Australia have effectively used supply-side controls, including limiting the number of medical practitioners, to contain costs.

To reduce the pressure for increased funding, governments and other third-party payers try to squeeze more out of the existing funding by increasing the efficiency and effectiveness of services. This is not simply a matter of containing health care costs. It involves changing funding incentives and difficult structural reform of the service delivery system. It involves stopping or reducing inefficient or ineffective services, many cherished by vested interests, and introducing new ways of financing and providing services. The unfortunate lack of routinely collected outcome data has seriously compromised this reform. As a result, cost reduction, as opposed to quality and health gain, has driven the microeconomic reforms. Services can be denied because of their cost, regardless of their effectiveness.

Unfortunately, the heat generated in the health reform debate between consumers, professionals, governments, and funders has shed little light on the matter. The Oregon experience (Haas & Hall, 1992) and debates within the UK National Health Service (Calman, 1994) are notable exceptions. One of the problems has been the different perspectives and languages used by clinicians, funders, and consumers. Health professionals have been trained to deal with individuals who present for treatment. Their aim is to provide the best care for those patients who manage to see them, and they base their professional standing on achieving and maintaining high-level clinical skills. This is, of course, appropriate and the tradition is centuries old. Clinicians tend not to think about those patients who cannot see them or do not present.

A clinician's decision to undertake one particular type or occasion of service is also a decision not to undertake another. The cost of giving up this next best alternative, the opportunity cost, does concern governments and third-party payers. Rational decision-making about which services should be provided is needed, especially in regard to people whose need will be unmet (McGuire, Henderson & Mooney, 1988). To make these decisions, governments, professionals, health service managers and society as a whole need to be better informed about who is and who is not receiving services. The US Epidemiologic Catchment Area and National Comorbidity Surveys, and epidemiological surveys in the UK, Canada, Australia and other countries are providing crucial data on these matters.

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While all countries ration public goods and services, it is politically unpalatable that large numbers of people with serious health problems are not receiving care. As well as needing to respond to this unmet need for humane reasons, government economists know that one of the determinants of the economic health of a country is the health status of its population. The rising burden of neuropsychiatric disease is now well documented (Murray & Lopez, 1996). The debate is not purely academic.

So the challenge for governments is to influence the allocation of scarce resources on a rational basis to optimize the health status of the population for both humane and economic reasons. It has been suggested, I believe with merit, that the burden of illness on the individual and society (measured for example by quality- or disability-adjusted life years) combined with treatment efficacy could be used to inform these decisions (Andrews, 1997). This would mean that disorders with high prevalence, mortality or disability that respond to effective treatments would receive funding, with those interventions demonstrating the greatest health gain for the lowest cost being highly prized.

Who receives care in the health system of the future will continue to depend on the way the system is organized and financed, as well as on the specific training of the clinicians in the system. Inevitably pressure groups promoting areas of special interest and media 'shroud waving' will distort resource allocation. Nevertheless, the debate must be conducted openly and publicly. Epidemiological data on both met and unmet need is crucial to the debate so that we can scrutinize the true opportunity costs of what we are currently providing in health care.

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## Meeting the unmet need with disease management

Gavin Andrews

Half to three-quarters of the people identified in epidemiological surveys as meeting criteria for a mental disorder do not report receiving treatment. All mental health professionals are busy and there is usually no prospect of an increase in the available labor force. So what should be done? One view is that scarce health resources should be offered to those who are sickest. The techniques for ranking diseases by the burden of mortality and morbidity they generate are well advanced. However, if we focus on the sickest, we risk running out of resources before we maximize any health gains. Wouldn't it be better to identify the diagnosis/treatment pairings that offer the greatest prospect of reducing mortality and morbidity, that is, the greatest health gain, and deploy our resources accordingly? This would certainly impact on health, but what if maximizing health gains means that some severely ill people must go untreated? We must develop a mechanism to prioritize the delivery of health care to maximize the attainable health gains, while still attending to the chronically sick. Yet it is this balance between care and cure, between equity and efficiency, that is so difficult to achieve. Thankfully, there is a further alternative to this scenario of chronic shortage. We could supplement the expensive medical model with a public health disease management approach to emphasize primary prevention, community education, and patient self-help by using books and the newer interactive technologies via the automated telephone and Internet. Sadly for doctors, but fortunately for sufferers, the doctor-patient relationship is not essential if one has effective and proven treatments. And psychiatry has many effective treatments that could be delivered without the need for a physician to be involved. We do need to use all possible resources.

### The problem

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*Met need* is defined as the proportion of people with a disorder who see a health professional. It will be a considerable overestimate, for many seeing a health professional will not be correctly diagnosed, or get appropriate treatment, and will not have their need for a reduction in the burden of their