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PART I

INTRODUCTION

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Deinstitutionalisation: promises, problems and prospects

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Introduction

Over the past several decades many nations have embarked upon dedicated efforts to reduce, if not to eliminate, the role of psychiatric hospitals in the treatment of mentally ill persons. This movement, popularly known as ‘deinstitutionalisation’, has greatly altered the lives of psychiatric patients throughout the Western world. This chapter will examine the history and current status of the deinstitutionalisation movement and identify some specific problems that may be traced directly to the implementation (often incomplete or faulty) of deinstitutionalisation policy. A ‘new chronic’ patient population will be described, and the positive legacy of deinstitutionalisation will be noted. The chapter will conclude with a plea for a new, more realistic understanding of what successful deinstitutionalisation must entail. This discussion is based largely on service delivery trends in the United States. However, both the popular and professional literature (Thornicroft & Bebbington, 1989; Schmidt, 1992; Thornicroft *et al.*, 1993), as well as extensive personal observation, suggest that other countries are encountering similar circumstances. Precisely why this is so is an intriguing question that merits serious consideration, in view of vast differences in nations’ health care philosophies and service delivery practices. One may speculate that there are common issues in serving psychiatric patients in the community that transcend national boundaries, and that these must be frankly examined for their broader implications.

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Deinstitutionalisation: definition and background

Deinstitutionalisation, which refers to a complex series of interrelated events and policy decisions, may be defined as *the replacement of long-stay psychiatric hospitals with smaller, less isolated community-based service alternatives for the care of mentally ill individuals*. In theory it consists of three component processes: the release of patients residing in psychiatric hospitals to alternative facilities in the community; the diversion of potential new admissions to the alternative facilities; and the development of special community-based programmes, combining psychiatric and support services, for the care of a non-institutionalised patient population (Bachrach, 1976). The last of these processes is held to be particularly important, for it is assumed that patients' altered life circumstances will inevitably result in new configurations of service need.

In the United States the depopulation of psychiatric hospitals began in the mid-1950s with the introduction and rapid spread of psychoactive medications. However, official policy supporting deinstitutionalisation was not articulated until 1963, when President John Kennedy, prompted by numerous disclosures of inhumane conditions inside psychiatric hospitals, called for a 'bold new approach' in mental health service delivery. In response, the federal government undertook to replace the country's psychiatric hospitals, which were largely administered by state governments, with some 1500 community mental health centres. About half of these were eventually funded and built before the federal initiative ended in the early 1980s. Community mental health facilities exist today in both the private and non-federal public sectors, and they constitute the most highly utilised psychiatric service sites (Manderscheid & Sonnenschein, 1992). The effects of pursuing deinstitutionalisation policy are dramatically portrayed in service utilisation statistics. In 1955, the resident patient count in American state psychiatric hospitals stood at a record high of 560 000. That number has declined in each successive year and stands today at 101 000, a reduction of 82%. Even more striking is the drop of 88% in the resident patient rate, from 339 per 100 000 population in 1955 to 41 per 100 000 today (Manderscheid & Sonnenschein, 1992). The rationale for pursuing deinstitutionalisation, combining elements of idealism and pragmatism, reflected justifiable concern for the well-being of psychiatric patients, many of whom

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were living miserable lives inside the state hospitals (Bachrach, 1993a). It encompassed several critically important assumptions. First, it was widely, even passionately, assumed that community-based care would be instrinsically more humane than hospital-based care. Second, it was similarly assumed that community-based care would be intrinsically more therapeutic than hospital-based care. And, third, it was further assumed that community-based care would be more cost-effective than hospital-based care (Bachrach, 1976, 1978; Thornicroft & Bebbington, 1989).

These assumptions had, however, not been tested empirically, and there has been cause over the years to question their validity. We have, for example, begun to realise that community care may indeed hold the potential for being more humane and more therapeutic than hospital care; however, this promise cannot be realised unless comprehensive services for the most severely disabled patients have been mandated, and adequate resources have been provided to ensure their implementation. We have also begun to understand that if one considers all the hidden costs associated with responsible programming, it is generally not accurate to conclude that community services will result in substantial savings over hospital care (Aldrich, 1985; Kovaleski, 1993; Okin, 1978, 1993).

We have learned as well that we are not ready to close all our psychiatric hospitals, although their imminent demise was often predicted in the optimism of the 1960s. Many planners who continue to harbour the hope that we will some day eliminate these facilities increasingly acknowledge the difficulty of establishing alternative sites where patients can be admitted for intensive hospital-based observation or comprehensive care.

Issues in deinstitutionalisation

Since deinstitutionalisation began in the United States, the first two of the three component processes mentioned above – releasing patients from and reducing admissions to psychiatric hospitals – have proceeded apace. However, the critical third process, that of developing a full array of services in the community to meet the unique needs of a non-institutionalised patient population, has often lagged. This has resulted in a variety of serious service delivery problems in many communities.

One such problem is related to the fragmentation of the patient population, for a once relatively stable hospital cohort has been splintered as long-stay patients have been released to the community. Although some individuals have been successfully placed in community-based facilities, others have been shunted to 'mini-institutions' where the quality of their lives has actually deteriorated. Other patients have become homeless (Bachrach, 1992b), or been incarcerated in jails and other correctional facilities (Anon; 1993). And still other patients have demonstrated a persistent dependency on institutional care and developed 'revolving door' patterns of repeated admission and discharge (Cohen, 1993; Geller, 1993). However, not all long-stay patients have been released; for some, considered to be poor risks for discharge, remain inside psychiatric hospitals. Many more recently admitted individuals have become 'short-stay' hospital residents, staying for only days or weeks before their release; but others have become 'new long-stay' patients. Still other mentally ill individuals, many of them severely symptomatic or disabled, have avoided admission altogether and spent no time at all in hospital. Indeed, some American communities report that the number of never-hospitalised mentally ill people now exceeds the number who have ever been hospitalised (Bachrach, 1978).

This diversity in patients' histories represents a major change in service utilisation patterns. Before deinstitutionalisation most mentally ill people entered psychiatric hospitals and generally stayed for extended periods, often for the rest of their lives. There was relatively little variation in their treatment histories, and individual differences among them were easily overlooked. Today in the community, however, those differences have become difficult to ignore. It is increasingly apparent that patients vary not only in their diagnoses and functional levels, but also in their symptomatologies, available support systems, and treatment needs. And although the acknowledgement of such diversity may be considered a major positive outcome of the deinstitutionalisation movement (Bachrach, 1993b), it also holds certain disadvantages from a service planning perspective. Our imagination and our creativity, to say nothing of our financial resources, have not always been equal to the challenge of responding to the varied treatment needs of mentally ill people living in the community.

A second problem revolves around difficulties inherent in achieving continuity of care for long-term patients outside the hospital setting – an

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issue that was easily overlooked in the early years of deinstitutionalisation when many proponents believed that, absent the negative effects of institutional residence, chronicity would disappear. Programme planning today frequently focuses on patients' immediate requirements and ignores the future, even though their service needs tend to endure no matter where they live. Indeed, all aspects of continuity of care, including patients' access to needed programmes over time and their ability to establish therapeutic relationships with caregivers, have been jeopardised (Bachrach, 1993c).

Third, attempts to provide comprehensive care have similarly met with difficulty. Long-term mental patients, precisely because of their illnesses and related disabilities, generally require a wide variety of psychiatric, medical, social, rehabilitative, residential, vocational, and quasi-vocational services (Belkin, 1992). Some also need sanctuary or asylum: an escape from the pressures and threats of the world (Bachrach, 1984; Wasow, 1993). Some may require such asylum temporarily, until a crisis can be resolved, although others may need it indefinitely.

In the past, providing comprehensive care to psychiatric patients, including responding to their need for asylum, was relatively easily accomplished, since virtually all services could be arranged within the single physical setting of the psychiatric hospital. And although we may not always have liked what happened inside some hospitals in those years, particularly in the large and isolated 'warehouse' facilities, centralisation carried certain practical advantages.

Today, by contrast, the authority for providing services is typically divided among many separate health and human service agencies in the public and private sectors, and successful programming depends upon the fine tuning of initiatives that orginate with separate, and sometimes competing, authorities. To use a cliche, our service systems are often hopelessly fragmented.

A fourth major problem attending deinstitutionalisation in many communities is related to patient selection and gatekeeping. In the early years of the movement there was a clear intention that the new community mental health programmes would serve the most severely mentally ill individuals – i.e. those who would otherwise be hospitalised. However, with increased 'boundary busting' in the selection of patients for care (Dinitz & Beran, 1971), many agencies came to favour individuals who were less symptomatic and disabled; and they overlooked, either unintentionally or sometimes quite by design, those who were originally intended to be the major beneficiaries of deinstitutionalisation (Bachrach & Lamb, 1989). Thus, many needy persons have been left to fend for themselves, although they may lack the skills and confidence, and almost certainly the resources, that would enable them to seek out services on their own.

Fifth, we have generally not developed the kinds of information and communication links that are essential in fragmented systems of care where services are housed in administratively and geographically separated agencies. In fact, we require ready access to at least three varieties of information if our deinstitutionalisation efforts are to prove successful. We must, first, have simple, descriptive, and timely data about the people whom we serve. We must, for treatment planning purposes, know who they are, where they have been sent, and what happened to them after they arrived at their destinations – if, in fact, they ever arrived.

We also need reliable programme evaluations so that we can establish whether the services we promote are living up to their promise. And, in this connection, we must have meaningful and valid measures by which to assess programme outcome, including indices of incremental progress for those patients who appear to proceed slowly or who, as part of their illnesses, experience episodic reversals (Bachrach, 1987b; NASMHPD, 1993).

In contradistinction to programme evaluation, we must also have system-level assessments that tell us whether services are actually reaching those whom the system is meant to serve; or whether, alternatively, there are numbers of potential service recipients who are routinely overlooked (Neigher & Schulberg, 1982). However, all three data bases tend to be poorly developed (Graham & Birchmore-Timney, 1989; Thornicroft & Bebbington, 1989; Johnson & Thornicroft, 1993; New York State, 1993). Information about patients, for example, is frequently ill-suited to clinical use, for it tends to be incomplete, difficult to access, and slow to retrieve. Programme data are also less than ideal, for our evaluations often focus on questions that lack relevance to the clinical process. For example, we generally fail to inquire about the small but critical kinds of progress that many patients make, or about the quality of their care or the quality of their lives in the community. We tend instead to employ gross measures of hospital utilisation and are often discouraged from focusing on the more subtle variables by funding agencies that prefer uncomplicated and politically popular questions.

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In fact, this tendency has spawned a preoccupation with statistical analysis and experimental design in programme evaluation that is irrelevant or at least premature much of the time. It sometimes appears that an investigator's ability to demonstrate technical competence in these areas, and not his or her appreciation of clinical reality, has become the major criterion for research support, at least in the United States (Brand, 1983).

As for comprehensive system-level information, that too is often compromised, for we frequently settle for circumscribed programme evaluations instead of attempting to assess the effects of our gatekeeping. There are, unfortunately, mentally ill individuals who, at best, remain on the fringes of our care systems and whose experience cannot be captured in programme evaluations because, very simply, they are not enrolled in any programmes. Many are homeless and sleeping rough, and I regret to report that I have seen them in every country that I have visited in recent years. Not to include them in our system assessments is both diversionary and deceptive.

The new chronic patient population

It is within this paradoxical service delivery climate, with its idealism and its problems, that a population of new chronic psychiatric patients has become increasingly evident in deinstitutionalised service systems (Bachrach, 1982; Pepper *et al.*, 1981). I use the term 'new chronic patient' with misgiving, for many individuals so labelled find the title to be objectionable. Nevertheless, the term is descriptive and can serve a useful function by providing a new perspective from which to view contemporary service delivery problems. It can thus be regarded as a metaphor for long-term patienthood in an era of deinstitutinalisation; and just as other metaphors do, it serves the purpose of refining our understanding of reality.

Diagnostically, new chronic patients have the same range of psychiatric illnesses as other severely mentally ill individiuals. Most have been diagnosed with schizophrenia, and many others with bipolar disorders. In some communities, substantial numbers have been diagnosed with personality disorders, often in addition to other major diagnoses. Thus, what distinguishes them from long-term psychiatric patients of the past is not their illnesses *per se*, but rather their aggregate demand for services and their unique impact on the service system.

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Those new chronic patients who are enrolled in psychiatric services tend to be pervasive users of the system. They regularly appear in psychiatric hospitals, general hospitals, community mental health centres, and all kinds of outpatient psychiatric facilities. However, at any given time, substantial numbers of these patients are enrolled in no psychiatric services whatever and are essentially unserved by the system of care.

Those who utilise the service system tend to do so in a 'revolving door' manner and frequently move among facilities. They often appear in the criminal justice system in addition to, or else in place of, the mental health service system. In many communities, new chronic patients become general hospital emergency room regulars, but their referral out tends to be problematic for they generally lack an established niche within the system of care.

Other characteristics of these patients as they are described in the American literature are their high risk for suicide, their fragile ego development, and their vulnerability to stress and personal rejection (Ely, 1985). In addition, practically every reference to them comments as well on the high prevalence of alcohol or other substance use within the population.

Thus, new chronic patients tend to present for treatment in ways that puzzle and discourage service providers; and clinicians and administrators are often confused and frustrated in their attempts to engage and serve them. Harris & Bergman (1979) have written, 'After several rounds of bouncing between hospital and community, no one expects these patients to change. They are treated perfunctorily by a staff that is too discouraged to do more than go through the motions.' Similarly, an article by Robbins and his associates (1978) describes these patients as surly individuals whom staff perceive as 'negativistic, difficult, and frightening'.

Although these fairly typical descriptions come from inner city service settings, new chronic patients are found in suburban and rural places as well (Bachrach, 1982; Claiborne, 1993). A particularly revealing account documents new chronic patients who migrate into rural Montana, a relatively remote and isolated part of the United States (Bachrach, 1988). There they are admitted to the state psychiatric hospital for brief stays, during which they receive food and temporary shelter before they leave to wander again. In fact, patterns of gross geographical mobility characterise the lives of many new chronic patients. Their apparent restlessness often makes them