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THE CHALLENGES OF DEINSTITUTIONALIZATION: LESSONS FROM THE U.S. EXPERIENCE

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INTRODUCTION

Romania is currently making efforts to deinstitutionalize residents of its mental health hospitals and initiate a system of community-based mental health care. Many lessons can be learned from the challenges faced by the United States in its respective deinstitutionalization efforts. Recognition of the various pitfalls may help Romania preventing the adverse consequences associated with such efforts in the United States.

This article begins with an examination of the various challenges associated with the efforts in the United States to deinstitutionalize individuals who have been hospitalized for mental illness. The discussion first focuses on the various cycles of reform in the field of mental health care. It then proceeds to define deinstitutionalization and to identify the forces that have underlain such efforts in the U.S. The article then explores the requirements for deinstitutionalization and the consequences of deinstitutionalization efforts in the absence of an adequate attention to these prerequisites. The article concludes with an examination of the critical policy, ethical, and legal issues and associated challenges facing Romania in its efforts to depopulate its mental health institutions and the strengths that can be leveraged in its efforts to do so.

CYCLES OF MENTAL HEALTH CARE REFORM IN THE U.S.

Scholars have classified mental healthcare reform in the United States into three eras (Durham, 1989; Morrissey & Goldman, 1984). The era of moral treatment and asylum-based care prevailed through the greater part of the nineteenth century. This was followed, in the early twentieth century, by the mental hygiene movement and the psychopathic hospital. The movement towards mental health care in community mental health centres came into being in the mid-twentieth century and continues to the present day. Each of these eras is described in greater detail below in order to provide the context of the development of the U.S. movement towards deinstitutionalization.

Moral Treatment and the Asylum

The concept of moral treatment was based on the belief that humans could be perfected through the manipulation of their social and physical environment. This perspective ultimately led to the medical-psychological model of mental illness, replacing the theological model (Morrissey & Goldman, 1986). At its core was the belief that individuals could be cured by segregating them in an asylum and providing them with humane care and the repudiation of physical violence.

The effective implementation of this generally caring perspective required a low staff-to-patient ratio, in order to provide each patient with the attention and support that he or she required. However, the situation in asylums has deteriorated drastically during the period of industrialization (1840s – 1850s). The increasing numbers of seriously mentally ill persons admitted to the asylums led to lower cure rates and increased patient populations. The situation was further exacerbated by the attitudes displayed by state legislatures that, too often, defined asylums' purpose as one of only custodial care, with an emphasis placed on the protection of the community; treatment of those with mental illness was of secondary importance. As a result, asylums were transformed from therapeutic into custodial institutions (Morrissey & Goldman, 1986).

Mental Hygiene and the Psychopathic Hospital

The psychopathic hospitals and the mental hygiene movement grew out of the deteriorating conditions in asylums and various exposés of these dehumanizing conditions (Morrissey & Goldman, 1986). Psychopathic hospitals were created by mental hygienists outside of psychiatry in order to provide acute treatment in facilities that were affiliated with universities and research institutes. However, this goal of improving mental health services was overshadowed by reformers' efforts to apply psychiatry to eugenics, the management of children, the treatment of criminals, the prevention of prostitution, and industrial nonproductivity (Morrissey & Goldman, 1986).

Accordingly, insanity was redefined to include dementia and senility. This redefinition of insanity allowed local officials to transfer individuals from local almshouses to state mental hospitals. This transinstitutionalization was premised on financial considerations, rather than medical or humanitarian concerns (Grob, 1983), by transferring the individuals from the care of local alms-houses to state mental hospitals, the cost of their care being transferred from local governments to the state.

Community Mental Health and the Community Mental Health Centre

The transition to community mental health centres began with WWII and with the notable success of brief forms of treatment for "war neurosis". The development of new drugs that were found to miraculously aid patients who had until then been seemingly untreatable lent further impetus to the movement towards community mental health centres (CMHCs) (Talbot, 2004). Increased federal activity in provision of funding provided status with additional motivation to deinstitutionalize their mentally ill patients (Bachrach, 1983; Grob, 1987; Scherl & Macht, 1979; Talbot, 2004).

DEINSTITUTIONALIZATION: DEFINITION AND IMPLEMENTATION

Deinstitutionalization has been defined as "the replacement of long-stay psychiatric hospitals with smaller, less isolated community-based alternatives for the care of mentally ill people" (Lamb & Bachrach, 2001, p. 1039). It encompasses (1) the prevention of inappropriate mental hospital admission through the provision of community alternatives for treatment; (2) release to the community of all institutional patients who have been given adequate preparation for such a change; and (3) the establishment and maintenance of community support systems for noninstitutionalized persons receiving mental health services in the community (Bachrach, 1976).

Successful deinstitutionalization efforts necessitate the development of a community support system, that is, "a network of caring and responsible people committed to assisting a vulnerable population meet their needs and develop their potential without being unnecessarily isolated or excluded from the community" (Turner & Schiffren, 1979). Services within this network must include:

basic support; an adequate number and range of supervised community housing options; adequate, comprehensive, accessible psychiatric and rehabilitative services, through outreach if necessary; continuity of care; the availability of services on an ongoing basis; sufficient flexibility of services so that they are responsive to fluctuations in illness; available, adequate, and accessible crisis services; a system of responsibility and management of individuals' care in the community, e.g. case management; enrichment activities; rights protection; respite care for families caring for mentally ill members; and adequate funding for needed services (Anthony, 1993; Freedman & Moran, 1984; Lamb, 1993; Talbott, 2004).

The unofficial onset of deinstitutionalization in the United States began in 1955. From the 1930s to 1955, inpatient totals rose from 332,000 to 559,000 (United States Bureau of the Census, 1975). By the end of 1986, however, the inpatient count had declined to 109,939, representing an 81% reduction. Additionally, the average length of stay had decreased from 421 days, in 1969, to 143 days in 1982 (Kiesler & Sibulkin, 1987), while the median length of stay had decreased from 41 days in 1970 to 23 days in 1980 (Manderscheid, Witkin, Rosenstein, Millazzo-Sayre, Bethel et al., 1985). In 1973, there were 334 mental hospitals (asylums) in the United States. This number had dwindled to 286 in 1986 (Mechanic & Rochefort, 1990; National Institute of Mental Health, 1989). The average number of inpatient beds decreased from 1311 in 1970 to 467 in 1984.

This movement towards deinstitutionalization consisted of two phases. The first, called the *benign phase*, occurred from 1956 to 1965 and focused on the placement of newly admitted patients in alternative settings. The *radical phase*, begun in 1966 and extended to 1975, being characterized by patient diversions and massive discharges, which were often effectuated as a means of addressing economic difficulties (Morrissey, 1982; Morrissey & Goldman, 1986).

Deinstitutionalization efforts were motivated, in part, by economic concerns (Durham, 1989). Government agencies believed that it would be less costly to treat individuals in the community than in hospitals (Lamb, 1993). The National Institute of Mental Health (NIMH) developed research and action agenda premised on prevention, which provided funding support for these efforts. The federal government promulgated legislation and allocated funding for community care programs and the training of mental health professionals. The establishment of Medicare and Medicaid programs stimulated an increase in nursing homes, which provided an alternative to mental health hospitals (Mechanic & Rochefort, 1990). Just as a redefinition of insanity in an earlier era had allowed local communities to shift the financial costs associated with care to the state governments, the development of the Medicare program effectively allowed states to shift the cost of care to the federal government (Talbott, 2004).

Ideological motivations also provided impetus to deinstitutionalization efforts. Mental health professionals, increasingly horrified with the performance of lobotomies and the misuse of electroshock therapy (ECT) (Isaac & Armat, 1990), came to believe that community care would be more beneficial and humane (Durham, 1989). The development of phenothiazines, during the 1950s, allowed for the relaxation of restraints that had been utilized with patients (Kiesler & Sibulkin, 1987; Mechanic & Rochefort, 1990). Legal advocates argued as well for reliance on the least restrictive alternative and the recognition of patients' autonomy and rights (Brooks, 1974; Ennis, 1972; Scherl & Macht, 1979; Talbott, 2004).

Less restrictive alternatives included nursing homes which, immediately following deinstitutionalization, became the largest single provider of long-term custodial care for mentally ill persons (Freedman & Moran, 1984). Unfortunately, this care was characterized by high costs and a lack of expertise in geriatric psychiatry. Other alternatives to institutionalization include group homes and jails and prisons (Manderscheid, Gravesande & Goldstrom, 2004). The transinstitutionalization of mentally ill persons to these settings reflects the changing demographics of the mentally ill population of the U.S., the restrictive nature of civil commitment laws, and the relative absence within hospitals of more secure facilities for those engaged in criminal activities. However, jails and prisons frequently lack the necessary personnel with training in mental illness (Freedman & Moran, 1984).

CONSEQUENCES OF DEINSTITUTIONALIZATION

Deinstitutionalization efforts in the United States have resulted in numerous unwanted consequences. These include the shift of an increased proportion of individuals to nursing homes; the incomplete and inadequate performance of community mental health services; the increased role of general hospitals in meeting patients' needs; and the development of a two-tiered system of mental health care. There has also been an increase in homelessness; it is estimated that approximately one third of all homeless individuals are suffering from mental illness (Institute of Medicine, 1988). A significant number of individuals in local jails are mentally ill, raising the question of whether mental illness has been criminalized or criminal behaviour has become psychiatricized.

In addition, mental health care for people diagnosed with chronic mental illness has evolved to become an episodic hospital care (Lamb, 1993) which, due to the structure of Medicaid, is characterized by with relatively short lengths of stay and inadequate community follow-up (Mechanic, 1989). Subsistence levels through publicly funded programs (Medicaid, SSI) have not been maintained relative to the numbers of seriously mentally ill individuals (Curtis, 1986). These circumstances have given rise to two named "syndromes": "falling between the cracks", signifying a lack of follow-up and aftercare for discharged patients and "revolving door", referring to the increased number of admissions and readmissions with shorter lengths of stay (Bachrach, 1976; Talbott, 1974).

The reasons underlying these dismal consequences of deinstitutionalization efforts in U.S. are many and varied. There was a notable lack of consensus regarding the advisability of deinstitutionalization (Scherl & Macht, 1979). Society was ambivalent towards mentally ill persons, accepting the idea that society has an obligation to provide assistance for disabled persons but simultaneously assigning blame to individuals who are poor and unable to care for themselves, a perspective believed to have derived from a "pervasive ideology of individualism" (Aviram, 1990). While sympathetic towards mentally ill persons, societal concerns also focused on the potential cost and safety concerns associated with deinstitutionalization. There was relatively little planning prior to and during deinstitutionalization, so that the development of community facilities lagged behind the increased numbers of discharges and the decreased numbers of admissions (Talbott, 2004). No provision was made for either supplying patients with the full array of services that were available to them in the hospitals, such as nutrition, income maintenance, and vocational rehabilitation or for assistance with the coordination of their care. Care delivery was characterized by fragmentation and inadequate organizational coordination. Mental illness continued – and continues now – to be stigmatized, increasing the difficulties faced by mentally ill persons in locating affordable housing (Talbott, 2004).

These circumstances continue to exist, despite the time that has elapsed since the initiation of deinstitutionalization. There have been significant changes in the service needs of mentally ill persons. Drugs and alcohol, which may adversely impact the course of an individual's mental illness, are easily available. An unexpectedly large proportion of new mentally ill persons present diagnoses of schizophrenia, schizoaffective disorder, bipolar disorder, and major depression (Lamb, 1993). Mentally ill individuals who have been incarcerated in jails and prisons often face difficulties in obtaining necessary care and treatment (Lamb & Bachrach, 2001). The side effects of medications may decrease individuals' willingness and/or ability to adhere to prescribed regimens; this may be even more true for individuals who are reliant on publicly funded health care programs that may not pay for the newer, more expensive medications that produce fewer unwelcome side effects. Not only is there a high rate of homelessness among mentally ill persons, but the severity of mental illness among homeless persons is greater than among mentally ill persons in general (Lamb & Bachrach, 2001).

Moreover, the movement away from institutionalization towards community care was premised on numerous misplaced assumptions about the resources available to previously hospitalized patients. For example, it was assumed that patients have a home; that they have a sympathetic family or other person who is able and willing to assume responsibility for the patient's care; that

the organization of the patient's household would not impede his or her recovery process; and that the patient's presence would not place undue burden on the family (Aviram, 1990; Grob, 1994).

What actually occurred, however, differed significantly from this idealized vision. There was, frequently, a lack of notice to the family of the patient's discharge; a lengthy waiting period for community services; a lack of respite services for care giving family members; unrealistic expectations placed on family members by professionals; inadequate levels of service coordination, supervised and adequate housing, transportation, vocational training and work activity; and bureaucratic delays with the concomitant expectation that even severely mentally ill persons could negotiate complex bureaucracies to obtain their needed services. Families frequently rejected their mentally ill relatives, while at the same time, a lack of adequate community education regarding the nature of mental illness diminished patients' acceptance by their communities.

Additionally, there has been a focus on short-term crisis intervention rather than the provision of care for chronic serious mental illness (Freedman & Moran, 1984). The movement towards community mental health care also failed to recognize that the recovery from mental illness is not linear, but may ebb and flow and that recovery can occur even though symptoms may recur (Anthony, 1993). Recovery encompasses not only recovery from the illness, but recovery from the consequences of the illness. Further, recovery from a serious mental illness does not mean that one is free from mental illness. Instead, recovery progresses through various stages: impairment, which is a loss or abnormality of psychological physiological, or anatomical structure or functioning, e.g. hallucinations, delusions; dysfunction, such as a lack of social skills; disability, meaning a restriction or lack of ability to perform a role in the manner or range considered normal, such as employment; and disadvantage, representing a lack of opportunity that limits or prevents the individual from fulfilling a role considered normal for that individual, for example, discrimination (Anthony, 1993; Anthony, Cohen & Farkas, 1990).

ROMANIA'S DEINSTITUTIONALIZATION EFFORTS

Romania must address numerous critical policy issues as it attempts to deinstitutionalize mentally ill persons and return them to their families and communities. These include the following:

- Identification of the goals and expectations of deinstitutionalization;
- Understanding the impact of funding policies and funding mechanisms on the quality of care;
- Whether to provide services as an extension of hospitals/government or to purchase them through community-based entities. Buying these services requires that such services actually exist and monitoring the quality of such services may be extremely difficult. However, the purchase of the services allows the government bureaucracy to be bypassed, provides a greater administrative flexibility, and encourages diversity of services;
- The role of the family in the care of mentally ill persons;
- The importance of case management, including medications;
- The role of the criminal justice system and whether specialized courts will be established to hear cases involving mentally ill persons;
- The role of psychiatry and other mental health professions in the provision of community-based care, e.g. psychologists, social workers, paraprofessionals, psychiatric nurses, public health professionals;
- The extent to which and under what conditions hospital care will still be available;
- The cultural relevance of services that will be provided, e.g. response of formerly institutionalized patients in stereotypical ways;
- The extent to which mentally ill persons and their families will participate in planning services;
- The range of services that will be available and for whom;
- Delineation of which services are essential to basic community living, necessary to improve patient functioning, and helpful to enhancing patients' quality of life (Freedman & Moran, 1984).

Critical ethical issues must also be addressed, including whether patients will have the right to refuse medication, how public concerns will be balanced with individual rights, and when and under what circumstances the effort to maintain an individual in the community is outweighed by the costs and negative impacts on community and families. Legal issues requiring attention include how to best address housing discrimination against mentally ill persons and their families, employment discrimination against mentally ill persons, the extent to which involuntary commitment can be used, whether mentally ill persons have a legal right to treatment, how to protect mentally ill persons from violence and abuse by family and community members, and the extent to which supportive services, such as employment training, will be made available (Freedman & Moran, 1984). It may also be important to assess whether legal provisions lead to a disparate impact on subgroups. As an example, in the United States, women were more likely to have been institutionalized, and more likely to become caregivers of those who are deinstitutionalized (Bachrach, 1984).

Romania faces numerous challenges in conjunction with efforts to address such critical issues. In April 2000, Romania disbanded its system of nationalized health care established under the Ceausescu regime (Cockerham, 1999) in favour of an employment-based insurance approach. As a consequence, unemployed/underemployed persons may be without adequate access to medical care. Nursing homes, orphanages, and psychiatric hospitals have faced shortages in medications, food, and cleaning supplies and institutional staff have walked out several times during the past few years in response to the government's failure to pay wages.

Care for mentally ill persons is further complicated by the role of the Orthodox Church. Clergy within the Orthodox Church regularly provide mental health counsel to adherents (Hrisostom de Etna, 2003). For example, approximately 6 % of mentally ill persons in Iasi seek care from priests prior to consulting mental health professionals (Gater et al., 2005). However, almost no clergy have received any training that would enable them to diagnose mental illness or substance use (see, e.g., Bran, 2006).

The World Health Organization (WHO) found that as of 2004, Romania's National Mental Health Programme of 1999 continued to be inadequately funded. Romania spends 4 % of its GDP on health, and only 3 % of that 4 % specifically on mental health treatment (World Health Organization, 2004). The poor economy and the resulting lack of financial support for the health care infrastructure raise serious ethical issues for Romania and have led to a drastic shortage of trained mental health professionals and mental health researchers.

Romania has attempted to identify existing gaps in its system of mental health care. Its 2004 Mental Health Policy requires that the Ministry of Health develop training programs in mental health for medical students, psychiatrists, psychologists, nurses, social workers, and other mental health professionals; develop mechanisms for attracting other specialists into the mental health field, including psychologists, sociologists, and lawyers; introduce mental health issues into the syllabus of medical schools; and establish a Mental Health Research Institute in collaboration with the National Academy of Medical Sciences (Ministry of Health, 2004). The Mental Health Policy also calls for the use of quantitative and qualitative methodologies, epidemiologic analyses, and organizational assessments in order to assess community attitudes; the identification of service needs of mentally ill persons and their families as well as the mental health training needs of professionals across a wide range of disciplines; and the evaluation of existing mental health treatment approaches, services, and the institutions responsible for their delivery.

Significant research is needed as Romania moves forward to deinstitutionalize its mentally ill citizens. Focus of research should include the effectiveness of alternative treatment venues such as day hospitals and programs versus inpatient hospitalization; an examination of levels of symptomatology, readmissions, social functioning, medication adherence, and subjective distress; the impact of discharge on patients, their families, and their communities; the extent to which families actually provide care and the extent to which they are burdened; the nature and effectiveness of family intervention programs; and cost-effectiveness research.

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