P. E. Dietz,[1] *M.D., M.P.H. and J. A. Dvoskin,*[2] *M.A.*

Quality of Life for the Mentally Disabled

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SYNOPSIS: Case illustrations are given to suggest the complexity of the effects on the quality of life of developments in psychotropic medicines, deinstitutionalization, and patients' rights. Community services often do not provide the mentally disabled with the benefits predicted for such programs. Whether the net effect of the revolutionary extrusion of the mentally disabled from public hospitals will be beneficial remains for history to judge.

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During the past quarter century, changes of great significance have occurred in the lives of the mentally disabled in the United States. We hope to convey to forensic scientists from disciplines other than psychiatry and psychology a sense of the nature of these changes. This task can only be attempted at the risk of being criticized for having oversimplified a highly complex subject. Psychiatry and psychology are diverse and evolving disciplines, not easily reduced to unidimensional descriptions. We believe, however, that three developments stand out against all others in their impact on the lives of the mentally disabled. These developments—psychotropic medications, deinstitutionalization, and patients' rights—have not been universal in influence, and their effects are by no means simple. We will attempt to convey the complexity of these effects on the quality of life through case illustrations, for it is individuals whose lives are affected, for better or worse, by technological and social change.

In order to appreciate changes in the quality of life for the mentally disabled, it is first necessary to understand what conditions are mentally disabling, particularly because misunderstanding has been the cardinal feature of society's response to the mentally disabled for thousands of years. Four common types of mental impairment are severely and chronically disabling: schizophrenia, affective illness, mental retardation, and dementia. Other conditions, such as neurosis, personality disorder, and psychosomatic illness are also prevalent but are less often disruptive to every aspect of life. In contrast, schizophrenia, affective illness, mental retardation, and dementia frequently limit the educational, social, and occupational functioning of afflicted individuals.

For many years it was customary for such chronically disabled individuals to be ware-

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[1]Assistant professor of psychiatry, Harvard Medical School; director, Forensic Psychiatry and the Medical Criminology Research Center, McLean Hospital, Belmont, Mass.; and director, Forensic Psychiatry and Research, Bridgewater State Hospital of the Massachusetts Department of Correction.

[2]Doctoral candidate in clinical psychology, University of Arizona; intern in clinical psychology, McLean Hospital, Belmont, Mass.; and forensic psychology fellow, Harvard Medical School.

housed at large, overcrowded, understaffed, and thoroughly dehumanizing institutions where their functioning continued to deteriorate. The public mental hospital, evolving as it did from the poorhouse, provided primarily custodial services: shelter, food, and clothing. Even those hospitals with adequate facilities and staffing levels offered little hope of returning the chronically disabled patient to a meaningful life in the community. This pattern of custodial care went unchanged for many years until disrupted by the widespread use of psychotropic medications.

Psychotropic Medications

Psychotropic medications revolutionalized the treatment of patients with schizophrenia and affective illness. For the first time, safe and effective treatments became available to tens of thousands of patients housed in the public mental hospitals. Despite some misuse of these medications, there is little question that their availability has resulted in great improvement in the quality of life for many mentally disabled persons.

Treated with antipsychotic medications, many persons with schizophrenia are caring for themselves, living with their families, and taking part in the occupational and recreational opportunities of their communities. Treated with antidepressant medications or with lithium carbonate, many persons suffering affective disorders return to the same levels of functioning that they enjoyed before becoming disabled.

Thus, in the last quarter century, two of the four great cripplers of the mind have become as treatable as diabetes and tuberculosis. Proper treatment with these psychopharmacologic agents frequently makes the difference between lifelong institutionalization and a nearly normal lifestyle.

Psychotropic medications, like most blessings and all drugs, have risks. Side effects are common and not always easily managed. A small proportion of patients is permanently harmed by properly prescribed psychotropic medication. Like other medications, psychotropics can be abused. The overmedicated patient may be unable to benefit fully from other treatment modalities, and patients are sometimes overmedicated for the convenience of staff members. Many patients do not like their medication.

Case 1

Patient 1 is a 30-year-old chronically schizophrenic black male. He is committed to a state psychiatric hospital and likes it there very much. His only complaint is his dislike of psychotropic medication, to which he responds well. In fact, when medicated properly, his condition improves to the extent that he is discharged from the hospital and sent to the community where he is expected to be responsible for himself. Unfortunately, he does not like to be responsible for himself and loathes the medication, which he perceives as pushing him out of his dependent existence in the hospital.

As a result of court decisions affirming the rights of patients to refuse treatment except in emergency situations, he is permitted to refuse his medications. Unfortunately, when he is not medicated, he experiences frightening delusions that lead him to violence, both toward himself and toward other patients.

Case 2

Patient 2 is a 39-year-old married male. He suffers from manic-depressive illness and responds well to lithium carbonate. He also has a personality disorder not unlike that which characterizes many residents of our prisons. He has particular difficulty dealing with authority figures, especially the police, and is unable to tolerate his angry feelings toward the police. Whenever he wishes to combat the police, he stops taking his medication, knowing that in a relatively short time he will become manic. He then commits any number of crimes

that infuriate the police, but because of his well-documented mania, he is always adjudicated not guilty by reason of insanity. He is thus able to act in hostile, inappropriate, and illegal ways, with repeated reassurance from society that he is not responsible for his behavior, despite the fact that his exculpatory psychotic episodes are the result of his intentional and purposeful failure to take prescribed medication.

Deinstitutionalization

The widespread use of psychotropic medication made possible a second important change in the lives of the mentally disabled in this country. That change, the banishment of chronically disabled patients from the public mental hospitals, has been labeled deinstitutionalization. A major review of the care of the mentally ill in the United States culminated in an extremely influential 1961 report entitled *Action for Mental Health* [*1*]. That report recommended the development of community-based services for the mentally disabled, a recommendation adopted wholeheartedly by President Kennedy.

President Kennedy urged a new mental health program, the cornerstone of which was to be a network of comprehensive community mental health centers throughout the country. President Kennedy predicted that when his bold new plan was carried out "reliance on the cold mercy of custodial isolation will be supplanted by the open warmth of community concern and capability" [*2*].

Through the Community Mental Health Act of 1965, the concepts proposed in *Action for Mental Health* and endorsed by the Kennedy administration began to be implemented and largely determined the course of future events. Federal funds were made available for planning, demonstration, and development of Community Mental Health Centers (CMHCs) throughout the country. These CMHCs were to provide a comprehensive range of services through facilities located in the midst of the population served, and it was hoped that the large, isolated public mental hospitals would undergo a decrease in census such that their levels of staffing would be appropriate for those severely impaired patients who were unable to return to their communities. From the beginning, federal funds were intended to stimulate the development of CMHCs by the states, and the states were expected to support them when the seed money ran out.

From our vantage point 15 years later, some of the failures of this grand plan are all too obvious. Through the combined effects of new medications and CMHCs, the public hospitals have indeed returned many patients to the community. Hospital populations are less than half of what they were in 1960. This failed to increase staffing ratios in many hospitals, however, because the decline in patient populations was accompanied by a decline in staff populations. The same bureaus that administered state hospitals became responsible for CMHCs, so money was diverted from the hospitals to the CMHCs, particularly where such diversion led to additional federal contributions. The CMHCs, being labor-intensive in design and mandated to provide more comprehensive services than the hospitals ever attempted to provide, diverted so much of the budget that state hospitals were in some instances left worse than they had been. Many patients require continued hospitalization, including a core of chronically institutionalized patients who have been damaged by a lifetime of incarceration. In addition, some patients who are suicidal, assaultive, or otherwise troublesome can only be dealt with in a closed setting.

Case 3

Patient 3 was born with "congenital defects" in 1950. Slow to develop, at age four he was evaluated at the state school, where his IQ was established as 33. He spent 22 years at the state school. His entire file over that time consisted of two pages. In 1975, because of his assaultive behavior, he was transferred to a state hospital. By this time he stood some 183 cm

(6 ft) tall and weighed well in excess of 90 kg (200 lb). After ten days at the state hospital, during which he severely injured four patients, he was moved to his state's institution for the criminally insane. Upon his arrival there, he was reportedly unable to talk. For the past five years, he has lived in a maximum security unit, where he has developed a strong attachment to several correctional officers. The officers have taken him to ball games and picnics, and in some ways he has been accepted into their own families. He functions well in this setting, with the exception of occasional assaultive outbursts, and has even learned (or re-learned) to talk.

The institution for the criminally insane is limited by statute to care of the mentally ill, a category which does not include those with his diagnosis of mental retardation. His commitment there is thus illegal. Unfortunately, because of his occasional violent outbursts, there seems to be no other facility that can accommodate him. As a result of a 1978 court order, his state's department of mental health is "attempting" to create a program appropriate for him. From time to time he has been readied to leave the security hospital, and on these occasions the officers have become angry about the legal necessity of moving a man from a place where he receives love and care to a place where he may be unwelcome. Despite their reservations, the unit staff wholeheartedly helped him to develop a relationship with a department of mental health employee who was to serve as liaison to the new program. After several months, that employee quit.

Case 4

Twenty-eight-year-old Patient 4 has been suffering from chronic schizophrenia since age 19, and in that time has had at least 11 inpatient admissions to various psychiatric facilities. Upon each admission, he has been overtly psychotic and aggressive. On these occasions he has attacked family members, sometimes causing them to leave their homes to avoid him. The family has responded by pressing criminal charges and seeking his long-term commitment. He responds well to medication and the structure of inpatient treatment. Because of the deinstitutionalization policy of his state's department of mental health, each time his condition improves he is released from the inpatient setting and referred to an outpatient setting, his local community mental health center. That center, being understaffed, has been unable to help him to meet the practical demands of his environment. Unable to secure a job or housing, he becomes anxious, stops taking his medication, and soon decompensates into his most psychotic and violent state. The inevitable result is a repeat of the cycle, with new criminal charges and eventual civil commitment.

Patients' Rights

Just as the mental health system was most unsettled by all of these developments, our brethren at the bar began to batter psychiatrists, hospital superintendents, and mental health institutions with the greatest broadside of lawsuits any profession has ever suffered. Armed with the criticisms of radical psychiatrists and sociologists and the spirit of the human rights movement of the 1960s [*3*], attorneys filed one suit after another against the public mental hospitals and their staff members. Ironically, the suits came from without at the very time the system was undergoing unprecedented changes from within in an effort to alleviate the centuries-old conditions that the suits sought to remedy.

These suits established new rights for the mentally disabled, but they left a wake of destruction. In Alabama, site of the landmark right to treatment case of *Wyatt v. Stickney* [*4*], the state mental health system is now in receivership. Other suits, challenging the bases of involuntary confinement and ensuring that due process be exercised in all civil commitments, have promoted open-door policies in state hospitals, so patients are free to come and go. New suits and standards of practice have also greatly diminished the willingness of

staff to administer medication to reluctant patients by force, coercion, or persuasion, and many psychotic patients go untreated and out the open doors.

Case 5

Patient 5 is a 59-year-old man who has carried a number of diagnoses in his 50 years of institutionalization. He has been called mentally retarded, childhood schizophrenic, brain damaged, simple schizophrenic, and for most of the last 40 years, chronic undifferentiated schizophrenic. Currently he is committed to his state's maximum security psychiatric facility, despite the fact that he has never been assaultive or suicidal. It seems that he is simply unable to care for himself on the streets. He has been placed in a number of civil hospitals and halfway houses, but he periodically wanders off or sneaks out of these facilities, and they do not have adequate staff or security to keep him on their wards. Consequently, he is committed to a place for violent dangerous men when his only apparent desires in life are to sleep, eat, and wander around.

Case 6

Patient 6 is a 55-year-old manic-depressive alcoholic who has been hospitalized some 40 times. Committed to a state hospital for pretrial evaluation of his competence to stand trial on a disorderly conduct charge, he was permitted to refuse medication. A few weeks after discharge, still psychotic, he created a public disturbance when the telephone operator would not let him charge calls to the governor and the head of the National Guard. He was uncooperative with arresting officers and was charged with multiple counts of disorderly conduct and assault and battery on a police officer, leading to another pretrial commitment, this time at the maximum security facility for the criminally insane.

Discussion

As the public hospitals loose their budgets and patients, and the costs of heating those old buildings soar, states have been closing one hospital after another, thereby eliminating the usual facilities of last resort.

These many changes, all reflecting good intentions, have so crippled the traditional institutions that those mentally disabled persons who remain untreated or untreatable are no longer automatically provided with food, clothing, and shelter. Many are homeless and wander the streets, while others who manage to pick up their welfare or Social Security checks live in boarding homes, unlicensed nursing homes, or other community facilities that are worse than the old state hospitals [5].

Those who are most troublesome or embarrassing to those around them are eventually extruded from their communities in one way or another. The form such extrusion takes is a function of the alternative dumping grounds available. Some communities have residential facilities for alcoholics, and some mentally disabled persons land there despite an absence of alcoholism. Every community has jails and prisons, and other sites for extrusion being lacking, that is precisely where many of the mentally disabled land. The mechanism for this is perfectly predictable. When all other means of keeping the troublesome out of the way fail, they are charged with whatever offenses can be claimed and sent to correctional facilities or security hospitals for the criminally insane.

Some are sent with minor charges. In 1978, for example, 135 men were sent to the maximum security facility for the criminally insane in Massachusetts for evaluation of their competence to stand trial or criminal responsibility for such charges as disorderly conduct, disturbing the peace, trespassing, failure to pay child support, and driving without a license.

Others are not sent until they have committed serious offenses, such as robbery, rape, aggravated assault, or murder. Their extrusion is more successful, for they are often held for years.

How are we to evaluate the quality of life for these men and women? Is it better to be free to live in squalor or in prison with one's psychosis intact than it was to be locked into an overcrowded ward and coerced into taking medication?

Conclusion

President Kennedy's prediction that the mentally disabled would receive "the open warmth of community concern and capability" [2] has not been realized. The fond hope that community services would bring the mentally disabled in proximity to family, friends, and employment has for many culminated instead in proximity to enemies, alcohol, drugs, crime, and unemployment.

Whether the net effect of this revolutionary extrusion of the mentally disabled from the public hospitals will be beneficial remains for history to judge. For the moment, no simple truth is discernible.

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Address requests for reprints or additional information to
Park Elliott Dietz, M.D., M.P.H.
Harvard Medical School
McLean Hospital
115 Mill St.
Belmont, Mass. 02178