

FORUM

**DE-
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A Vastly Oversold
Good Idea...

by Amitai Etzioni

For New Yorkers the "deinstitutionalized" are familiar fixtures. On upper Broadway, for example, they line the benches of the traffic islands, next to paper bags which contain the full measure of their belongings. Others scavenge trash baskets in the Bowery, or sleep in the doorways in the Bloomingdale's area. Some look like a burnt-out building; others are younger, angrier who spend their days pacing up and down a piece of sidewalk, or loudly haranguing passersby.

The deinstitutionalized owe their freedom to struggle for survival in New York's streets and SRO hotels

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to an odd coalition of do-gooders: public interest lawyers, social scientists and the Governor. It's not your usual combination of the greedy and the mighty who exploit nursing home patients or "ping-pong" patients through Medicaid mills. The do-gooders' intentions are noble. They found nearly two hundred thousand New Yorkers rotting away in institutions for the mentally ill and retarded which often resemble prisons more than hospitals or schools. Here, conveniently out of sight of most citizens, often unvisited by their own kin, they have been locked in—many thousands of people together—in oppressive jail-like brick compounds that are overcrowded and understaffed.

Medical care has been poor; rehabilitation work meager and ineffectual; sexual abuse, exploitation and violence common. Cure is rare and if achieved often accidental.

Indeed, in the over one-hundred-year history of such institutions, the main improvements their inmates have gained are the introduction of television, the replacement of strait-jackets and rolled wet sheets with chemical restraints, and mass dosing with tranquilizers.

In recent years, three energetic constituencies, each with its own rationale, have fought for a new policy toward the mentally ill and retarded—the policy referred to as "deinstitutionalization." Like many fashionable public policies its essence is simplicity. The core idea is: get the mentally ill and retarded out of these human warehouses and put them back "in the community."

Fighting the legal battles of deinstitutionalization were the public interest lawyers. While in other states the landmark decisions usually involved mental patients, in New York the most significant case, at



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least in terms of the number involved, was a class action filed on behalf of over five thousand mentally retarded residents of Willowbrook by the American Civil Liberties Union and the Legal Aid Society. They argued that the institution was harming the retarded persons and achieved a ruling that the residents be transferred to families or smaller institutions as soon as possible. Recently the judge demanded of the New York State agencies involved that they accelerate the release from Willowbrook.

In a conference on dependency, organized by the Center for Policy Research and the New York Council on the Humanities, chaired by Dr. David Rothman, lawyers Bruce Ennis and Ira Glasser took the position that the state had no right to confine mental patients; that such confinement was a violation of their civil rights, and was done under the pretense that rehabilitation would be provided, which it as a rule is not. In the arguments that followed, it became evident that the lawyers tended to see most mental patients and even retarded persons as basically "competent" to decide whether they wish to be institutionalized, and—to make it in the community. Others, including this

sociologist, countered that many of the persons involved are not equipped for autonomous living and hence need help, at least shelter, if no rehabilitation is available.

But it should be made clear that there is no agreement on this matter among social scientists either. Indeed several leading social scientists (most notably Professor Erving Goffman of the University of Pennsylvania) have contributed significantly to the notion that institutionalization dehumanizes people by making them into dependents, unable to function on their own, and devastating their egos with regimentation and boredom. Some go so far as to attribute most of the "sick" behavior many ex-patients exhibit not to their underlying mental illness which has not been cured, but to the horrors of institutionalization and to the stigma of having been labeled and sent away by a fearful family or public.

Governor Carey, in his message to the legislature accompanying his 1976-77 budget, put it quite squarely: "We can no longer afford—in terms of cost and conscience—to institutionalize people who can be better treated at the community level." While the Governor refers to both cost and conscience considerations, most of the rest of the message naturally deals with the budget, figures, and hoped-for savings. For instance, it is reported that while it costs the state \$23,000 to keep a young person in a state institution, the cost in the community in residential centers is \$13,000. Parents who take their retarded child home from Willowbrook will be paid the same as if they took in someone else's child—\$291 a month—saving the state about \$16,000 a year in the process. Legal briefs, social science argumentations, budget savvy: a compelling coalition. What went wrong? First this: it is one thing to criticize existing institutions, which in this case is especially proper, and quite another to fashion viable alternatives. Sure it sounds good to

send "them" back to their families, only some don't have any families and many others are quite unwanted by their kinfolk. Indeed, it was often they who sent the retarded and mentally ill to the institutions in the first place because the families could not or did not want to cope with their "disturbed" members.

One study of 125 families of released mental patients found that initially 75% did want their relative to come home, but when he or she returned with the same aggressive or bizarre behavior that had led to hospitalization, the percentage who were willing to keep the relative fell to a mere 7%.

And if their own kin do not want them, their neighbors want them less, much less. After some 700 ex-mental patients moved into the decaying beachfront hotels of Long Beach, Long Island, the city council passed an ordinance seeking to ban all ex-patients requiring medication. In this instance, the authorities seem to have been as concerned about the atmosphere created by those who preyed upon ex-patients as by the patients themselves. According to the deputy police commissioner: "It's like sucker fish who feed off food that falls from the mouths of sharks. The going business here is ex-mental patients and senior citizens. It seems that some of the owners of adult homes are sharks and others—druggists, doctors, ambulette and taxi companies—are sucker fish. Probably others will come around looking for scraps too.

So you can sing the merits of cozy care in the community versus isolation and neglect in the countryside, till the schmaltz floods the Empire State, but that will not make residents of Forest Hills, Yonkers, Central Park West or most other communities welcome "residential" centers for the retarded or the mentally ill. Actually most communities fight them tooth and nail, fearing for their children's and their own safety. Their fear is part rational (it is rather difficult to tell the "harmless" from the "dangerous" patients, at release point); in part based on calculations other than safety (e.g., property values); and in part an irrational fear of those who

are peculiar. But whatever the motivation, their opposition is likely to be quite fierce.

Likewise, you can repeat after Schumacher "small is beautiful" until all the big institutions are broken up into small ones, but please also note that the greatest abuses occur in the small ones. Thus, horrid as the huge state institutions are, many "adult" residential halls and nursing homes, in which many of the so-called "deinstitutionalized" persons end up, are more scandal-riddled and more abusive than anyone ever charged any state institution of being. "Small" here means even more difficult to oversee, inspect, and keep tabs on, than big, and hence even more unresponsive to reform. Also, "small" often means run on a profitmaking basis. And these small institutions are often run not by normal businessmen, but by profiteers. As Senator Frank Moss said when he released a report on the boarding home industry, prepared by the staff of the Senate Subcommittee on Long-Term Care: "Operators understand that the way to make a profit is to cut back on food, staff, bedding and other vital services. Whatever is not spent becomes profit."

All this is not to say that deinstitutionalization has been a total disaster, and we should go back to the traditional policy of long-term incarceration. Some, perhaps as many as a third, of all those deinstitutionalized are picked up by their families (or by foster ones) where they are assumed to be better off, or placed in good-to-reasonable (often voluntary rather than profitmaking) small community institutions. But the rest—somewhere between half and two-thirds of all those involved—end up in the streets, or back in the big institutions, or both. Both? Yes, both. They become caught in what is known as the "revolving door treatment," a cynical term if ever there was one. Kicked out of the big institutions, they try to cope on their own: roam the streets haunting the stoops of dark SRO hotels. When they run into trouble, from being mugged, to drunkenness, to causing a disturbance, they end up in the city

hospitals' emergency rooms and wards, from which they are returned to the big state institutions, soon to be released again. Each turn of the wheel exacts a sad, human cost in psychic if not physical damage.

According to 1973 statistics, the best available to us, 28% of the patients discharged were back—within six months. As the Community Council of Greater New York reported, "Since 1968, thousands of state-hospitalized patients have been discharged to local communities, and virtually none of the suggested alternative plans have been put into effect." Since that report was issued late in 1974, the flood of discharges has been slowed somewhat, and the number of community facilities expanded. Nonetheless, there are still thousands of discharged persons without adequate care.

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hus it is not a question that the do-gooders' deinstitutionalization policy is wrong in principle; it was just vastly oversold and overbought. Yes, huge institutions are bad for body and soul. Yes, return

to home and community may be better if these are available and properly prepared, and in the case of small institutions, properly supervised. No one should be released unless there is good evidence that there is something better awaiting the person at the other end. Yes, the streets are worse than the horrid institutions, and releasing sick people into the street does not generate pressure to hurry up the preparation of community facilities for them. It just accelerates the turns of the institutions' revolving doors. The mentally ill, the retarded, the senile have disabilities enough to cope with without adding the burden of adjusting to oversold public policies.

Let's also realize that good "in the community" care often is quite costly. The family which must cope with a severely retarded child may require public assistance if it is poor or near poor; good foster care or honest, effective small facility care is expensive, too. Dr. Laurence C. Kolb, New York's mental hygiene

commissioner, recently informed the legislature that the shift to community facilities would save at most 15%. Actually, he expects the saving to be even smaller. Hence, much of what we hope to save by closing the huge institutions must be allotted to their replacements. To cut the budget of huge institutions, and not substantially increase the budget of other services, simply means poorer services for those who badly need them.

And let's not kid each other that people who have been institutionalized will quickly flourish (or "normalize") just because they have been deinstitutionalized, and overgeneralize from a few heart-warming successful cases. Most retarded persons, and those suffering from serious mental illness, will need to be sheltered for the rest of their lives, in or out of institutions. It is all right to hope for more, but to base a public policy on more optimistic assumptions is one reason, however well-intentioned, so many helpless souls wander the city's streets. □

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