

IS DEINSTITUTIONALIZATION WORKING?

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The Questions

Were the traditional institutions bad? What is bad? Are the new ones good? What is good? Is an Intermediate Care Facility for the Mentally Retarded (I.C.F.M.R.) an institution? Is a large group home an institution? What is large? What is small? What is just small enough? Or not too large? Can the state ever provide decent care for people? Can for-profit corporations? Can there be not-for-profit corporations--truly not-for-profit, and by design? Should parents be given a subsidy to care for their retarded children at home? Is such a subsidy wrong? Is it even unamerican? These and other particular questions come to mind, or have been asked (and hurled) to me. But one also asks the larger question: Is deinstitutionalization working? I won't deal with all of these particular questions here, except by indirection and in response to the larger question. Rather, my greater purpose is to encourage you to ask your own questions--about deinstitutionalization, but also about what prompts the very discussion, institutions.

I also dwell on such topics as an antidote to our failing memories. There's something about our past in mental retardation--about our institutions and what we have done with them, our seclusion and other punishment policies, our ideas on nature/nurture and segregation of all types--that promotes intentional amnesia. We have to work hard to remember and to encourage others to remember.

Is New Better?

You have heard about the scandals in the field, the exposes, the litigation, the progress. There has been talk of a "Revolution." To be sure, there have been

reforms and there has been a "revival of conscience." The institutions have been improved, refinanced, made smaller. The community programs that serve them now are larger (or smaller; I forget which, but in whatever direction they are taking I've been advised that they and we are better for the change). Now we are left with the question, "Are the new smaller institutions better? And if so, are they better than other arrangements? Better than no institutions? Better than what?"

Evaluations are necessary to determine what's good, what's better, what's best in the best possible world. To accomplish an evaluation of this sort, we must ask the following questions:

- (1) What is a slogan and what are the facts? Is deinstitutionalization little more than another slogan in acceptable form, little more than that which has been part of the mental retardation scene for generations? Some professionals in the field make that claim. Others make the claim that institutionalization of the mentally retarded is no more serious than institutionalization of the college student, or the monk, or the Army recruit. After all, the college, the church, and the military are also institutions.
- (2) When is a program beneficial and when is it merely incarceration? Is the six-hour treatment day "too much" for incarcerated clients? Not enough? Or irrelevant?
- (3) Is the community prepared to accept the deinstitutionalized ex-resident? And if it is, under what conditions and for what purposes? And if it isn't, what does that mean to those who would deinstitutionalize these people? And what does it mean to those who would not?
- (4) What are the economics of the situation? Is it the accountant who will tell us that the deinstitutionalization was proper or improper? Who will inform us about cost-benefits? And what does

the term actually mean--"cost-benefits"?

There is yet another issue connected with evaluations of the new institutions. Is it mental retardation we're dealing with here or civil rights? That's an important issue, one which must cause us to pause, to wonder whether there will ever be a satisfactory science to resolve the question if it's more an issue of civil rights than damaged brains.

And how do we deal with the truth? How do we know who's telling the truth, when there are so many lies? Plaintiffs in litigation exacerbate the problem, and defendants minimize the problem. Even when the plaintiffs and defendants make their cases in the courts or seminar rooms, almost invariably, plaintiffs portray the stark reality by clever utilization of black and white slides. And it's also to be counted on that defendants will portray progress with color slides. One suspects that, had the liberators of Nazi concentration camps used color photography to portray the horrors, it might have looked more like a Disneyland than a Buchenwald. That's harsh, and hyperbole too; but it may be no more of a lie than the color photograph of the human warehouse (or the black and white photograph taken by the advocates). But, then again, there may be a critic so disenchanted with institutions that, to him, dwelling on the type of photographs--black or color--is akin to the Elephant Man's doctor recommending contact lenses; or, using an enema bag to clean out New York City's East River; or excavating the Grand Canyon with a teaspoon. There are considerations, but they may be trivial. No?

What about the experts? One set of experts is asked to evaluate the situation for the parents' group, or for a group of other plaintiffs, or for those who would tear down the institution. And another group of experts is asked to evaluate that same situation, but their "employer" is the state. So while experts argue with experts only to befuddle the court, the court (and the people) are left to resolve the dilemmas, become the experts.

What happens after the court has spoken, or the legislature, or the people themselves? There is a decision, or a stipulation (an agreement by both parties). And funds are found to supplement the new mandate. However, the funds are not usually created for this specific purpose. More often than not, the funds are taken from other programs. Peter robs Paul; the state withdraws resources from one bad institution to make another terrible institution merely bad. That assertion too may be hyperbole, but there may be more morality to it than the original deed itself--robbing Peter to pay Paul. I have said before that the more things change the more they remain the same, but now they don't change differently from the way they haven't changed before. What also seems to be unchanged is the widespread belief that, like the three bears' porridge, most institutions are never just right--either too new or too old, too conservative or too liberal. But don't most people think life, itself, is either too long or too short--never just right?

There is debate concerning the quality of the new institutions. But there is little or no debate concerning the effects of deinstitutionalization in terms of sheer reductions in the number of people who are exiled to the state's large facilities. During the mid-seventies, there were upwards of 170,000 people in state institutions for the mentally retarded in this country. Today, that number has been greatly reduced (Conroy, 1977; Scheerenberger, 1976). Furthermore, the trend seems to be continuing in that direction. However, while the deinstitutionalization movement for the mentally retarded continues--sometimes feebly, but continues--attempts to create alternative living arrangements for such people also continue, also sometimes feebly, sometimes unwillingly. Of course, there have been concerns raised that these reductions in institutional populations are more superficial than they are genuine. Those critics also point out that, while the institutional population in this country has been on a decline, the reduction is not as impressive as the national deinstitutionalization effort on behalf of mental patients. Insofar as the latter group is concerned, there were more than a half million such patients

hospitalized during the mid-1950's, while today the amount of mental hospitalization is quite similar to the amount of institutionalization of retarded people, approximately 130,000 people. Therefore, while many applaud the vigorous deinstitutionalization programs on behalf of mentally retarded people, there are few critics of institutionalization who feel satisfied that enough has been accomplished and, furthermore, they worry that the dangers for new institutional building in the United States remain ever present. And "everybody" realizes--those for and those against, whatever--that the metaphors and the words, that the promises are not the solutions. So we return to the question.

The Larger Question

Is deinstitutionalization working? That all depends--or how you answer questions concerning what deinstitutionalization means, what freedom means, whether any human being can or can't benefit from an educational program, whether it makes any difference whether the community is or isn't prepared to accept retarded people, whether the accountants will be the first to be satisfied in determining what is a benefit. I have some doubts about the victories claimed in the name of deinstitutionalization. But, of course, 35 years ago I had neither doubts nor vision. I have made progress. We all have.

References

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- Scheerenberger, R.C. Deinstitutionalization and institutional reform. Springfield, Illinois: Charles E. Thomas, 1976.