

## EDITOR'S NOTEBOOK/Bernard Rimland, Ph.D.

### Community, my foot!

#### *The LAPD, autism, and residential alternatives*

Many months have passed since the vicious unprovoked beating of motorist Rodney King by members of the L.A. Police Department first appeared on our TV screens. Most of us have seen the replays so often that we can summon them to our mind's eye without the benefit of electronic equipment.

The Rodney King affair unleashed a storm of public outrage and protest. Cries for reform were widely heard and many suggestions for improving police accountability, in Los Angeles and elsewhere, were made. Some reforms have been adopted. Despite the highly emotionally charged situation, there were, so far as I know, no calls for the total abolition of the Los Angeles Police Department, nor the abolition of other police departments elsewhere, where similar incidents have since surfaced. It is widely understood and accepted that even though there are instances of abuse, police departments perform an important and necessary social function, and the good they do far outweighs the bad.

Contrast the above situation with what has occurred during the past several decades with regard to "mental" institutions. Historically, people with serious mental incapacities such as schizophrenia, severe retardation, or autism were left to wander the streets of cities and towns, defending themselves as best they could from attack by others, scrounging food from wherever they could find it, including the gutter, trying to find shelter from cold and snow. To create a safe and humane environment for these unfortunate individuals, society created asylums—places of safety and refuge—far better than living the life of homeless and despised vagrants on the streets. Many of these institutional asylums did a wonderful job. Others did a very poor job, and permitted terrible abuse and neglect of the residents to occur.

Along came television. Guess what? The public was not treated to the spectacle of clean, well-fed and well-treated mental patients basking in the sun or participating in exercise classes in well-equipped gyms. Instead the public was shown the worst of the "snake pits." *Christmas in Purgatory*, and the horrible revelations about patients' lives at Willowbrook, were presented to national audiences. This of course is to be expected, and is in fact a good thing, because it exposed problems that required reforms and led to the establishment of state and federal guidelines. But it gave a very distorted picture of the true situation. How much national media coverage would have been given to secretly videotaped images of LAPD officers helping little old ladies across the street?

The exposés of neglect and abuse at some institutions led to an indiscriminate smearing of the reputations of all institu-

tions everywhere, and a concerted effort to get patients out of institutions into what is euphemistically called "the community."

The deinstitutionalization movement took hold with a vengeance. Countless thousands of people who are unable to cope with the problems of survival in a harsh and uncaring society were dumped into the streets, or into small, privately run facilities, under the supposed protection and care of a large number of expensive, but inadequate and ineffective, "community mental health centers."

Deinstitutionalization proved to be a cure worse than the disease. At least five books have been published in the past three years detailing its tragic consequences. Seymour Sarason of Yale University, one of the leaders of the deinstitutionalization movement in the U.S., describes these efforts in his recent autobiography, *The Making of an American Psychologist*. He concludes that the most serious professional mistake of his life was his advocacy of deinstitutionalization. (I tip my hat to you, Dr. Sarason. Few of us have the courage and integrity to own up to our mistakes.)

As the legions of poorly fed, physically and mentally ill homeless persons on our streets attest, moving people out into that wonderfully warm and nurturing mythical "community" wasn't necessarily a bright idea. Some of the institutions they left were excellent places; others were terrible. Some of the community places they were moved to were excellent; others were terrible.

If abuse and neglect are going to occur, they can occur far more easily and more secretly in small group homes in the community than they can in a major institution with many other people present. Group homes can come and go very rapidly. Some last many years, others last only months. It is not unknown for the residents of such homes to be left on the street when the owner of the facility decides that he or she can no longer tolerate the stress of trying to find enough semi-qualified, minimum-pay, high-turn-over workers to care for the residents.

The word "community" needs careful examination. It derives from "common," and implies a degree of coherence, shared interests and concerns that is today rarely found in urban environments. The word "community" conjures an image of a white-haired grandmotherly lady at one's door, asking, "Can you use this freshly baked apple pie? We just have too many apples this year." When was the last time this happened in your neighborhood? Many group homes in the U.S. are located in places that would be better described as urban jungles than communities. I am aware of group homes in areas that are so dangerous that the social workers will visit them only in pairs—on those rare occasions when there is any su-

pervision at all. I am aware of institutions where real community, caring people, long term relationships, exist in abundance.

Community once implied human relatedness. Now it refers merely to an urban area. Community living—with no other options—is an ideology pushed with religious fervor by the sanctimonious but misguided Association for Persons with Severe Handicaps (TASH). I read with grim amusement the complaint in their most recent newsletter: "Although persons with severe disabilities have been living in the community physically for some time, they have not generally been participating in the shared life of those communities." What shared life? Community, my foot!

Let us not be misled by the warm fuzzy feeling that the word "community" is intended to instill. Let us not be misled into the feeling of abandonment and neglect that the word "institution" has come to connote. I am in touch with literally thousands of parents of autistic children and adults throughout the world. Many of these children are maintained in healthy, happy, and to them and their parents, satisfying environments on farms and ranches and in institutions, public and private, that parents do not want to see closed or abandoned.

While many, perhaps most, urban group homes are excellent, I disagree strongly with those who insist that urban group homes must be the only residential option. I favor the existence of a variety of options to fit different family and individual needs and preferences. We need not only urban group homes but rural residences, such as farms and ranches. And we need institutions—good, well-run institutions—for some of our sons and daughters.

I believe that with the proper technology, all kinds of residential facilities can be run in safe and responsible ways. Both small group homes and large institutions could be monitored frequently by randomly scheduled surprise drop-in visits from inspectors who are employed by advocacy groups, rather than by the organization running the group home or institution. Monitoring by electronic surveillance provides another means of protection.

Last year we published in ARRI (4/3) an editorial titled "The Non-Urban Alternative," in which we advocated the availability of farm and ranch residences for autistic individuals, such as Bittersweet Farms or Rusty's Morningstar Ranch. For many months afterward, and even to this day, we receive enthusiastic letters from parents who want that option available for their children when they are no longer here to care for them. That rural option, the urban group home option, and the state institutional option should all be available so families can exercise freedom of choice.