

Editor's Notebook

Reopen the institutions?

Advocates Reverse Stand as "Community" Tragedy Unfolds

By Bernard Rimland, Ph.D.

The road to hell is indeed paved with good intentions. For decades, institutions housing mentally retarded, autistic, and other behaviorally disabled persons have been under sharp attack. Spurred by revelations of deplorable, neglectful, and abusive conditions at some institutions, well-meaning advocates of the disabled have demanded the closing of all institutions. They insisted upon the resettlement of the residents in smaller group homes (and sometimes apartments), in what they euphemistically (and naively, as it turned out) call "the community."

As we observed several years ago in our editorial, "Community, My Foot!" (ARRI 5/3, 1991), "Community once implied human relatedness. Now it refers merely to an urban area. Let us not be misled by the warm, fuzzy feeling that the word 'community' is intended to instill. Let us not be misled by the feeling of abandonment and neglect that the word 'institution' has come to connote."

It has quickly become evident that the cure—closing the institutions—is often worse than the disease. A 1993 report by Congressman Ron Wyden noted that "the private sector residential facilities for the mentally retarded have become an \$11 billion-a-year business... Millions of Americans with these life-long handicaps are at risk for poor quality care, questionable and even criminal management practices by service providers, and lackluster monitoring by public health and welfare agencies.

"A disturbing pattern of abuse, neglect, and fiscal mismanagement has emerged:

—"Employees at small community based facilities are often under-trained, poorly paid, and inadequately screened. As one New York State official put it: 'some consumers leave institutional programs where staff have received 100 hours of training, and move to homes where staff do not even know first aid.'

—"...Former employees of one facility reported that prescribed medications for residents are routinely discarded."

—Dr. Cindy Ochs, of Livonia, Michigan, who cares for mentally retarded residents at about forty metro Detroit homes, stated, "They're hiring people off the street for five or six dollars an hour to care for patients who have complicated seizure disorders, feeding tubes, all kinds of problems."

Under these conditions, it should surprise no one that death rates have risen to horrifying proportions. As we recent reported (ARRI 10/4, 1996), a study by David Strauss and Theodore Kastner, based on 18,000 adults who were "clients" of the Department of Developmental Services in California from 1980 to 1992, found the death rate to be 72% higher in group homes than in asylums. A more recent study of nearly 1,900 California patients transferred to group homes from asylums in 1993-1994 showed an 82% higher death rate in group homes. In both studies, the "institution" and

"community" patients had been carefully matched on all known risk factors.

Death can come quickly to those removed from institutions. Ten patients died after being discharged from the Porterville Developmental Center into group homes. "Most were middle-age and had lived much of their lives in state centers," the *San Francisco Chronicle* reported on February 25, 1997. "Their average life span after leaving Porterville: just 62 days"

As Strauss points out, "deaths are but the tip of the iceberg. Where there's an excessive number of deaths, there's an excess of other types of medical problems... for every death, there are many emergency hospitalizations..." And, obviously, for every emergency hospitalization, there are a multitude of untold

UPDATE: A study just accepted for publication found that when unavoidable cancer deaths are separated from the statistics, the excess mortality in the community versus institutions is 96%—a substantial increase over the 72% reported by Strauss and Kastner.

and unrecorded tales of hunger, neglect, and abuse of every imaginable kind. The situation is so clearly monstrous that even the most vocal advocates of the "close the institutions" school of thought (actually, non-thought) have been forced to change their tune. On December 14, 1996, the ARC of California, which has strongly supported the movement of the mentally handicapped from the "Developmental Centers" into the so-called "community," petitioned the state for a two-year moratorium on further closings of institutions, and for discontinuation of its "deflection" program, which largely prevented any new patients from being admitted to these institutions. (ARC is the organization that was initially—and informatively—called the Association for Retarded Children.)

What caused ARC-California to (thank Heaven!) retreat from its anti-asylum stance? It wasn't just the mortality statistics, though the statistics are hard to ignore. Horror stories about individuals also abound: the *Chronicle*, for example, described one 42-year-old woman who "survived her discharge from Porterville, but... returned to the center last month seriously ill and in agonizing pain." The woman had been placed on 13 different medications, ranging from narcotics to tranquilizers and anti-psychotics, and the report says that "by the time she was returned to Porterville, fluid discharges from her ears soaked her hair. She had ringworm. She was dressed only in an orange jail jumpsuit. Some staffers who saw her were moved to tears."

"They come back here to get well," a Porterville staff member told the *Chronicle*, "and then we send them out again for someone else to kill."

Let us be very clear: we are not opposed to group homes. Some are excellent, just as some institutions are excellent. I have seen both group homes and institutions which have outstanding programs, committed and well trained staff members, and happy residents. Conversely, I am aware of both group homes and institutions which I would consider "snake pits." This does not mean that either type of home should be shut down. It means that both must be improved. And both must be vigilantly monitored.

It's time to replace the deinstitutionalization movement with a "common sense" movement that acknowledges the diversity of our children and the need for institutions and group homes, and other options as well. Some of the obvious truths this movement should acknowledge:

—Many medically fragile or behaviorally disordered clients are a danger to themselves and others when placed in group homes where staff training is inadequate, supervision is lax, and local doctors are ignorant about developmental disabilities. Such individuals need other options, including institutions.

—Rather than closing down institutions, we should update them, replacing the very expensive medical model of wards and white coats with the residential model in which residents live in home-like settings where they are protected from, but not isolated from, the outside world. This is already being done at many, if not most, institutions. A parent in California, for instance, recently told us that her son—a resident at a state institution—lives in a college-dorm-like room, participates on a bowling team, and even has a paper route. In many similar institutions I have visited, such real communities are very much in evidence.

—Farms and ranches should be encouraged, as they may readily combine the best features of institutions (safety, trained staff, low turnover, healthy lifestyle) with the best features of group homes (home-like settings, "real world" activities, potential for contact with neighbors). Regulations discouraging such settings in favor of smaller group homes should be abandoned.

Some advocates have tried to convince us that a "one size fits all" residential program—the group home—is optimum for all autistic children, regardless of their medical needs, behavioral problems, and skill levels—and regardless of their families' wishes. But one size doesn't fit all. If the rest of us can thrive in a wide variety of settings, ranging from apartments to school dorms to military barracks, single-family homes, and farms—why can't our children? In their case, it's not just a matter of personal preference. As the statistics of Strauss and Kastner show, it can be a matter of life or death.

We join the outstanding advocacy group Voice of the Retarded (VOR) in urging an immediate national moratorium on the closing of asylums for the mentally handicapped. Too many innocent lives have already been lost. To Join VOR, call 847-253-6020.