

N.Y. Times

Somers

Beyond Institutions and 'Deinstitutionalization'

By FRANCIS X. CLINES

Special to The New York Times

SOMERS, N.Y., April 13 — There is a certain slowness, as of sowers pausing at the earth, and a curious stare, but then sparks of friendliness from the farm crew — David, Ken, Norman and John — who seed peas, onions and radishes into the broken ground.

The spring labor has begun on another year's crops to be grown and eaten by the 21 mentally handicapped adults of Opengate, a 10-year-old experiment in the search for a decent and challenging life for such people as they head inexorably into the unknown years beyond institutions, beyond the family, beyond the official definition of childhood.

"Is this something against me?" Catherine, a former patient for 25 years in Letchworth state hospital, asks, watching a visitor take notes.

"No, no," she is told. "Everyone gets nervous when they see this. You should see some of the politicians squirm."

Catherine smiles at her relationship to other people, and she responds with a friendliness that, because it is guileless, is very refreshing, something for the politicians to envy.

The residents of Opengate are warming up. Ken, a man in his 20's with a halting but good vocabulary, comes over wearing a crash helmet. "In case I fall down," he explains slowly.

Danny, a hefty, smiling resident commentator on life at this country estate in northern Westchester County, adds, "He has seizures."

It is all very understandable, particularly Ken's pride in working three jobs (the farm and collating table at the workshop here, and the Xerox machines down at the Medical Rehabilitation Institute in Valhalla), and Danny's vow to control the temper outbursts that prevent him from entering the community's new independent living program.

This program — the "ILP" — is both scary and exciting for the Opengate residents, for it is aimed at something few of them have ever fully conjured, a competition to reach a level of self-sufficiency that would permit the four best members of the community to reside eventually in the outside world as an adult group with no resident supervisor. To do this, all sorts of basic wage and budgeting, shopping and scheduling tasks must be mastered by the Opengate residents, who average 29 years of age and in behavior are considered at a 12-year-old's level, at the most.

They are developmentally disabled — restricted by retardation, epilepsy, emotional wounds, professional neglect or a combination. In a way they suffer, too, from society's short-term attention span, its predilection for taking on



The New York Times / Edward Hausner

Jerome Spiegel, lower left, director of Opengate, and residents yesterday

or "scandal" followed by election-time reforms and nostrums, and so on to the next one.

Everyone knows, for example, what the word "Willowbrook" means. It means a graphic scandal of neglect of the retarded by the state (the people?). And now we have come to know it means another word, "deinstitutionalization," whereby the residents of the large isolated places are being moved into smaller places with resident supervision in communities.

But did you know that "Willowbrook" once meant reform, back at the institution's founding, and that parents once handed over their troubled ones to its care with relief and hope? So asks Jerome Spiegel, the director of Opengate, a tolerably hopeful and cynical man who watches the issue of the retarded move, he says, like a pendulum.

On Thursday, Mr. Spiegel surprised his staff (16 full-timers and 16 part-timers) with a taste of champagne to celebrate what he says is a rarity in his business — the application of objective standards of care. Opengate had been inspected and, finally, granted accreditation by the mental retardation council of the Joint Commission on Accreditation of Hospitals.

"Now I feel entitled to shoot my mouth off," Mr. Spiegel says. "We have a proven program with standards of accountability."

His "mouthing off" contention is that government, despite an impression of decent reform lately, is spending money on the problem with more of an emotional commitment than a rational one backed by objective standards.

"I'm frightened," he says. "I fear

field. You'll always have Bergmans if no one's following the money. For the public, 'deinstitutionalization' means some neighborhood controversy about having them next door, but the public should be looking into the standards of the places and where the money goes."

Opengate was started outside the government run of things by a group of parents who had raised their functionally retarded children at home rather than institutionalize them. They became concerned about the decades of later life, and they pooled resources to buy a 27-acre estate at auction and establish a private, nonprofit residence. The aura is busy and hopeful, a mood set by the morale of the residents even more than the surrounding beautiful acreage.

Residents meet regularly with a team of therapists and teachers, setting behavior goals that are charted for everyone to see, establishing jobs and salary incentives, relating regular paydays to necessities they can buy on trips to town. Mr. Spiegel says Opengate does the job better and more cheaply than the state, with fewer bureaucratic and labor shibboleths to crimp the program.

Opengate runs at a deficit, and the parents have to raise funds every year. Mr. Spiegel says one irony of the system is that, because the parents reared their children at home, they miss out on some of the full-scale support government extends to retarded adults who were brought up in institutions as children. But he argues that the founding parents of Opengate have proved wiser than government, and he invites anyone who challenges this to take a look around at the farm crew's fresh labors