

SECTION V. IDENTITY

RETARDED CHILDREN

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with
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You see the children first. An anonymous boy, about six, squeezes his hand through the opening at the bottom of a locked door and begs, "Touch me. Play with me." A 13-year-old boy lies naked, on his own wastes, in a corner of a solitary-confinement cell. Children, one and two years old, lie silent in cribs all day, without contact with any adult, without playthings, without any apparent stimulation. The cribs are placed side by side and head to head to fill every available bit of space in the room.

I have recently seen these children in the back wards of four Eastern state-supported institutions for the mentally retarded. Although I had visited these "homes" before--and scores of others like them during my 18 years as a member of long-forgotten advisory panels--I had paid little attention to their back areas. (Several colleagues arranged my tour through the places few but selected staff personnel ever see. With me was photographer Fred Kaplan, who would take pictures with a concealed camera.)

Now I know what people mean when they say there is a hell on earth.

The institutions I visited, located in three different states, are huge repositories for human beings. The largest contains some 6,000 adults and children. The smallest, about 1,000 of all ages. It is the sight of the children that tears at you.

Each of the dormitories for the severely retarded had what some like to call a recreation, or day-room. Groups of young children occupied them, lying on the floor, rocking, sitting, sleeping--alone. An attendant, silently watching, was the only adult in many of these rooms. Some had no adults at all.

The six-year-old who begged, "Touch me," was one of 40 or more unkempt children of various ages crawling around a bare floor in a bare room. Their dormitory held about 100 children. It was connected to nine other dormitories containing 900 more.

In one dayroom, two male attendants stood by as half a dozen fights flared in different corners of the room. Three teen-agers were silently punching each other near a barred window. One young child, about five, was biting a second boy. Another resident, about

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20, had backed a boy of about 10 into a far corner and was kicking him viciously, every now and then looking back at us. There were about 50 persons in the room. Their ages ranged from about 5 to 80.

Some dormitories had solitary-confinement cells. Attendants called them "therapeutic isolation." They were solitary confinement in the most punitive and inhumane form.

These cells were generally tiny rooms, approximately 7' X 7', shielded by locked, heavy doors. A small opening, covered by bars or a closely-meshed screen, allowed observation.

Some cells had mattresses, some blankets, some nothing but the bare floor. None that I saw, and I examined these cells in every institution I visited, had either a bed, a washstand or a toilet.

I found the naked, 13-year-old boy in one of these cells. He had been in confinement for several days because he had cursed an attendant. A younger child, at another institution, had been put into solitary confinement for five days because he had broken several windows.

I asked the attendant in charge of one dormitory what he needed most to supervise residents better and to provide them with a more adequate program. His answer: The addition of two more cells.

(These solitary cells are usually on an upper floor, away from the scrutiny of official visitors. A commissioner of mental health in a Western state, who had heard I was preparing this story for LOOK, called to ask if these conditions existed in his state's institutions. He is the chief mental-health official in his state.)

Children are tied down. I saw many whose hands or legs were bound or waists secured. (One boy, tied on the floor to a bench leg, was trying to roll away from a pool of urine. He could not.) The terribly un-dermanned staffs used binds as their ultimate resort. The attendant who asked for two new solitary-confinement cells was, with one assistant, responsible for an entire multilevel dormitory housing 100 severely retarded residents.

Almost in desperation, he asked me, "What can we do with those patients who do not conform? We must lock them up or restrain them or sedate them or put fear into them."

I felt at that moment much the same as men of conscience felt, I imagine, upon reading Dr. Johann Christian Reil's description of institutional problems. "We lock these unfortunate creatures in lunatic cells, as if they were criminals," that physician said. "We keep them in chains in forlorn jails...where no sympathetic human being can ever bestow on them a friendly glance, and we let them rot in their own filth." This, in 1803.

Every room in the living quarters of young children--and the moderately and severely retarded of any age--had a stout door and locks. Attendants routinely passed from room to room with a key chain in hand, locking and unlocking as they went.

Some of the children's dormitories offered "nursery programs." These were few and primitive. Several children in one of the "nursery" rooms had severe lacerations from banging their heads against walls and floors. When confronted with young, severely retarded children, many professionals believe head-banging inevitable. This is arrogant nonsense. Head-banging can be drastically reduced in an environment where children are not ignored.

Adults in these institutions fared no better than the children. Many of their dayrooms had a series of bleacherlike benches. Residents sat on them all day, often naked, jammed together, without purposeful activity or any kind of communication with each other. Countless human beings on rows and rows of benches in silent rooms, waiting for--what? One or two attendants stood in each room. Their main function was to hose down the floor periodically to drive wastes into a sewer drain.

Although men and women were kept in separate dayrooms, the scenes in each were the same. The odor was overpowering. Excrement was seemingly everywhere, on walls, ceilings. The smell was permanent and ghastly. I could not endure more than a few minutes in each room.

The physical facilities contributed to the visual horror. All of the quarters were gloomy, barren. Even the television sets in several of the day-rooms appeared to be co-conspirators in gloom: they were broken. (The residents, however, continued to sit on their benches, in neat rows, looking at the blank tubes.)

I heard a good deal of laughter, but there was little cheer. Adult residents played ring-around-a-rosy. Other adults, in the vocational-training center, were playing jacks. Although they were not always the severely retarded, this was the only way they were allowed to behave.

I was told, during one visit, about the development of a new research center. The assistant superintendent said "materials" would come from the institution, and the center would need about 30 or 40 "items."

I didn't know what he meant. After some mumbling, I finally understood. At that institution, and apparently at others in that state, patients are called "materials"; and personnel, "items."

It was so difficult not to believe that this man was joking that, during later visits to other dormitories in that institution, I asked the attending

physicians, "How many 'items' have you in this building? How much 'material' do you have?" Each man knew exactly what I was asking.

Each of the institutions was incredibly overcrowded. The one housing 6,000 had been built for 4,000. Beds were jammed so tightly together that it was impossible in some dormitories to cross parts of the rooms without walking on the beds. The beds were often without pillows. I saw mattresses so sagged by years and the weight of countless bodies that they scraped the floor.

Signs of gross neglect pockmarked many of the older buildings. I saw gaping holes in the ceilings of such vital areas as a main kitchen; in toilets, urinals were ripped out, sinks broken, bowls backed up.

I will not reveal the names of these four institutions. First, it would lead to the inevitable dismissal of the men who arranged our visit and photography. They want conditions altered as badly as we do. Second, I don't want anyone to think that we are discussing just these four "homes." They are the symbol of a national disgrace. These four institutions represent the current conditions in portions of the majority of state-supported institutions for the retarded in this country. This story arose in the hope that attention directed to the desperate needs of these institutions would help open the way to improving them.

Tax-supported institutions for retarded children and adults do not have to be like this. We know better. We can do better--if we want to. A pleasant, estate-like home and school, the Seaside Regional Center in Waterford, Conn., has shown us how.

Seaside resembles a private, and expensive, school. It explodes with noise, the healthful noise of activity, and with color--walls, draperies, decorations, wherever children are. It also explodes with the pride a person takes in doing an important job better than most.

Tim was one of Seaside's youngest admissions. Uncontrollable at home, he had been placed in another institution two years earlier. He was four when he reached Seaside, and helpless. He lay in bed all day. He could not walk or talk. He was totally unaware of anything occurring about him. His label from the earlier institution: severely retarded.

He began to get individual attention. He was taught to dress, to eat, to go to the bathroom. Slowly, words came and then steps. He was put into a preschool class at Seaside. Six months later, he joined a preschool class with children of average intelligence in Waterford. Last fall, he entered kindergarten, and 11 months ago, went home. He is now in first grade in his home community. His IQ, which leaped dramatically before he left Seaside, may yet move into the average range.

Chester, 12 when he came to Seaside, had already spent four years in another institution. He could barely talk. He trembled when anyone approached him. In 12 months, he was discharged. His IQ had risen almost one-third. He is now in public school for the first time.

A mother writes a note to Seaside superintendent Fred Finn: "... [after] a year...it almost seems like [our son's] rebirth." Another parent adds, "Betsy entered Seaside a year ago.... There had been much newspaper publicity about the terrible conditions in some state institutions for the...retarded. Seaside is the living proof that it doesn't have to be this way. My husband and I drove up to look the school over for the first time with a considerable amount of apprehension.... To our amazement, instead of shock and sadness, the strongest emotion in our hearts on our drive back was a feeling of joy. ...This was...a big, loving home. [... Betsy would not be] a number, but a very special person.... If I were to talk to parents who have just learned that they have a retarded child, I would tell them two things. First, don't be afraid to love and to get to know your child, no matter who advises you to the contrary. Second, don't be afraid to investigate your state institutions. You may be pleasantly surprised as we were. If you aren't, join those who are trying to do something about it. It can be done."

Each of these children came to Seaside from other state institutions, diagnosed as custodial cases. Each could have been groveling in the back wards of the four institutions we visited, had they been there.

Seaside is a clear break with the past. Opened six years ago as an experiment, it is a small, state-supported regional center designed to be a clearing-house for all problems involving retardation within a two-county area. It was the nation's first. It has been so successful that Connecticut has already approved 11 more like it.

Two hundred and forty men, women and children of all ability levels live at Seaside, a 36-acre complex of grassy-areas, buildings and woods on the shore of Long Island Sound. Everyone works at something, every day.

One hundred and sixty children attend school, half in the Waterford system and the rest in classes of five or six at Seaside. Forty, the most severely retarded, have daily activity and self-help programs. Forty young adults are getting job training. Some will move into the community and become self-supporting with little or no supervision. Others will stay at Seaside as paid, part-time employees.

Seaside reaches out. The panic that can crush a family unable to cope alone with a retarded child is relieved by the safety-valve role Seaside plays. Half of

its programs are in the community. The center helps 850 nonresident retarded children or adults and their families. It operates recreation programs in seven communities, day-care centers in five (for children able to live at home, but not eligible for school), two sheltered workshops and two day camps. There is no waiting list. No one is ignored.

Seaside, for the first time in this nation's history, has given parents alternatives to keeping an unmanageable child at home without anyone to turn to (more than half the nation's school districts have no classes for the retarded), or putting him into the usual institution, often for life.

Relatively few children must be placed in an institution. Most parents, in these cases, want to stay close to their children and to take them home as soon as possible. Too many institutions have built-in systems to separate a child from his family. Some, organized for the convenience of the staff, operate like prisons. When parents visit, for example, their child is brought to, and taken from, a common visiting room.

At Seaside, parents are virtually everywhere. They have no special hours or off-limit areas. They can come when they like, make special trips to feed a youngster if they want. Seaside will take in a child for a month to give her harrassed mother a chance to rest, or for a week if parents want to take a vacation trip.

This takes money. Seaside costs more than the typical institution. Nationally, the average cost in institutions for the retarded is less than \$5 per day for each patient. Six states spend less than \$2.50. Only seven spend more than \$5.50.

The Federal prison system spends \$7.67 daily to maintain each inmate. Our better zoos average \$7 a day for the care and feeding of some of their larger animals.

Seaside spends \$12 a day for each resident. In terms of human suffering and the potential for human growth, places like Seaside are among the few really economical, government-sponsored institutions I know.

Our nation's "homes" for the retarded contain thousands of Timmys and Chesters. Almost 200,000 persons are now in them. About 50 percent are under 20.

Conservatively, at least half of these young people could live and work in their communities if they were properly taught and if supervision were available. We spend about \$200,000 to support one person for his lifetime in a state institution for the retarded.

Seaside discharged 40 percent of its residents last year, about eight times the national average. Children went home and into public school, able to live within--not destroy--their families. Adults got jobs.

Seaside is proving that retardation is not unalterable. The capacity of a retarded person can be changed, up or down, within limits, depending upon the

way he is treated. Most retarded youngsters can be taught to support themselves. Intelligence is influenced by practice and training, just as it is enhanced, or limited, by inheritance, injury or environment.

Seaside wages a strong fight against inertia. Its staff has scant patience for tomorrow, for in a few short tomorrows, children become adults, and residents potentially able to develop can be transformed into stagnant inmates.

"We have no magic," says Superintendent Fred Finn. "We just do not believe that because a child hasn't, means that he can't. The children who have made remarkable progress...at Seaside after years of institutionalization [elsewhere] obviously had this potential, but...it was not developed. Each of these children is entitled to the best and the most my child gets. If one of them can do nothing more than creep, then he will learn to creep."

Teaching a retarded child with an IQ of perhaps 30, and a severe emotional problem, is like teaching no other youngster. You have to want to teach him. Then you have to fight with him for each micro-inch of progress. When you win a little, you glow. I had lunch one day recently in Seaside's dining hall with two teachers who were gloating because one seven-year-old charge had just, that morning, uttered his first comprehensible, one-syllable word.

A special love exists at Seaside, a love capable of belief in the fulfillment of another human being. I am exasperated with institutional staffs that have offered me excuses, rationalizations and explanations for their behavior. Although I am not unsympathetic about their inadequate budgets, over-crowded dormitories--leading to the concessions they make and the programs they conduct--their actions speak primarily of their character.

Mental retardation can bring out the best in healthy people as well as the worst. The retarded will not get the care and education they deserve until institutions cause those who minister to their needs to become more rather than less sensitive.

Some human beings have been taught to conceive of others as they think of animals. It isn't that some attendants are cruel--although, too often, they are--but that they have come to believe that those in their charge are not really human.

When one views a group of human beings as "material," an increased budget for resident care and additional staff alone could never cause the radical changes necessary in institutional treatment. The use of such terms demonstrates the basic problem that has to be solved before state institutions for the retarded will alter substantially: We must become more optimistic concerning human behavior and its ability

to change.

William James wrote, "The greatest discovery of my generation is that human beings can alter their lives by altering their attitudes of mind." The belief that intelligence is educable refers both to children and those who must deal professionally with them. For Helen Keller to have changed as she did, Anne Sullivan also had to. For children in back wards to change, their attendants must, too. To the extent we can influence the latter's concept of human potential, we shall influence the former's educability.

Every institution, including those discussed earlier in this article, has superb, dedicated attendants and professional staffs. Yet for so many of their residents, they could not possibly do any less than they now do. It is irrelevant how well the rest of an institution's program is being handled if these back wards exist. We have got to instill a fundamental belief among all who work with the retarded that each of them is equally human, not equally intellectually able, not equally physically appealing, but sharing a common humanity.

What can we do? We must at least double per capita expenditures in state institutions and reduce the size of these institutions. In addition:

1. In each state, a board of impartial institutional visitors should be appointed by the governor. This board would report directly to the highest state officials. Appointments should be without regard to political affiliation. They should be based on both knowledge of human welfare and demonstrated public service.

2. Within each state institution for the retarded, the staff of each department (e.g., medical, educational) should have its own board of advisers. This board, through regular visits, would know the institution's problems. Its members could become involved without endangering employees who trust them, because the board would not be responsible for ratings, raises or promotions. Problems now hidden could be given the exposure necessary for solutions.

3. In each state, one university should be given responsibility and resources to provide adequate refresher training and counsel to all institutional employees, from chief administrative officers to rawest attendant recruits.

4. In each state, at least one institution for the retarded should become a center for compulsory, periodic retraining of everyone employed by the state to work with the retarded. Each new employee should have to spend a specified period in the training center.

Few institutions for the retarded in this country are completely free of dirt, odors, naked patients, children in locked cells, horribly crowded dormitories and understaffed and wrongly-staffed

facilities. Countless people are suffering needlessly at this moment. The families of these victims of our irresponsibility are in anguish, for they know, or suspect, the truth. Unwittingly, or unwillingly, they have been forced to institutionalize their loved ones into lives of degradation and horror.

I hold responsible each superintendent, each commissioner of mental health, each governor--ultimately, each thoughtful citizen--for the care and treatment of individuals committed to institutions in their state. I challenge every institution in the U.S. to look at itself--to justify its programs, admission policies, personnel, budgets, philosophy.

I challenge every family of a resident in a state institution for the retarded, if it is dissatisfied with conditions at that institution, to protest immediately and repetitively to the governor and to join with other families to force legislative action.

The President's Committee on Mental Retardation reported in August: "Three-quarters of the nation's ...institutionalized mentally retarded live in buildings 50 years old or more." It demanded the virtual doubling of the full-time staff in these institutions "to reach minimum adequacy." Among its conclusions: "Many [facilities and programs] are...a disgrace to the nation and to the states that operate them."

We must have a national examination that will inspect the deepest recess of the most obscure backward in the least progressive state. A national, qualified commission with authority should review state budgets for the care and treatment of the retarded. Sincere state officials will leap to cooperate.

I will be surprised if this article will change the nature of state institutions for the retarded. My current depression will not permit such grand thoughts. But, as Albert Camus wrote: "Perhaps we can't stop the world from being one in which children are tortured, but we can reduce the number of tortured children."



SEX IDENTITY AS DRAWN BY A THREE YEAR OLD GIRL