

Part III: Reactions to Current Residential Models in the United States

Chapter 4

A Scandinavian Visitor Looks at U.S. Institutions

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A SCANDINAVIAN VISITOR LOOKS AT U.S. INSTITUTIONS

"to believe you are born with bad luck though you are merely born"
-Erik Lindegren, from "The Man Without A Way" (Mannen utan Vag), 1942.

Foreign visitors to the United States are likely to be impressed by the seemingly inexhaustible resources and wealth of America. Thus, a visitor who works in the field of mental retardation in another country would be inclined to expect that public institutions for the retarded are planned, constructed, and operated with the same thoroughness and lavish disregard for cost that appear evident in the planning, construction and operation of other facilities such as expressways, motels, hotels, skyscrapers. A visitor with such expectations is in for a rude shock.

In the last 2 years, I have visited a number of public institutions in several states, and on each occasion I have reacted with disbelief and bewilderment to what I saw. I found it difficult to understand how a society which is built on such noble principles, and which has the resources to make these principles a reality, can and will tolerate the dehumanization of a large number of its citizens in a fashion somewhat remindful of Nazi concentration camps.

Since my first visit to the United States I have seen the book by Burton Blatt and Fred Kaplan (Christmas in Purgatory. Rockleigh, New Jersey: Allyn & Bacon, 1967) in which the conditions I have alluded to above were described and pictorially shown. Actually, I can add relatively little to this description except to say that my observations are similar to those of Blatt and Kaplan. I must, however, take exception to the use of the word "Purgatory," and not merely because I observed worse things than those depicted by the hidden and horrified camera at work in that too-little-known book. Once upon heathen times, there was an image of the god Moloch, an Iron sculpture of a man, hollow, and made to be heated as a furnace. In the outstretched arms of this horrifying image of iron and fire, children were placed to be sacrificed for shallow reasons. Upon signals of the officiating witch-doctors and priest, the agonizing and sorrowful screams of the parents were solemnly and respectably drenched by the sound of trumpets and kettledrums. The image was placed deep down in a little valley 200 yards below what later was called Mount Zion. This place was named the Valley of Hinnom--thus giving the name to Gehenna, and later in slightly more enlightened times,, to Hell.

Erik Lindegren, who died in 1968, was a major Swedish poet of the 20th century and a close personal friend of the author (Eds.).

Below, I will briefly sketch some of my observations. Upon entering a certain building of Institution No. 1 in the North-Central state M, personnel could be seen supervising, through a glass wall, a huge L-shaped dayroom, each wing of which was about 20 yards long and 10 yards wide. The bottom of the windows of this room was at eye-level for an adult. On the large terrazzo floor were a few wooden tables and benches and a couple of metal carrousels. In this dayroom no toys were to be seen. Some of the children had their heads lying across the tables; others huddled on the floor along the walls, or in the darkest corners if they could. This was the only dayroom for the severely retarded residents of this building. The adjoining room was their bedroom, with 87 beds in endless lines. About 10 children were lying in bed, some with excrement in their hands and mouth. Only one person was working with the children, and she was a mentally retarded girl about 16 years of age. The majority of the children spent only a few hours each day outside the building for recreation or for training purposes.

In the special hospital unit for low-functioning children with medical complications, I found several children tied to their beds, with plastic nose-feeding tubes constantly fastened to their noses and hanging over the high bars of their cribs.

In another and new building at Institution No. 1, moderately retarded girls of ages 10 to 16 were housed. Most of these girls apparently attended a training program, but 40 of them slept in the same bedroom, and the huge dayroom was equipped with only a few benches and a TV set. This created a deadening atmosphere for the girls upon their return from classes or recreation.

Another building at Institution No. 1 consisted of two large dayrooms, one dining hall, and a large single dormitory with 104 beds for severely and profoundly retarded adult men; large unsheltered toilets, without doors, opened directly into the dayrooms; the dayrooms, also without doors, opened into the bedroom. Since many residents were incontinent, a huge ventilation system had been installed on high legs at one end of the dormitory to eliminate most of the odors. At the side of the dormitory were isolation cells for residents engaging in destructive and disturbed behavior. Each cell was equipped with a toilet and a wooden chair. On the floor of one cell, a naked man was squeezing his own excrement. I was informed that the number of attendants on this ward for 104 men was a maximum of three, and often only one. The number of chairs was not sufficient for the number of residents, and most of the men who were not sitting were walking aimlessly around, some naked, some half-dressed in very simple clothes. Few residents of this building leave the building or its fenced-in outdoor exercise areas.

One hundred twelve profoundly and severely retarded children, ages 5 to 12, lived in a building at Institution No. 2 in state N. Some had physical disabilities, and a few were bedridden. The children lived in dormitories with 23, 44, and 45 beds respectively; they had one large terrazzoed dayroom with about 30 to 40 chairs and one TV set. Most of the children received occupational therapy on the bottom floor of the building once a day, aided by two therapists. The personnel consisted of 28 persons during a 24-hour period, with 9 to each 8-hour shift.

In another building in Institution No. 2, 146 severely and profoundly retarded adult men lived in three bedrooms and one enormous, long dayroom with some wooden chairs. There was also a large fenced outdoor area which could be entered from the dayroom. About one-third of the residents left the building for occupational training a few hours a day. Walks outside the building and the fenced-in area were arranged three times a week. The residents were regularly served by 8 to 10 attendants during the day and by 5 during the night.

One superintendent told me about an institution in state O where a building for 180 moderately and severely mentally retarded males also had a fenced-in outdoor area. Ninety of the men were regularly led out to the fence, where they were attached with leather straps to the fence posts, their hands buckled to their waists with leather loops. They could move in a radius of only 24 inches, and along the fence there were a series of deep circles of that size.

The dayrooms at the various institutions described permitted only aimless and endless milling around or lying on the floor. No personal activity nor group interaction in any meaningful sense of the word was observed. Methods of feeding were often primitive and hurried. A superintendent told me about another institution (in state P) with 109 profoundly and severely retarded children living in four wards where one attendant has to spoon-feed 25 children in 75 minutes. Such a task can never be satisfactorily completed, as it consists of only three hurried minutes per child--the spoon clanking against the teeth.

The backwards as well as the regular wards of the large institutions I saw all had a uniform pattern: the large facilities with their often ceramic tile and terrazzo floors were seemingly constructed as extensions of the open toilet facilities. The construction seemed to make it as easy as possible for the attendants to mop up feces and urine from the floor. Organized activities, either individual or group, are out of the question in this type of setting; nor can the results of any training or occupational therapy activities be consolidated or reinforced in these dayrooms and bedroom settings. Retarded residents and attendants have little opportunity to interrelate in a personal and constructive way. In these wards, a mentally retarded person is mainly

left to contacts with other retardates who might be as withdrawn, confused, and insecure as he is--the single individual always is the outsider here "where one becomes one of the far too many" (Lindegren).

But it is not only the backwards that are too large. Even the so-called good wards, houses, or sections are too large, even though they are admittedly overcrowded and understaffed. Very often the sleeping halls are designed for 30 to 40 persons, and the inhabitants of two sleeping halls frequently have to share a single common dayroom. Even in brandnew institutions I have seen sleeping facilities arranged in two sections of 28 beds with only a wall between sections. Frequently, all buildings are of the same construction, irrespective of whether they are intended for children or adults, physically disabled or ambulatory, profoundly or mildly retarded residents,

Conditions like these allow for a minimum of social life, since few meaningful contacts between individuals are feasible. There is no privacy, and nothing personal is possible. Such wards offer only dehumanizing and impersonal life conditions. The persons living in these wards seem to be anonymous, having neither name nor number. They cannot count--tnuch less be counted upon.

Such conditions are shocking denials of human dignity. They force the retarded to function far below their levels of developmental possibilities. The large institutions where such conditions occur are no schools for proper training, nor are they hospitals for care and betterment, as they really increase mental retardation by producing further handicapping conditions for the mentally retarded. They represent a self-defeating system with shockingly dehumanizing effects. Here, hunger for experiences is left unstilled; here, poverty in the life conditions is sustained; here, a cultural deprivation is created--with the taxpayers' money, with the concurrence of the medical profession, by the decisions of the responsible political bodies of society.

I have been told that not all the institutions are as bad as some I have seen, or that within a given institution, good buildings and programs may be found as well as bad ones. However, I find this type of apologetics difficult to understand. Even the so-called good institutions or units are too far from a decent interpretation of the rights to life, liberty, and pursuit of happiness--and in the backwards these words are almost quenchable. Prejudice is built on the seemingly firm foundation of fear--but if society's fears of the mentally retarded had any firm grounds whatsoever, the walls of the wards would have been broken through long ago. Because they understand less, have less know-how and initiative, and are essentially too kind and inoffensive, the mentally retarded have not broken through those walls, not escaped from those wards. They would have broken out and been free long ago--if they were not retarded. Who and what devised "this abyss of the rat trap and the long hour of waiting"? (Lindegren).

A reaction to conditions such as I observed cannot be sufficiently described in general terms, nor can it be made constructively meaningful without a defined point of view. The point of view which I choose to apply will be referred to as the "normalization principle," and will be discussed in a later section of this book.