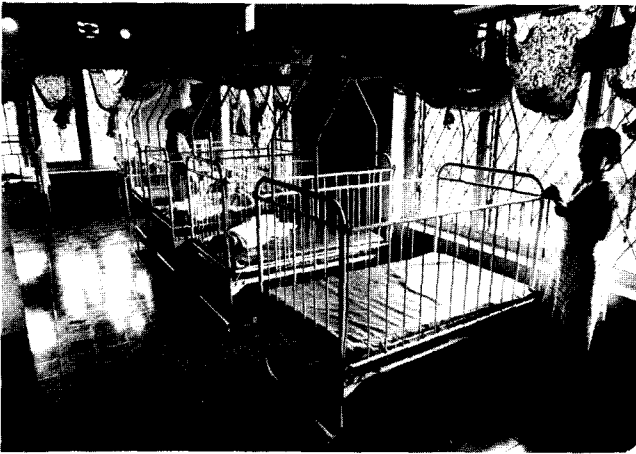


## THE LOYAL OPPOSITION

BY BURTON BLATT



Photographs by Andrejs Ozolins

## Rediscovering the Nineteenth Century

**I**ndonesia has but one residential facility for mentally retarded children, located near Jakarta, the largest city. Several months ago, before I went there for a visit, I had heard that the institution, like the country itself, was very poor and scientifically backward and that I should not expect to see much. I later learned that although the facts that I was told about this Indonesian institution were true, what I was led to believe about it was untrue.

Constructed from my notes from that visit, this is the "true" story, or as much of a true story as I can give, being a person who hardly knows the country, its history, or what the people think about themselves.

We were told that Indonesia is the fifth largest country in the world. If that was so, then how could it be that an ordinary-looking house for 16 children was the country's *only* institution for disabled children?

We were also told that this was our lucky day: the *rupiah* had been devalued by approximately one third and our hotel bill would, therefore, be reduced by a third. But if we were so lucky, then why didn't we feel lucky to be sitting in the back seat of a car that was taking us to an institution, the likes of which was more commonly seen in rural America 100 years ago? And as we rode on that bumpy, dusty road, with the windows closed to keep out the choking pollution which was so heavy, we hoped that our faces would not betray the anxieties which we were trying to keep in check. We didn't want to insult our volunteer guide.

The institution was built about eight years ago. Before that, nothing of a group residence was provided for handicapped children. (What happens to the thousands of others in this country who are very delicate and very handicapped? We mustn't rule out the possibility that some disabled children do survive this harsh environment and are cared for by family or others. And I also won't rule out the possibility that thousands of children die needlessly because there is no one to care for them or to fix their broken spines or malfunctioning enzymes.)

We were met at the door of the institution by the nurse in charge. She was an old woman, recently retired from a position in a general hospital. She was assisted by eight or ten young women who are also called nurses, but who probably don't have any formal nursing training. There was also an old man who serves as some sort of caretaker for the facility.

The main floor consisted of a couple of small dormitories, a staff dining room, some sort of a reception room, and possibly another small room or two. The cribs were lined up side by side. We went from crib to crib. One blind child was trying to get about by himself. He was the only child who seemed to have the freedom of the dormitory. We asked if he was being taught anything. No, there was no itinerant teacher of the blind to come to teach him—no Anne Sullivan for this child. We moved on.

In the next crib was a child with hydrocephalus. His enormous head tells us that there may be little hope here. Through Julie, our interpreter, we asked

the head nurse if a shunt operation had been attempted. We learned that not only was it not attempted, but such an operation was unknown. We moved on to a child with beautiful eyes who was lying in his crib, staring. He seemed to want to say something to us, but we don't understand Indonesian. We moved on to the next crib, and the next, and then to the next room. We asked about the rest of the institution, but they told us that was it. There was a second floor, which served as a dormitory for the nurses. We chatted for a few more minutes and thanked each other for the visit. We were grateful and they seemed very grateful.

In some respects, this institution was exactly like Willowbrook, Belchertown, Fernald, and the others. There was nothing here for the residents to do. It's a typical institution. But this institution smells sweetly—it's clean—unlike our institutions.

We were in an institution whose entire operating budget is 10,000 American dollars per year, less than \$700.00 per resident. And we returned to a land where yearly institutional budgets for 3,000 residents often run higher than \$75 million—\$30,000 per resident—and sometimes higher than \$90,000 per resident.

Of course, we know that the average Indonesian doesn't earn \$700.00 in a year, and even if he did, one cannot compare Indonesia to the United States in this regard. And we know that in America, children with hydrocephalus are afforded shunt operations to sometimes prevent the devastating effects of this malady.

Although we know that even 75 years ago in America, there was an Anne Sullivan for a Helen Keller, we know some other things too. We know that in our multi-billion dollar mental retardation system, children lie in beds unattended. We know that what happened between Helen Keller and Anne Sullivan was an official miracle. We know that institutions which spend \$50,000 a year per resident still send their clients to bed without proper food, still can't find ways to provide their clients with decent clothes, still have dormitories which stink. We know that everything is supposed to be better in the United States, and lots of things are better in the United States, but not so many things are better for severely and multiply handicapped children.

How could it be that in Indonesia, which hasn't yet discovered shunt operations, a country that spends only \$700.00 per year, per child in an institution, a country whose city streets stink, could have created an institution whose dormitories smell sweet? How could it be that a country whose dollar was devalued a third during the few days we were there, whose average citizen doesn't read, whose institutional superintendent doesn't have a college degree, who doesn't know about Braille, who doesn't know about peripatology, who doesn't

know about all the things which make life beautiful in the United States, can run a cleaner and more decent institution than we in New York State run?

There's going to be a howl about my assertions. There's going to be a howl from not only commissioners of mental retardation but even from some of my friends who will point out all of the flaws in this argument. But I wonder if there would have been a howl from Jean Marc Gaspard Itard, Edward Seguin, Maria Montessori, Samuel Gridley Howe, or Albert Schweitzer. Was it really as bad as we'd like to say it was before the dawn of science? Are we as good as we like to think we are, as we marvel at the wonders created during this modern era? Although science does a lot of good, perhaps it does good in such a narrow way that only very few people profit from it. Is the magic cure of science miraculous for only the few with PKU, RH, and the handful of others with specific and controllable conditions, while it ignores the teeming mobs? ■

Burton Blatt, Ed.D., is the Dean of the School of Education at Syracuse University. He is the author of *Christmas in Purgatory* (Boston: Allyn and Bacon, 1965) and co-author of *THE FAMILY PAPERS: A Return to Purgatory* (New York: Longman, Inc. 1979).



## PARENTS SEMINAR

Practical approaches to mobility and transportation for your child:

- physical limitations
- what to expect in his future
- cost
- his chances for adult independence
- what is available now

Seminars will be held on weekends at various national locations. Fees will include texts and literature.

Forward your request for applications to:  
Institute for Handicapped Transportation  
C/O Dr. William B. Campbell  
717 Kempton Road  
Knoxville, Tennessee 37919