

part 1

COMMON NONSENSE



DISABILITYLAND

“THERE IS NOTHING WORSE
THAN **AGGRESSIVE**
STUPIDITY.”

JOHANN WOLFGANG VON GOETHE

In one of the wards of the large state school, an attendant noticed that some of the severely retarded young adults had been chewing on the rugs and causing a bothersome amount of damage. What apparently wasn't noticed was the fact that this large, colorless day room, occupied for endless hours by an unchanging collection of semi-clothed individuals, had no books or games or other diversions. There was no opportunity for any kind of stimulation. Rug-chewing was it. The problem could have been easily solved. Bring in some amusements. Some educational materials. Let there be something to do. Let there be life.

That would have been the easy solution. The common sense solution.

The institution's solution was different. The institution's solution was to bring each and every one of the young adults to the institutional dentist to have all of his or her teeth removed. The rug-chewing problem was solved.

Then there was the other problem, a slightly more delicate matter. It seemed that some of the residents were discovering their sexuality. And they were using the trees and bushes of the well-tended grounds to find the only privacy available to them. This set off an institutional alarm. Something needed to be done. But what? Was it right for retarded young adults to know about sex? Was it right for them to experience it? Where does the responsibility lie?

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These are not small questions. They linger, largely unanswered, even today. But back then, the institution's first attempt at a suitable response was straightforward: They tore out the offending shrubbery. The only aspect of the institution that was truly beautiful—and truly cared for—was literally uprooted. It was as if the institution's response was, quite simply, "If you want to discover yourself in this way, fine. We don't quite know what to do about it. But you sure won't be doing any discovering behind our bushes."

In a similar institution, the problem was an increase in the number of pregnancies among mildly retarded women who, as a reward for appropriate behavior, were allowed off the grounds on day passes. It seems that some of the local men—the "townies"—were taking easy advantage of these vulnerable women. The institutional response was to implement a new policy whereby the women could no longer go into town on their own. Instead, they had to be paired with a buddy, another woman who had also earned the right to leave the grounds for a day.

Problem solved, the institution believed.

But not exactly.

Within four months, the pregnancy rate doubled.

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COMMON NONSENSE

Back in the late '60s, a good friend of mine lost a leg in a freak boating accident. A year and a half later, he was called to report to the draft board and, good citizen that he was, he went. With his right pant leg pinned up, he presented himself to the orientation interviewer and sat while she took down his name, address and other demographic information.

Midway through her note taking, the interviewer paused and appeared to be studying her clipboard. She then looked at where his leg used to be and asked, "Will this disability be of lasting duration?"

My friend, the good citizen, said nothing.

He stood up.

And hopped away.

* * *

Jimmy was 6 years old and deaf. His parents bought him a puppy. Three days later,

the parents discovered that the puppy, too, was deaf. They returned the puppy.

He sat on the middle swing all by himself, not moving. Just staring downward, occasionally banging a rhythm on his left leg. Waiting for a push? Waiting for friends?

His overalls were faded, the sleeves of his flannel shirt were frayed and one of his sneakers had fallen to the dirt. They called him **Billy**. He was 63 years old. They would soon bring him back to class to continue teaching him to write his name in script. Maybe they would succeed where the five previous decades of teachers had failed.

Everything about this scene was wrong to me. Why was this disheveled, overweight man left sitting on a swing meant for young children? Why was he alone and so unkempt? Why did his teachers, at least 40 years his junior, call him Billy?¹ And was there any point at all in

1: Let's say his last name was "Smith." As I watched him sitting on the swing, I wondered if he was *ever in his life* accorded the respect of being called "Mr. Smith."

teaching him—at his age, in this place—to write his name in script?

He was developmentally disabled and had lived in this state school all his life. He'd most likely die here. The only thing certain about his remaining years was that he'd never, ever, *ever* have an occasion where he'd need to write his name at all. Ever.

Never mind writing his name in script.

Many people do today what they did yesterday simply because that's what they did yesterday. Yesterday, they reason, was more or less ok. They act automatically. Unthinkingly.

They press on, trying to teach a 63-year-old man how to wield a crayon.

JUST ASKING.

Think of it, for a moment, this way. If the personal computer had been invented by someone paralyzed from the neck down, do you suppose it would have included a keyboard or a mouse as standard equipment? Or if the personal computer had been invented by someone who was blind, wouldn't it follow that the standard computer screen might have been available only as a special option for sighted users?

But the personal computer wasn't invented by people with disabilities. It was invented instead by some talented engineers who, like most people, had little or no personal experience with disabled others. As a result, obstacles were unintentionally part of the original design.

In most cases the obstacles weren't very big. But then again, the 2-inch curb on the sidewalk doesn't seem to be much of an impediment either.

Unless you're driving a heavy wheelchair.

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Years ago I published a book for young children. In it were color pictures of kids I'd come to know over a number of years, each of whom was diagnosed as retarded.

Out of the hundred or so photos, only a few included children with Down syndrome.

"How come you didn't include more pictures of kids who really look retarded?" the adults asked. "How come all but a few look pretty much normal?"

Understand that most of the children in the book had thick files attesting to their various developmental disabilities. These were all, if you will, bona fide retarded kids. But each one's photo reflected a moment in time no longer than 1/60th of a second. And in that instant, the faces that were captured were simply children's faces. Most charming. Most adorable.

Had these same adults seen, say, five minutes of videotape of the kids—their behaviors rather than just their faces—they'd have no question about the kids' problems.

But to them, the faces in the book didn't look like what they imagined the faces of retarded children to be.

Funny, I thought, that when an image of someone doesn't match the prevailing misconception, it must be the picture that's wrong.

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COMMON NONSENSE

For the past five years, it seems to me that every conference I've attended on "Education Reform" has been exactly the same.

There's something not right about that.

If the conferences don't change, what chance does Education *Reform* have?

I'm reminded of the teenagers who gather together to assert the importance of their individuality.

"Be yourself."

"Be who you are."

But even amid their odes to uniqueness, most of the teens are dressed almost exactly alike.

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“YOU WILL ALWAYS FIND SOME
ESKIMOS **READY** TO INSTRUCT
THE CONGOLESE ON HOW TO COPE
WITH HEAT WAVES.”

STANISLAW LEC

“This is a wise woman,” my hosts told me. “A very savvy mother.”

I shook her tiny hand. To me, more than anything else, she looked sad.

Several years ago, her son was born with one hand slightly disfigured. She demanded that it be amputated immediately.

She had lived all her life in this underdeveloped place and was certain that her son was destined to be a beggar. In her wisdom, she knew that a slight deformity wouldn't generate much sympathy. Or much giving. Without his hand, she reasoned, his begging would be much more effective.

Maybe today that boy is a poet or a programmer or a teacher. But I don't think so. I fear he's a beggar—no doubt a successful one.

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Onstage in front of hundreds of children who had gathered from around the country to celebrate exceptional young artists with disabilities, the blind celebrity recalled how he'd always been encouraged to pursue his dreams. His rhetoric was stirring. The crowd of children, themselves disabled, applauded throughout, especially when he came to his conclusion:

“So don’t let anyone tell you what you can’t be. Because you can be anything you want. Anything. If you want to be a teacher, be a teacher. If you want to be a doctor, be a doctor. And if you want to be an astronaut, then get going and become an astronaut. And don’t let anyone or anything get in your way.”

He thanked the admiring crowd and walked off the stage waving and smiling. He knew he had done a good job.

What he didn’t know and never will, is that at least 14 blind middle-school students felt completely betrayed. “We liked listening to him,” one of the girls said later. “We thought he was smart. And we thought he was funny.”

“But then,” said one of the boys, “he lied to us.

“Who does he think we are? We’re blind just like him. And if we know anything, we know—and so should he—that we’ll never be able to become astronauts.”

“But don’t you think that he just said it to get you thinking about your own dreams?”

“But that’s the point,” said the boy. “He said it. If he didn’t mean it, he shouldn’t have said it. He shouldn’t have reminded us of what we know we’ll never be.”



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The Commission had funded a study to see whether an underground subway station needed to be made accessible. The researcher descended two steep flights of stairs to the subway platform and, with his clipboard at the ready, he began observing. And counting.

He did this every day for two weeks.

When the final report was released a month later, the Commission was told that there was no reason to be concerned about the expense of accessibility renovations. In fact, the researcher reported, throughout the entire two-week period only one individual in a wheelchair had used the platform.

“And I don’t think it was really a problem for him,” noted the researcher. “His friends seemed content to carry him down.”

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COMMON NONSENSE

“NO ONE TESTS
THE DEPTH OF A RIVER WITH
BOTH FEET.”

AFRICAN PROVERB

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I was greeted at the entrance to Ward 3 by a smiling, middle-aged woman loosely wrapped in a bright, white lab coat. From one pocket hung a pen fastened with colored ribbon; from another, a ball of keys on a plastic chain. Her costume gave her the look of a surgeon or someone who works in a deli or a janitor. She was, in fact, the Associate Psychologist in this place for men and women with disabilities. She was to be my guide into the world of volunteering.

I was ready. I was anxious. Mostly I was naive. I wanted to be a terrific volunteer. I wanted to help people.

“Why don’t you read these files,” she suggested, “in order to get to know the patients?”

I was new here. No experience. Certainly no authority. So I didn’t question the inverted logic. I just read.

I read about presenting problems and about family backgrounds. I read of fluctuations in test scores and in weight. I read about diagnostic hunches, treatment courses, day-pass privileges and recurring behavioral episodes that certainly seemed, from the writings, to be annoying the staff.

In files whose unnumbered pages averaged more than an inch in thickness, I continued to read others’ descriptive phrases, others’ numbers, others’ assertions, others’ questions.

I was getting to know these others pretty well. But I had practically no feel at all for the people they were writing about, the people I could hear behind the locked door in the very next room.

I pretended to finish the reading by late afternoon. I got to know “the patients.” I’d get to know the people tomorrow.



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“COMMON SENSE IS NOT SO COMMON.”

VOLTAIRE