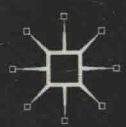
THE MEDICALIZATION OF AMERICA'S SCHOOLS

CHALLENGING THE CONCEPT OF EDUCATIONAL DISABILITIES

JOEL MACHT



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Thanks to Lee, Nancy, Jack, and Jon, the children at the Valley of the Sun, those at SEMBCS, those at Davidson Community, those I've met over these many years, and always my own, all my mentors.

And the Dragon, who with effort will be slayed.

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CHAPTER 1

From Educational Differences to Educational Disabilities

I made my way through grade school and high school in the 1950s and never once met face-to-face any classmate with more obvious challenges than a kid negotiating a crowded school wearing a sling to support a broken arm. If children who fared worse than my friends or me existed, I never knew about them, nor who they were, nor where they lived.

As a boy in the mid-1940s, I had my own scare with polio, but the high fever melted away without any trace of what annually frightened a large segment of the US population. I was too young to have understood what might have happened had the poliovirus established itself. Had I the words in those carefree days, I'd have described life as fair, decent, and thoroughly equitable. I'd have to wait until my 20s before my naiveté was ripped away.

Behavioral Psychology Laboratory; Educational Practices

It was the late summer of 1966. I attended Arizona State University, the doctoral program in psychology. Knowing few specifics of the recommended course, I drove into the desert to the psychology department's behavioral laboratory attached to a state-operated residential facility for children. The term "residential" had no special meaning, and I'd have done poorly on any quiz that asked me to describe who I expected to

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find living at the state's center. Equally eager and anxious, I parked on my side of an encapsulating linked fence built high enough to keep outside out and inside in. Standing under a spacious sky, I glanced at the residential center's bleak and vacant landscape. The effect was unsettling. I had expected groups of children running about, laughing, playing games, a park with swings and seesaws and a nearby duck pond.

They saw me first. Two of them, buddies standing side by side. Short-statured, they gawked at me, their faces flat and broad, their eyes oddly shaped, their mouths drooped lazily, their tongues wide and large and protruding. I judged they were eight or nine years old, with no assurance that my guess was close.

Unsettled by their look, I managed my best smile, told the boys my name and asked them theirs. Staring back, they remained silent. I thought they were waiting for me to say more. For someone who was an inveterate yapper, I was straightaway tongue tied, grateful the boys didn't ask me what I was doing on their property.

One stretched his fingers toward me through the fence, a universal invitation. When I touched his fingers, he smiled. "Thank you," I said with a sigh of relief. At once I wanted to be on their side of the fence. They were just kids—like all kids—with differences. Not liking the fence, or the boys' captive place behind it, I made small talk mostly to relieve my persisting unease.

I looked about and realized this was their home, day and night. It seemed a thoroughly inhospitable setting, desolate and disconnected, as if designed intentionally to keep itself out of sight, not unlike an embarrassing generational relic you'd hide from neighbors. I couldn't help thinking that it was not a proper place anyone should call "home." I looked at the boys. Was that what this off-campus course was all about? These youngsters? Someone's children? I wondered what I could do for them, something that might better their lives. Nothing came to mind, my earlier graduate training without any connection. That didn't sit well. With little confidence, I wished the boys a good day and headed toward a flat-roofed cinderblock building, my steps without their characteristic bounce.

I entered the behavior lab that would become my home for nearly three years. Within days, I switched programs to the Educational Psychology department to be mentored by one of its professors who co-directed the laboratory. Nothing about me would ever be the same.

The class consisted of six graduate students, and three renowned professors—a tipoff this wasn't a typical class. The initial lab lasted three hours.

The six of us sat in a semicircle within the one-story, cement-floored building. Black noiseless electronic recording devices covered one wall, and several enclosed cubicles with one-way windows were visible in the rear of the room. After brief introductions, the lead professor reminded us that the university's drop/add option remained available for three more days. It was clear the announcement was for our benefit. Only the professors and two senior graduate students who stood nearby knew what would soon take place.

Formalities and niceties concluded, we were led on a tour of several cottages all punctuated by a thick sweet smell as if the buildings' interiors had been deodorized to cover other smells. One cottage after another, we witnessed exceptional children the likes of which few people would ever see: children who watched a vinyl record spin endlessly on an antiquated player; children in wheel chairs who sat slumped and silent and by all appearances defeated; children who rocked ceaselessly staring at what only they knew; children who screamed and kicked at their cribs the moment we entered their cottage. None of the children spoke to us, not in words or functional gestures, raising the question whether they spoke at all. Few had the opportunity to move about. Most were confined to their undersized cribs, while others, removed from their cribs, were placed on the floor and secured by short tethers tied to a sturdy center post that supported the ceiling.

Two children wore boxing gloves to stop them from sucking on fingers that were raw. One boy walked the floor in a tight circle wearing a football helmet to prevent him from harming himself, we were told. (My earlier masters in clinical/counseling psychology failed to prepare me to fully grasp the phrase "harm himself." I'd be inalterably educated within the half hour.)

We returned to the lab in silence, the cottage experience numbing. We had been seated only moments when our attention was drawn to a young girl brought into the lab by a uniformed nurse who held firmly to the child's right wrist. The child was blonde, blue-eyed, skinny as a pencil, maybe six or seven years old, wearing a cute flowery dress. She walked on tiptoes as though she was dancing. She seemed very much alive and spirited. Her bright eyes suggested that she was happy, that she was in touch with her world and herself. Quite the contrast from the kids we had just seen. I offered her a smile, if not a tentative one. I had noticed that the nurse's expression was grim, the professors' as well.

A male graduate student who stood nearby moved forward and took hold of the child's right wrist, the exchange accomplished without a hitch—as if *any* hitch would have created a problem. With his secure hold

on the child's wrist, the graduate student walked the youngster over to where we sat. Impishly, she brought her face close to each of us, peering into our eyes as though playing some enjoyable but unnamed game. She never said a word, never responded to our offered greetings. As she was now in front of me, feeling her breath, I was taken aback by the pronounced half-inch line of uninviting white tissue that divided her forehead. It ran from her hairline to the bridge of her nose, the chalky line noticeably pronounced against her tan skin. I stared at the line without premonition.

"She's been with us for three years, her parents unable to care for her," the major professor began, his tone somber. *Unable to care for her* pinned me to my seat. She looked so easy, so pleasantly child-like. Something was terribly wrong. "You've seen the scar tissue," the professor said, telling me what I should have known. "We've yet to discover how to prevent her from hurting herself. When she's alone, her arms must be restrained. That includes all through the night and most of everyday," he said, revealing his own frustrations. "Notice the darkened tissue at her chin. With her arms restrained, she would smack her chin against her shoulder, if permitted. She wears a neck collar during the night to prevent further damage."

The professor explained nothing else. He invited us to join him at a six-foot wide one-way window that was hidden behind a curtain. The nurse immediately moved to a door that opened to a secretive room visible through the window. The room was padded, and the spongy floor and walls covered with battleship gray canvas. The graduate student, his fingers firmly circling the child's wrist, walked the youngster into the room, leaving the door open.

The child entered willingly as if familiar with its confines, its procedures, and her task. She was light on her toes. A hint of a smile graced her lips, her eyes filled with their familiar brightness. Her left arm remained quiet at her sides; her narrow shoulders were relaxed. She might just as well have been on a picnic.

The graduate student moved the child to the center of the room. A rope with an attached dowel handle hung from its ceiling.

"We've tried teaching her to use her right hand for other purposes," the professor said, speaking of the hand the graduate student held. "By pulling the rope with her right hand a certain number of times—with no exhibited self-abuse, she earns treats she enjoys. The treatment has not been successful," he stated without passion. "Watch her right hand," he directed. Without pause, his voice weary, he said into a hidden microphone: "We're ready."

"We're ready," the graduate student replied, speaking for the child as well. He took a small step from the girl and released his grasp, leaving the child in her own space, a moment to enjoy her freedom.

The child's right arm and hand lay softly against her side, the deception brief. Without warning or change of facial expression, she coiled her right hand into a menacing fist, what she had been doing since she was three years old. As if controlled by an outside force, she brought her fist against the center of her forehead, against the thin line of scar tissue—the sound like a forceful hammer against a block of wood. The graduate student instantly grabbed the child's wrist preventing a second blow. That fast, with her wrist in the student's grasp, the child raised herself on her toes, her childlike dance returned as did her docile expression. With blood streaming from her forehead, her eyes, as before, sparkled.

Stunned into silence, we watched the nurse stem the blood while the child stood relaxed as if unfazed. If she were unfazed, she was the only person in the room so blessed. The nurse escorted her from the laboratory, returning her to her cottage and the jacket designed to restrain her thin arms against her meager chest.

The lead professor waited for her to leave before he took his seat. He wasted no time testing our convictions. "Is this how we wished to satisfy our professional lives? Are we prepared to commit ourselves to the task of helping these children improve their lives? Are we up to the challenge? Are we reliable? The children will test your skills," he warned. "They will test your patience," he promised. "They will test your endurance; they will test your commitment; they will count on you." He gave each of us a long, penetrating look. "Do you have any questions?"

When none of us spoke, he smoothed his voice and directed us, "Go home. Give what you've seen a chance to settle. Not everyone's suited to this work. You will earn my gratitude if you feel it wise to drop this lab. It's best you're not here unless you're entirely dedicated. There are other courses to take. Keep the image of this child in your mind as you consider your future. Your decision may affect her future as well."

Too upset to return to my apartment or the library, I chose to walk the grounds, the images of the child swirling in my mind. Without purpose beyond moving, I entered a three-story, administration building, its confines quiet as if most everyone had gone for the day. Off a hallway, I noticed an opened door and took a cautious step into a generously sun-filled room lined with large windows. I expected the room to be empty. I gazed left and froze. It seemed fate or chance needed to press me harder.

A bedded hydrocephalic child, perhaps five years of age, lay on his back in the room's farthest corner, the boy's immensely oversized head propped heavily on two pillows. He stared at me through large dark brown eyes. I felt my anger rise. As if I needed more evidence, the sight of the child shredded my previous delusion of fairness. I gazed at the child, helpless not to. I simply couldn't fathom what had happened that produced this end. To what purpose? I asked.

All these years later, I can still see the boy staring at me. I will not say to you that when his dynamic eyes and mine locked together, his did not implore. Despondent, I wished him goodbye and left impassioned and determined.

From the lab-course's first days, we were taught precision and patience and the realization that a child's smallest accomplishment could form the basis of prodigious growth.

We knew what we were expected to do: engineer solutions to help each child become more accomplished and confident every day. Further, we were to hold ourselves accountable, that is, improving a child's life was our responsibility. That realization left an indelible mark. We were to reject explanations that amounted to non-functional answers, where it was stated that a child's lack of progress was due to a faulty brain or a genetic error, inferred dynamics over which we had no control. We were to be self-regulating. If a child failed to progress, we were to change our tactics. Inadequacy was never attributed to the child, always to our strategies. That platform demanded and emboldened.

After weeks of intense lecture and demonstration, we were assigned children and goals to reach. In time, children who couldn't walk, walked, not necessarily three flights of steps, but enough to go independently beyond their cottage to enjoy what others took for granted. Many children who hadn't talked, talked, enough to visit a grocery store where they could manipulate their world by saying, "I want orange; I want milk." Children who would never read, read enough to find their name from the names of ten other cottage mates, enough to find their own labeled toothbrush, to look at picture books and discover with delight a recognizable word that transferred to a real object. Every child was a challenge, every child a puzzle to unravel, always the goal to help a child become stronger and more skilled.

It was impossible not to come away from the experience feeling empowered, with skills that provided a great sense of optimism, a confident perspective that most any difficulty a child presented, where time was not

a yoke, was to some degree remediable. That attitude accomplished what was intended. It produced problem-solvers, not problem-namers.

As it was, I had become too comfortable, with theory and practice fitted within their proper location. I had left myself open for a confounding lesson with all the impact of a door slammed on a misplaced hand. Unexpectedly, life changed, and everything I had learned, everything I had prized professionally, came under challenge.

A Special School, Denver, CO

Shortly after earning my PhD from Arizona State, good fortune followed me to the University of Denver where I co-directed the graduate school psychology and educational psychology programs. It was the early 1970s, a time when fundamental and far-reaching changes were about to take place in both special education and general education, the results then felt no less than today. With my department head's approval, I accepted a psych-consultant position with a special school not far from the university's campus. To my great joy, it was as if the desert laboratory had moved with me to Colorado.

The facility was a cooperative school used by many surrounding school districts that sent us their most challenging children, thereby avoiding expensive duplication of services across districts. It made good economic and programmatic sense since the cooperative school assembled under the leadership of a forward-thinking principal several extraordinary speech and language pathologists, a remarkable physical therapist, and a company of outstanding special education teachers who were trained specifically for the complex children they served.

Our children were multiply handicapped, a fair term in those days—deaf and/or blind, self-injurious, speech and language involved, and orthopedically impaired. We had kids diagnosed with cerebral palsy, Down syndrome, and spina bifida, kids with infuriating, intractable seizures, children with inoperable brain tumors, and children with unusual genetic anomalies, some with devastating effects—e.g., Sanfilippo syndrome[1]—a metabolic disorder resulting in severe intellectual deficiencies and early death, the syndrome affecting several children from the same family, the youngsters and their parents always in my heart. We also served "idiopathic" kids, children whose symptoms had no known etiology—an *unnecessary* prerequisite to begin with in most instances. To my recollection,

there were no children described by their districts' special education directors as "autistic."

We did not choose which children attended the school. Districts made those decisions. We had no problem satisfying a district's request to provide a unique program for any of their severely involved youngsters. We had buckets of money thanks to a cryptic funding formula used to reimburse school districts for their low-incident handicapped children. We could hire whatever staff we needed.

Our staff-to-student ratio was enviable. Most of our classes contained a maximum of six to eight children. Several classes, for a brief time, had as few as three children. Each class had at least one teacher and an aide. Our classrooms were spacious and bright, and the children's large playground was appointed with safe-play equipment. We had a multi-purpose gym that during the day was never empty of kids, teachers, and therapists, especially the physical therapist.

The children, as diverse as they were, many with limited functional communication skills, mixed well with each other. While they were taught mostly in self-contained classrooms, they spent enjoyable times mixing together throughout the day. No child was isolated for any length of time from the others, and all the children interacted with our adult staff. More so, the children were visited continuously by college students and younger public school children, often both groups joining the special school's children in their classrooms, the visitors gladly put to work. With some license, the special children at the Colorado school experienced a variation on what special education knew as mainstreaming, a point that would soon take on special significance as the following "FYI" will describe.

(FYI **A**: **Inclusion.** As the 70s ended, the federal concept of "least restrictive environment (LRE)"—"a gauge of the degree of opportunity a person has for proximity to, and communication with, the ordinary flow of persons in our society,"[2] gained momentum.

FYI **B**: **An error realized and rectified.** It was often customary to place, for example, a non-verbal child into a self-contained classroom occupied by all non-verbal children, an administratively easy choice. It was soon realized that grouping the similarly challenged children together was a poor decision—if all the children were equally non-verbal, there'd be no opportunity to model a speaking child thus, at the least, limiting the possible acquisition of oral communication. Such glaring mistakes no doubt fueled the fair and reasonable vision behind LRE.)

School districts, whether or not they approved the government's plan, adopted LRE. They had no choice if they wanted federal monies. Within several months, much to the disappointment of staff and parents alike, the self-contained, specialized Colorado school was closed, a decision made by the feeder districts' special education administrators who were acting within LRE's guidelines. The children once served at the cooperative school were dispersed to their individual home schools to be immersed within the population of general education pupils, the belief being that such inclusion would benefit the special children.

Shortly after the Colorado school's closure, at the behest of a parent of a former cooperative school pupil, I visited one of the schools where half a dozen transferred children were placed within the general education population.

As it turned out, the public school's officials had assigned the group of former Colorado special school children to their own small classroom space at the farthest end of a long hallway. Their lunch and outdoor recess were scheduled early when there'd be no contact with any other students but themselves, for their own safety, school officials claimed. By any measure, the move from the Colorado school to the public school was decidedly more restrictive. The children were kept from the general population, an example of LRE gone wrong. (The parents I spoke with were understandably incensed and gravely disappointed.)

Professionals working at the special school were not bound by any educational or psychological theory or current wave. Everyone's attention was directed toward each child's individual growth. Interventions were based on careful criterion assessment that relied almost exclusively on direct observation and in-class data collection rather than from standardized test numbers measured and provided by district school psychologists. Being told that a child had an 80 or 180 IQ, or a child was mildly retarded, provided us nothing that translated into effective strategies.

We had fashioned an ideal service delivery model, flexible enough to accommodate any unexpected request. I remember a call from one of the local special education directors, a strong advocate for all kids. "I have this child," he began. "She's 5, nonverbal, and has little interaction with anything outside herself. She suffers severe seizures that are frequent and uncontrolled despite medications. Nice parents. They're hurting. Put something together," he said, knowing it would be done within days.

The model was solutions oriented. We had virtually no encumbrances, no administrative edicts to follow—though we were required to submit formal categorical names/labels for districts to receive reimbursements.