unsilenced

A Teacher's Year of Battles, Breakthroughs, and Life-Changing Lessons at Belchertown State School

HOWARD C. SHANE
Foreword by Doug Flutie

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by

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The events that inspired this book took place decades ago in the late 1960s. The author relied on memory, supplemented by journals, audio recordings, photographs, and newspaper accounts when writing this book. While the information in this book is based on actual events in the author's life, names and identifying details of certain individuals have been changed to protect their privacy. When needed, actual names and identifying details were used with permission. Events, places, and conversations in this memoir have been recreated from and inspired by the author's memories. Selected historical accountings that document conditions at Belchertown State School were also referenced. The chronology of some events has been compressed and altered.

The author and publisher have referred to numerous historical accounts, newspaper stories, and other published books, in addition to the author's own records, in preparing this accounting of life at Belchertown in 1969–1970. The story of *Unsilenced* is not told to disparage any one individual or institution, but to inform today's readers and future generations so that a better life and more opportunity can be ensured for all people, with and without disabilities. If a reader feels there may be an error in a statement made in this book, please contact Brookes Publishing Co. at rights@brookespublishing.com to share that information.

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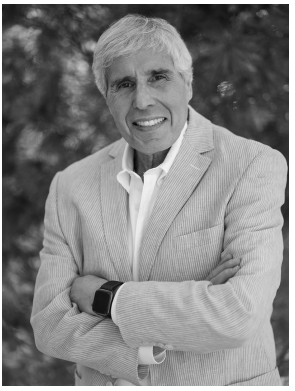
ABOUT THE AUTHOR



Howard C. Shane, Ph.D., is Associate Professor of Otology & Otolaryngology at the Harvard Medical School and Director of the Autism Language Program at Boston Children's Hospital. He has designed more than a dozen computer applications used widely by persons with disabilities and holds two U.S. patents. Dr. Shane has received Honors of the Association Distinction and is a Fellow of the American Speech-Language-Hearing Association. He is the 2019 recipient of the Frank R. Kleffner Lifetime Clinical Career Award. Dr. Shane received the Goldenson Award for Innovations in Technology from the United Cerebral Palsy Association and has authored numerous papers and chapters on severe speech impairment, lectured throughout the world on the topic, and produced numerous computer-based innovations enjoyed by persons with complex communication disorders.

CHAPTER 1

I glanced quickly in my rearview mirror. My vintage car was beginning to fall apart, and I needed to extend the life of the turn signal required by the state to pass inspection. Spotting no cars behind me, I made a sharp right turn without signaling off Route 21 and onto the grounds of Belchertown State School.

It was an early September afternoon in 1969. I had graduated from the University of Massachusetts, Amherst, that spring with a major in sociology and a minor in education. I was a typical college kid, moving from one step to the next without much forethought. After a congenital neck condition—exacerbated by an old football injury—delivered me from the Vietnam draft, I decided to find a teaching job. One of my fraternity brothers heard about a teaching position in this institution for people with physical and cognitive disabilities just ten miles outside Amherst, and after a mail-in application and a telephone interview, I'd landed the job. I would later learn that teachers actually seeking work at Belchertown were in short supply.

Belchertown State School was one of several facilities for people with intellectual disability. Historically, it had been called the State School for the Feeble-Minded, and it was operated by the Commonwealth of Massachusetts. I learned that these facilities, dotted around the state, were generally named for the small rural communities in which they were located, so in Massachusetts we had Belchertown, Monson, and Wrentham State Schools. I knew almost nothing about teaching or about people with disabilities, but I was glad to have a job and eager to get started.

This institution, and ones like it throughout North America, existed because separation and segregation were the norm at the time for people with disabilities. The birth of a child with a disability was often greeted with social stigma, and confused parents were typically advised to put their children away in the care of a state or private institution and forget about them. I came to learn that the parents who made this decision were mostly not uncaring people, but were themselves victims with little information and few options. The challenges of raising a child with a disability seemed insurmountable, with no resources from the state and no doctors

or religious institutions to help them find their way. State institutions like Belchertown were intended to be humane solutions to the painful and awkward problem of accommodating people who would seemingly never fit into normal society.

I drove slowly along a paved roadway surrounded by well-kept lawns and a scattering of large maple and oak trees. The gently rolling terrain was typical of rural, Western Massachusetts. There wasn't much difference between these grounds and those of any beautiful college campus or country club, but I felt an unusual awareness of the space, a prickling in my neck, despite the lovely setting.

I'd given myself plenty of time to make mistakes in the unfamiliar drive, and now I was early for my appointment with the institution's academic director. I turned off my radio and stopped near a groundskeeper who was down on one knee trimming grass, his blue work shirt thrown on the lawn in the late summer heat.

"How ya doin'?" I yelled out. "Can you tell me where to find the school building?"

The fellow stood up slowly and exchanged the clippers in his hands for his long-sleeved shirt. With the radio off, I thought I heard distant calliope music as he approached my car, but I dismissed it because it seemed so out of place.

"Drive straight ahead, and don't take either of the right or left side roads you come to. When the road begins to curve to your left, you look to your right, and the big brick building with the stone steps will be the one you're looking for. There's a parking lot just past the building. Can't miss it."

"Thanks," I said. As I started to pull away, I heard the music again. I turned back to ask where it was coming from.

He pointed toward a pretty meadow off to the right, on the other side of which stood a one-story steel building at the top of a knoll. "Up there at the merry-go-round. See that building at the top of the little clearing?"

"Must be fun for the kids," I said. As I drove forward, I could see one wooden horse after another through the large opening at the front of the building facing the meadow. Children sat on the brightly painted mares and stallions, some bobbing up and down and others sitting stationary.

Still half an hour early, I parked my car alongside the road and started walking across the mowed field to get a better look. Off to my left, a platoon

of over a dozen women were advancing up the knoll on their way to the carousel, dressed in mismatched and ill-fitting clothes. Most sported an identical hairstyle, a bowl cut just below the ears with Dutch-boy bangs sliced straight across the forehead. Rather than walking along with swinging arms, they each marched with one arm extended forward and the other back, touching or nearly touching the person in front and behind. From my vantage point, they looked like a string of paper dolls being propelled through the field by a gentle breeze.

I realized I had misjudged who was riding the merry-go-round. The people who appeared to be children when viewed from a distance were actually adult men. They looked a bit disheveled because their clothes were wrinkled and mismatched, but their faces revealed a definite look of contentment. There was something unnerving about the sight of adults—regardless of their intellectual abilities—being entertained with a ride intended for children, but I knew as a neophyte and outsider I had a great deal to learn.

I walked back to my car and drove on according to the groundskeeper's instructions, but my mind lingered on the peculiar image of adults gleefully riding a merry-go-round with no actual children in sight. Finding the gravel lot next to the two-story brick school building, I parked and then climbed the wide granite steps that led up to a landing at the front entrance. From there I turned and looked back across the grounds. It really was a beautiful day, with a nearly cloudless sky. The bright afternoon sun was warm but not uncomfortable. And yet... something was wrong. People... where were the people? The only living creatures I had seen were the groundskeeper and the handful of adults at the carousel. I knew that nearly two thousand people lived at Belchertown, but the place looked mostly deserted. The setting was orderly but empty. I was beginning to feel like I was in an episode of *The Twilight Zone*.

At the top of the stone steps sat a handsome young man of about twenty years of age, not much younger than me.

"Hey—can you tell me where I can find Mrs. Sharp's office?" I asked him.

He looked up and cupped his hand over his eyebrows to shield his blue eyes from the sunlight. "You Mrs. Sharp! You Mrs. Sharp!" he loudly blurted out.

I looked at him more closely. He wore an ordinary white t-shirt and loose jeans that partially covered a pair of black patent leather shoes. His hairstyle alone should have been a dead giveaway that he was not a worker taking a break but rather a resident just killing time. His dirty-blond hair was cut at one length just above his ears, the rest cropped closely to his scalp—similar to the hairstyles of the women I'd seen parading toward the carousel.

"Leo, what are you doing here?" snapped a sharp female voice. "You know you're supposed to be in your building!"

A matronly woman strode out onto the landing. She wore a brown flowered dress and heavy black leather shoes, and her face was pinched into a scowl. At her words, Leo jumped up, scurried down the steps, and darted off around the building. "I'll be with you in a moment," she said to me smoothly, and then turned and hurried back into the school building, yelling, "Alert security! Leo's on the loose again!" I heard the striking of her leather soles on hardwood and the echoing of her shouts as she disappeared down the long hallway. When she was out of sight, I decided to try to track down Leo myself. As I came around the corner, I caught a glimpse of his white shirt as he slid behind a huge oak tree. He was mostly hidden at the angle from which I approached, but as I circled around, I saw he was splayed frozen against the tree.

A security officer emerged from the school building and marched right to Leo's hiding spot. "Okay, Leo, I see you. It's time to go back to B Building." The guard reached out and grabbed the young man by his arm, then marched him back toward the school. "Son, this needs to stop," the panting guard said. "I'm getting tired of chasing after you."

I was curious how the security guard knew with such precision where Leo tried to hide. I had only to turn and look up at the school building for an explanation. There I spied the matronly woman from the steps staring down from a large first-floor window. The moment our eyes met, she drew back and vanished. I started back toward the school building for my appointment with Mrs. Sharp, feeling pretty confident that we had actually just met.

As she opened the main door to the building, she introduced herself as Mrs. Dorothy Sharp, Academic Director for Belchertown State School. "Now, that made for a rather inauspicious beginning to your tenure with us, Mr. Shane," she offered.

"What's the story with him?" I asked, recalling Leo being led away. "He looked pretty scared. He won't be punished or anything, will he?"

"Leo?" she said, then paused. "He's not in your class, so he's not your student, and if he's not your student, then he's not your concern," she responded with finality as we entered her office. Slipping behind her desk and sitting down, she continued: "Belchertown State School operates efficiently because everyone follows rules, without which there'd be chaos. We need to operate as a rule-based, fine-tuned machine for the safety of all the residents." She looked at me for a moment. "Now, on to why you're here. You have to keep in mind that while we run a school, this institution is also a lifelong residence for everyone who lives here. That is why you'll see adults as well as children who live and are educated here. I'm proud to say that our educational program is a model for the entire state school system. You will be working with both 'trainables' and 'educables.' Many of them are crippled, as well." She gazed at me with such intensity I squirmed in my seat. "What has been your experience working with crippled children?"

"Very little, actually, but I'm looking forward to learning," I said. At this point, I was just relieved that I didn't have to admit I had no experience with "trainables" and "educables," whatever they might be. I'd had a semester of student teaching in history at Amherst High School during college, but that was the extent of my teaching experience. I'd learned nothing in school about working with children with disabilities, and other than a few visits to a family friend with Down syndrome, I'd never spent any time around people with disabilities. I knew what Mrs. Sharp meant by "crippled," but I hadn't thought the word was used anymore. I could guess, of course, what the other labels meant. I cringed at how dehumanizing they sounded. The word "demeaning" came to mind. I had to school my expression as she continued.

As Mrs. Sharp spoke, she leaned slightly forward and never took her eyes off me. The intensity of her posture and unwavering facial expression made me uneasy. If she was attempting to use body language to prove who was boss, she was succeeding.

"School officially starts next Monday, so you will have a few days to get oriented. Most of our classrooms are in the school building, but you have been assigned to teach in the infirmary. We'll take a tour of that building shortly, but I just want to say a few words about your assignment. The

infirmary houses young and adult residents who require medical attention, many of whom are confined to wheelchairs or spend their days in bed. Most of your students will not be able to walk, and many don't talk. Your classroom is in the basement, but the students live on the two floors above." Without missing a beat, she asked, "Do you have an educational philosophy as it applies to the retarded?"

The word "retarded" also made me cringe, but I moved on. "Well, this is my first job, so I'm not very experienced, but I'm certainly eager to learn. As far as philosophy, I guess I would have to say that everyone learns and excels when doing something of strong personal interest."

She stopped me before I could continue and asked if I thought that idea applied to "retarded children" as well. I was lucky she'd interrupted me because I didn't have much philosophical fuel in my tank. However, I did suspect that personal motivation was indeed important for children—with or without disabilities—and I was comfortable reiterating that fundamental principle to her.

Without another word, she pushed a thin spiral notebook across her desk in my direction. "We have only a few days before school begins, but I thought you should look at this curriculum guide."

I picked it up, nodded silently, thumbed through it quickly, and moved to tuck it into my briefcase. As I fumbled with the latches, it might have become obvious to Mrs. Sharp that I was a briefcase neophyte. Truth be told, this was my first day lugging around a briefcase. Even that morning I wondered whether I was actually trading up when I grabbed it and not my battered backpack.

At that moment, the phone rang, and Mrs. Sharp picked it up before the first ring had ended. "That's all right," she said, staring out the window. "He can stay in his room for a while. He'll be fine."

I assumed the call was about Leo, but I knew Mrs. Sharp wasn't about to clarify anything for my benefit.

She hung up the phone and turned back to me. The room was silent except for the strumming of her manicured fingernails on the desktop. After an awkward moment, she folded her hands together in a manner which seemed to indicate that she was ready to move onto a new topic. "I think this is a good time to review some school policies. I'm referring to the rules I've created so that the education department remains on course. As

I said, rules are intended for the safety of the residents and to allow me to keep track of staff performance. I'm sure you understand that."

"Yes," I responded, wanting to seem agreeable.

"The first rule is," she began, "school begins at eight a.m. sharp and ends promptly at two p.m. Teachers usually arrive by seven thirty. I assume that works for you."

I nodded.

She signaled her approval with a small smile and a raised eyebrow, then leaned toward me and, punctuating each word, said, "Number two, never, never, never, ever transport a student in your car."

"Makes sense to me," I said.

"Rule three: Do not allow more than two students at a time in the elevator that brings students to your classroom—and I mean never."

This one confused me. I wondered if it was a problem because of the weight of more than two students or perhaps some state regulation that I wasn't experienced enough yet to understand. I wanted to ask her to clarify, but Mrs. Sharp barreled on with the next regulation. "Rule four: Residents are rarely allowed to leave the grounds for field trips, shopping, or visits to private residences."

"Quick question about this."

"Of course."

"Mrs. Sharp, are you saying that no one ever leaves?" I asked politely. I was sure that there must be safety and liability issues, but I felt uncomfortable with the suggestion that people who lived there were essentially captives. The finality of a no-leave policy suggested for me a life sentence without ever having committed a crime.

"Well, of course some people occasionally get to leave. They can go with family, and some do—especially for holidays. Long-time volunteers who become attached to some of our residents can request to take a person out. Just to be clear, the residents aren't exactly in lockdown, but we certainly do not have a come-and-go policy, and permission needs to be granted." She paused briefly. "Our door-locking policy comes next. It's pretty simple, actually. The rule is if you open it, lock it. Remember, that applies to every door and every cabinet."

She rolled her chair back, signaling we were through, and as she shifted her focus to the side drawer of her oversized wooden desk, I felt my

shoulders relax. I hadn't realized as they crept closer to my ears throughout the conversation. I was simultaneously intimidated by her brusque efficiency and suspicious of her callous discussion of the residents.

She rummaged in the drawer of her desk, retrieved a set of keys, and slid them across her desk to me. The key ring contained three keys and an oval brass plate engraved with *Belchertown State School 836*. She explained that the large skeleton key fit the main doors of the infirmary building. The other keys opened my classroom and got me into cabinets and desk drawers.

"Lastly, we have a mandatory monthly staff meeting. There are eight teachers based here in this building who teach about eighty residents. That staff meeting will include you even though you will be teaching in the infirmary rather than in the actual school building. The non-infirmary students can walk and don't require constant medical attention."

"Mrs. Sharp," I said, "is there a dress code for the staff?"

"Well, you won't be required to wear a tie, if that's what you're asking. Now, of course, you might from time to time see Dr. Bowser, the superintendent, in the building, but he isn't actually part of the school department. You'll know him because he normally wears a coat and tie—a rare fashion statement in this institution." This line could have been interpreted as a joke if she'd cracked a smile, but I was getting the feeling that Mrs. Sharp was the furthest thing from a joker.

Given the events of the day, I was beginning to suspect that these staff meetings would take me to foreign territory. I was a little overwhelmed and frankly uncertain that I had the right training for my position or for any position at the institution. It was sinking in that I had taken a full-time job for which my education hadn't prepared me. Now that I was actually at the school, I knew I hadn't—and likely couldn't—have anticipated the difficulties and conflicts that would arise in a state facility where people were seemingly prisoners. I didn't want to discuss much more about teaching until I at least had the opportunity to meet my new students and see my classroom.

As if reading my mind, Mrs. Sharp stood, retrieved a large black leather pocketbook, and moved toward the door. "Then we're off to visit the infirmary," she said. When we got to the bottom of the steps, she asked, "Do you mind driving? My husband has my car today."

"Not at all."

As we approached my car, I was startled to see a tiny smile tug at her lips. "You drive a... isn't this a taxicab?"

"This isn't just a taxi, Mrs. Sharp. This is an authentic British taxicab." I loved this 1951 black Austin Taxi, with its right-hand drive, jump seats, and glass window separating me from any passengers. I could count on lots of space for friends and lots of people staring when I drove past. I'd never been afraid of being a little different or standing out in a crowd.

I opened the large back door, and Mrs. Sharp shifted her black pocketbook to climb into the spacious back seat. I slammed her door shut, jumped into the front seat cubicle, and slid aside the glass divider.

Before I spoke another word, she said, "Straight ahead."

The infirmary stood about a hundred and fifty yards down the road from the school building, so the trip was brief. The campus itself consisted of ten dormitories for men and women and three nurseries for children under the age of six. To care for the considerable residential population, there was also a laundry building, kitchen, storehouse, hospital, private housing for staff, a power plant, and, of course, the infirmary. The school opened in 1922, built on eight hundred acres of former farmland. It surprisingly still operated a farm, which supplied a fair amount of the institution's food and employed some of the residents. It was a self-contained community that kept the residents safe but separate from the nearby town. The two-story infirmary, like most of the other buildings on the grounds, was constructed of red brick. Wings extended from either side, flanking the main section, each ending with a porch enclosed by screens to keep the insects out and black iron bars to keep the residents in. INFIRMARY was inscribed over the main entrance.

We were greeted by the frantic cries of a lanky redheaded teenager with freckles that covered his entire face. "Can I ride in your car?" he yelled from a clump of bushes in front of the left wing of the building. I knew the boy had Down syndrome because as a child, I had often visited Sam, my aforementioned family friend. Sam, who also had Down syndrome, lived in a noisy, smelly nursing home, and even as a young kid, I had felt sad that he had to endure a life of loneliness in such wretched conditions, spending most of his time staring out the window.

This boy's hair was cut in a shorter version of the bowl style. He wore a long-sleeved shirt with multicolored horizontal stripes tucked into pants

that looked clean but were extremely wrinkled. His zipper was down, and the hem of his shirt stuck out through it.

"No rides today," I said as he approached the car.

"Jimmy Kearns, zip up your pants and go wait for us over there." Mrs. Sharp pointed toward the front door of the building. Jimmy's demeanor quickly changed from delight to nervousness as his head went down and his zipper came up. "Do you know what he was doing behind that bush?" Mrs. Sharp inquired.

"I think so," I answered without hesitation.

"There is a lot of that going on here. What do you know about curbing such behavior?"

I indicated that I would look into it. In that moment, an unsettling understanding of the real-world problems I would have to face and solve in my new position began to creep into my mind. Here was a behavior, masturbation, that most young men would consider normal—in private, of course. But here, the residents had no privacy unless they snuck out and hid in a bush or behind a tree. This was my first inkling that very normal sexual behaviors were seen as deviant under pretty much all conditions here, and that controlling, not normalizing, the behavior was the goal at Belchertown. A normal act was abnormal at the institution, whether private or not, and it would be part of my job to determine a way to control it. I was extremely uncomfortable with the knowledge that I would likely have to find a way to influence or control the sexual behavior of other men or women.

She suggested, "Perhaps you might consider dealing with this in your classes this year. How about doing it as part of sex education?"

Jimmy approached us as we moved toward the infirmary, putting an end to the uncomfortable discussion.

"Jimmy, say hello to Mr. Shane, the new teacher," offered Mrs. Sharp pleasantly.

I asked, "Do you live here, Jimmy?"

"Me live in the infirmary. Can I ride in your car?"

"I don't think that's a good idea right now, Jimmy."

Together the three of us climbed the steps to the heavy door of the infirmary, where I entered a world I could never have imagined existed.

A SPELLBINDING MEMOIR OF A PIVOTAL ERA IN DISABILITY HISTORY

The year is 1969, and fresh-out-of-college Howard Shane has just landed his first teaching job—at Belchertown State School, a bleak institution where people with disabilities endure endless days of silence, tedium, and neglect.

Howard is stunned by the conditions at Belchertown and the challenges of his new job, but as he gets to know his diverse, endearing, and intelligent students, he becomes consumed with a mission: to unlock their communication skills and help them reach their full potential. Pitting his youthful idealism and passion against the rigidity of a rule-bound administrator, Howard battles his way to small joys and victories with his students—and, along the way, learns just as much as he teaches.

Unsilenced is a candid look at a pivotal era in disability history and a deeply personal account of how all human beings can flourish when we care for each other and fight for change.

ABOUT THE AUTHOR:

Howard C. Shane, Ph.D., is Associate Professor of Otology & Otolaryngology at the Harvard Medical School and Director of the Autism Language Program at Boston Children's Hospital. Dr. Shane has published widely and lectured throughout the world on inventive ways for persons with disabilities to communicate. He has designed more than a dozen computer applications and holds two U.S. patents.

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