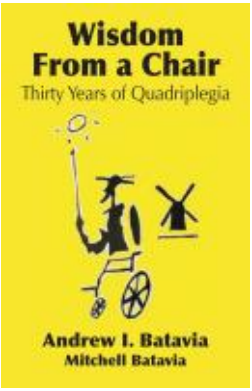
Wisdom From a Chair

Thirty Years of Quadriplegia

Andrew I. Batavia

Mitchell Batavia



In his memoirs, Wisdom from a Chair, Andrew I. Batavia shares the knowledge he acquired while living with a high-level spinal cord injury in a wheelchair, describing a life transformed from a quiet, conforming teenager to a Don Quixote of the disability community. A Harvard-trained lawyer and activist, he was a pioneer in the right-to-die debate, and wrote regulations for the Americans with Disabilities Act of 1990.

Wisdom From a Chair: Thirty Years of Quadriplegia – The Memoirs of Andrew I. Batavia

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Cover art: Don Quixote mounted on a wheelchair and fighting the windmills of injustice. Artist: Mitchell Batavia

Chapter 2. Preparation and Disaster

I was at the top of my game. I just celebrated my sixteenth birthday, completed my sophomore year of high school with pretty much straight As, finished my first marathon in good time, and had a very attractive girlfriend. I would be applying to some of the top schools in the country the next year, and I expected to be accepted by my top choices. The only thing I did not have was a job to pay for all the expenses I expected would be cropping up in the next year or so. I had no idea at the time what an impact my first job would have on my life.

Pursuing First Employment

In fact, I had never had a job. This was not because we were rich, which we were not. My family, with both my father and mother working, had an income that was average in our middle-class Yonkers community. We certainly had more than some, but much less than others, and I cannot remember a time in which money was not tight. However, my parents knew their priorities, and the top priority was for me to study hard and to maintain a good social life. They would not have allowed me to work during the school year if I had wanted to, and I gave no indication that I wanted to.

I do not like to think of myself as having been spoiled, but I suppose that must have been the way it appeared to some of my fellow students who did have to work part-time to help out their families. Some of them had a variety of jobs and consequently had some disposable income, which meant money in their pockets for things they wanted. This seemed to me to be a desirable thing.

For example, two small Italian cousins had a job in which they delivered betting sheets before the weekend, collecting the appropriate amount of money and paying off the winners at the beginning of the next week. This seemed like good work, if you could get it, which you could not unless you had the right family connections. Nepotism is a bad thing! I am not sure whether I thought through my jealousy of these guys; although this did not appear to be a very difficult job, a single arithmetic miscalculation could result in several broken bones.

The concept of having disposable income was very powerful, however, and my parents' prohibition of employment did not extend to summer work. One day, I went to school and saw a tiny notice on the bulletin board that said simply: "Job in summer camp. Call xxx-xxx-xxxx." I thought to myself, This is something that I am actually capable of doing. Along with my brother and sister, I had gone to summer camp for a number of years. I knew basically what a counselor was required to do, and I could do it. I went home and called the number.

The live voice on the other end of the line said something like, "Thank you for calling." Then the person asked if I was aware that this is a camp for children with severe intellectual disabilities. All of a sudden, I developed a distinct stutter that I never knew I had, and hung up the telephone fairly abruptly. I never really thought about working with anyone with severe

disabilities before, and working with children with severe intellectual disabilities did not seem as easy as serving as an assistant bookie.

But then I thought about it for a while. I really was not qualified to do anything, and a "normal camp" would probably not hire a sixteen-year-old boy, which was basically what I was. Then I started thinking that this could actually be the first important thing I had ever done. And it certainly did not sound boring. I decided to call the number again, this time better prepared for the conversation.

The Question of Fate

In the previous chapter, I use the term "fate" in stating that I would not be able to complete some of the things I started in high school. The notion that all things are preordained, and therefore out of our control, is somewhat offensive to me. It really takes away the whole purpose in living, because whatever you think you've chosen to do actually would have been predetermined by fate. So whether or not we are destined by our fate, I choose to reject this notion. (Of course, I recognize that my choice not to recognize fate itself may be dictated by my fate, if I'm wrong about this.)

In any event, while I do not believe that my every action is determined by fate, I do believe that certain things in life are meant to be. I believe that I was meant to work at Camp Lee Mar in the summer of 1973. I believe that my experience that summer would help prepare me for the rest of my life. Of course, I did not know or believe these things at that time. Basically, what I knew was that I needed a summer job, and this one was probably the only one I could get. If I could get it!

So I dialed the number again. And I set up a tentative interview. And I told my parents about it, wondering how they would react. After some minor initial shock, they were thrilled that I was finally getting off my butt and earning my own way. I say this only somewhat facetiously, in that I do think they were pleased that I had taken the initiative to find a summer job. I also think they were pleased with my choice, which was a job entailing significant responsibility.

There was still one small matter: getting the job. I honestly cannot remember the interview, or even if there was a face-to-face interview. I am sure that there was some type of interview by the camp director, Lee Morrone, one of the most respected people in the area of intellectual disability at the time and the mother of a child with an intellectual disability. Apparently, the interview must have gone well, because I got the job. I was particularly proud of this, in that it was my very first job and at age sixteen I was going to be the youngest counselor at a camp for kids with intellectual disabilities. Whether my getting this job was a matter of fate, I will leave to you.

My Best Summer Ever

I mentioned earlier that I spent much of my youth waiting for it to end. And this summer was as close as I had come to being on my own. Of course, there was still plenty of adult supervision, but it was a different type of supervision than I had experienced previously. The adult who would become closest to me was Bob Peters. Bob was a legend at the camp. He was a full-time teacher of children with intellectual disabilities during the year, who spent his summers as a counselor at the camp for many years. I am sure that he was assigned as a senior counselor of our group, in large part,

because Lee wanted to be sure I had appropriate adult supervision, and he was the best.

I can still remember the first week of camp in early July 1973. The counselors and other staff arrived the week before the kids. The administration held marathon meetings with the counselors, briefing us on every aspect of every camper, not just the campers assigned to our groups. Throughout the summer, each of us would work, in some way, with each and every camper. We needed to know their functional levels, medical conditions, medications, and other personal characteristics. Medical conditions were particularly important, because many of these children had multiple disabilities; for example, many of them also had epilepsy and required medications to control their seizures, which could be life-threatening.

I said that this was a camp for children with intellectual disabilities. Well, some of these "children" were about ten years older than I was and had more hair on their chests than I had on my entire body. The fact that their mental ages ranged from between seven and ten still did not reduce the initial shock of seeing them. At times throughout the summer, I had night duty, in which it was my responsibility to wake up some of these big guys very gingerly in the middle of the night to give them their antiseizure medications; if one were to wake one of them too abruptly, it could trigger an epileptic seizure, in which case I would have to basically wrestle the camper down to the ground and try to make sure that he did not swallow his tongue, which would be a bad thing.

The thought of engaging in a midnight wrestling match with someone twice my weight and three times my strength was not that appealing to me. However, this is what I was envisioning as we were being briefed in the first week. Fortunately, I never had to deal directly with a major seizure,

and I actually enjoyed working with these older campers very much. At one point in the summer, I was responsible for teaching sex education to these guys, which was extremely amusing. They seemed particularly fixated on the significance of the navel, on which we spent a disproportionate amount of time, considering its limited importance. However, during this first week, before I met them, it was starting to become apparent that this was some very serious business, particularly for a sixteen-year-old who was just learning to take care of himself.

This is not to suggest that every minute of the first week was all business. There was a fair amount of opportunity to meet the other counselors and staff members, who were truly a remarkable group of people. These were individuals who were deeply dedicated to their work, which paid more in personal fulfillment than financial enrichment. Among the most common topics of conversation was: "When is Bob going to get here?" I heard every Bob Peters story that the many returning counselors had to tell, and most of them came back year after year. It was clear to me that this was a very remarkable person and teacher. I was not disappointed when I finally met him later in the week. He taught me everything I needed to know, and we remain friends to this day.

Among the staff members were a group of waitresses, who were around my age, one of whom was more attractive than the next. During the off hours, we got to see a lot of each other and got to know each other fairly well in a brief period of time. In some ways, we really saw a lot of each other, in that the camp had one communal shower for staff, and when you were showering, it was not at all unusual for a young lady to be in the next stall. While everyone seemed very comfortable with this arrangement, I was a little concerned about getting somewhat overstimulated, if you get my

meaning. Sensing my anxiety over this, the head waitress comforted me by saying, "Don't worry, my girls have seen them up, down, and moving."

I do not mean to suggest that this was like Sodom and Gomorrah, with orgies occurring in the hallways, which was certainly not the case, but there was a fair amount of coupling up throughout the summer. This sexually charged atmosphere was particularly challenging to a person who was approaching his physiological sexual peak (which I subsequently learned occurs at about nineteen years of age for males) and who was trying to focus on learning his responsibilities. Fortunately and unfortunately, I was not exempt from all of this hyperhormonal activity, and I developed some experience that summer. In an attempt to alleviate my guilt over Lisa, I tried to convince myself that I was getting this experience for her, which demonstrates definitively that all men are, in fact, pigs.

This leads me to one episode of which I am not particularly proud. Apparently, as a result of one of these liaisons with a young lady, I managed to neglect some of my responsibilities at one point early in the summer. I really cannot recall the specifics, but I remember the consequences very well. The camp administration learned about this, and I was taken by Lee to the proverbial woodshed.

I had never been reprimanded for anything before at any time in my life, in part because I had never done anything wrong (with the possible exception of going to a Grateful Dead concert that ended in the middle of the night without having told my parents when it would be over, which they did not appreciate very much). As long as I can remember, everyone had always told me how mature I was for my age. They told me this at every age, which really started to get old after a while. For the first time, I was being told that I was

immature, which was somewhat refreshing for a change, though Lee really let me have it verbally. I was not about to be irresponsible again, and there were no further problems that summer.

In my defense, I think everybody has a time in which they go a little wild, typically during the first year of college, and I was being somewhat precocious in my responsibility. Of course, this is much less a justification than an excuse, and it is a fairly lame excuse. There is actually no good excuse for what I did, because these kids really depended on every one of us, and a single mistake could have been fatal.

My Utopian Preparation

When the campers finally got there, I went through a transformation. I think that at that moment I became an adult. Partly as a result of Lee's reprimand, and largely as a result of the enormous responsibility that I felt the moment I saw them, I was changed. I was also the happiest I had ever been. My happiness was in part the result of my transformation to early adulthood and the recognition that I was finally on my own.

But my happiness was even more a result of being a part of something much greater than myself. It was a result of being a part of the closest thing I would ever get to a utopian society. Everyone was there for the kids. These kids had more problems on a daily basis than I had experienced in my entire life. Yet they were happy. They were more than happy; they were filled with joy. They were sometimes frustrated with their limitations, but they learned to deal with it, and they taught me patience in doing so.

Most important, there was never any pettiness on the part of anyone. I am not sure whether this was because these people were just not inclined toward pettiness (which I am

sure was a lot of it), or because there was just not enough time or energy for people to be petty, or because people were just too happy to engage in such nonsense, but it was wonderful.

I did not know it at the time, but the summer would be the best possible preparation for the challenges I would face for the rest of my life. I had never really known a person with a disability before. The closest I had ever gotten to knowing such a person was my own father, but he just had a severe limp from his childhood polio, which resulted in a lot of pain but did not really limit his functioning. Now I knew an entire camp of people with disabilities. I would never trade the disability that I would acquire with that of any of the kids in this camp. Yet they dealt with it with dignity, courage, and joy. They will never know how much the few weeks I spent with them helped me for the next thirty years. That long period of time began toward the end of that summer, in one split second.

Disaster

One day toward the end of the camp season, on August 12, 1973, two of the waitresses and I decided to take our day off together and to go to the resort town of Monticello, New York. We had only one day off a week, and by that day we really needed to get away. Unfortunately, none of us had a car or even drove, so we decided to hitchhike. Now, I can just see the disapproving looks on some of your faces: How could we be so stupid as to hitchhike? Although I certainly do not contest that this was a stupid thing to do, in those days a lot of people hitchhiked. Unlike the situation now, in which hitchhikers occasionally have their heads stored in a bottle in some psychopath's refrigerator, this was before such horror stories.

Monticello was about a half hour or so away from Lackawaxen, Pennsylvania, where the camp was located. Somehow, we were able to get there, and we had a nice day. As the day progressed, however, clouds started rolling in, and it began to rain. We had to work the next day, so we started hitching to get a ride home. Thanks to the physical attractiveness of my traveling companions, we were able to do so in short order. A sports car stopped and took us in. The driver was a young man, and his dog was in the front passenger seat. The girls and I got in the backseat, and, being the gentleman that I was, I sat in the middle.

That is the last thing I remember on that day. Everything else was related to me by others after the fact. Apparently, the driver had been drinking or taking drugs, which we did not know when we got in his car, and he tumbled the car in the rainstorm. There were no seat belts in the backseat; consequently, the two girls smashed into the bucket seats in front of them, breaking a nose and arm, respectively. Being in the middle, I had no bucket seat in front of me, and I proceeded to fly through the windshield, ending up outside of the car. The driver had acquired a small scratch under his eye and lost his dog. I had broken my neck.

Commentary: Preparation for a Life Extraordinary
/Mitchell Batavia, Brother/

The accident—no one saw it coming. The best way Drew could have prepared for it, short of wearing body armor or lobbying for rear-center seat belts, was joining his high school track team. He had been cut from basketball tryouts, which likely broke his heart, but track strengthened it. And his training for the Yonkers Marathon he completed in the

pouring rain at the age of fifteen put him in the finest physical condition of his life, three months before it was almost taken from him. Without this rigorous training, recovery from his injuries may have been tenuous.

One of the great mysteries about Drew, however, was not that he survived—though he almost didn't—but that he, despite or perhaps because of his quadriplegia, had such an extraordinary life. By all accounts, there was no prescience, no warning; his childhood was typical if not nondescript. He grew up in an average middle-class community, attended a garden-variety suburban high school, and dwelled in a silly-sounding city, Yonkers. We even had the typical sibling bantering at home. I would proceed to call him names that underscored his jutting nose or his tinseled braces; he would retaliate, wrestling me supine over one of our unattached bunk beds and taking playful shots to my shoulder. When our family occasionally sojourned to our favorite neighborhood Chinese restaurant, Jade Garden on Jerome Avenue in the Bronx, the menu choices would always be arranged in two columns, column A and column B. I don't recall the significance of the columns—one may have had more pricey chef specials. In any case, Drew would be on top of me and query, "Do you like one from column A or one from column B?" Of course, the "one" referred not to a dish, but to a punch, a jab executed tangentially across the outer rim of my bony left shoulder, a sting that lingered. I must confess, it was good fun.

But aside from the banter, Drew was a gentleman, as evidenced by his chivalrous act of sitting in the middle of the backseat, over the hump of the doomed Toyota. He was a model kid, a conformist. He was also quite reserved. In fact, Drew was so quiet as a child that our mother enrolled him in an elocution class to improve his expression and speech when

he was about eight years old. For his final project, he was to present a speech in front of an audience—but he froze and said nothing. I mention this because this behavior is in stark contrast to the nonconforming, vociferous, activist role he later adopted, when not even a speech before the Supreme Court of the United States would rattle him. At conferences, Drew was known to give speeches of more than twenty minutes without using notes.

And Drew was well educated. He grew up in a Jewish family that placed heavy emphasis on learning. I remember my mother tenaciously drilling him in math in our Bensonhurst kitchen when he was seven or eight years old. She was a kindergarten teacher; her father, an assistant principal in a vocational school; and his father, a rabbi, a leader, and a scholar in his Brooklyn community: a lineage of teachers. And then there was our father, who was palpably intelligent and would have made a fabulous physician but chose a career in accounting, an occupation that can be conducted from a seated position, to accommodate polio scars from childhood. Although taciturn, whenever Dad offered advice (often on finances) it was piercingly wise and expressed in just the right number of words, no more and no less. Drew was surrounded by smart people.

All of this points to a childhood upbringing with good prospects for Drew—but an overly confident, Ivy League-trained, nonconforming activist? No one anticipated this. And the notion that he achieved more in his lifetime with only 10 percent of his body, and in half the time that most nondisabled persons could muster, was, well, somewhat baffling.

And while all this makes Drew sound like a saint, this was not completely true; there was just less to legitimately pick on. He did have strong, fairly unyielding opinions about most

things (Shall we say opinionated?) and was less empathetic to others, or at least to me, in less dire situations than himself—which was practically everyone! My progressive hearing loss, a delightful trait passed along in our family, for example, did not lend itself to his sympathetic ear. Drew also set high standards for himself and held everyone else to those same heights. So if those who worked with Drew didn't pull their weight on a project, Drew would just finish the job himself rather than remediate or provide mentorship; personnel development was not his strong suit. Nevertheless, he did encourage others. Finally, Drew's taste in art was somewhat questionable; he had a strong affinity for kitsch. But this is just to say that no one is perfect.

Of course, I can conjure up explanations for his success. One theory is that, like me, he was a "late bloomer"—a term I abhor—someone who needed a bit more time to "steady his feet" and fully develop his potential. As if eventually your brain will mature, your nerve impulses will conduct faster, and you will catch up with the others. But I rejected this theory. First, it is patronizing; second, it's nonscience; and chiefly, I have evidence to discount it. As a younger brother who shared a bedroom with him, I, during weak moments, alone and curious, would shuffle through his dresser drawers to see what I could borrow. And what I discovered was striking. I came across a ninth-grade book report. The writing assignment was so well inked, constructed, and argued that it could not have possibly been written by someone in our family at such a young age. Perhaps it was his use of transitional words ("moreover," "furthermore," "along the same lines"), or maybe it was his use of contrasts ("neither wealth nor poverty"). He seemed in high school to already be a gifted author, with the concomitant talent of persuasion.

Still another reason I reject the late bloomer theory is my mother's recollection of a high school teacher-parent conference she attended with Drew prior to his accident. The encounter went something like this: "Did you know your son is a math genius?" My mom was both speechless and clueless. Drew clearly did not bloom late, just quietly.

A second explanation for his success is what I call the Theory of Forced Use, that without the use of his body and all its attending distractions (sports, driving, happy hours), he was forced to turn inward, toward his own mind, perhaps gaining special knowledge in the same way a person who is blind can feel. This may also explain his increased assertiveness following the accident, a trait one must rely on to survive quadriplegia. If he didn't speak up, how would he get things? For example, when his power chair was too feeble to make it up the hills of the UC Berkeley campus, he had to ask others to push him to class. Nevertheless, while this theory of forced use is entirely possible, I know scores of individuals who do not flourish despite bodily infirmities.

Still a third theory, which I am inclined to believe when I have no other, is that we were simply unrelated. I call this the Baby Stalk Theory or, alternatively, the Alien Implantation Hypothesis. He belonged to some other family but was left at our front stoop as a newborn. Although attractive, this explanation is unlikely. For one thing, family resemblance hints at a shared genetic footprint. Also, our knees cracked similarly when we squatted, and we both suffered from the same pattern of acid indigestion when stressed. More compellingly, our senses of humor were too similar to be coincidental. All we would have to do is glance at each other to read a punch line. Once, while watching a science fiction movie on television as kids, we witnessed a menacing, tower-size mud-man fall to the ground in pieces. I don't recall why

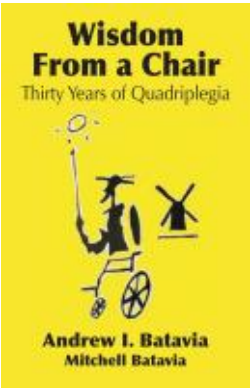
it was so funny, but at the time, we were on the floor, gasping with laughter. His sense of humor also carried over after his injury. When he went off to college, he would dress up for Halloween. One year, he was a half-man/half-woman. Another year, at a professional conference in New Orleans, he dressed as a crayfish during Mardi Gras. Then there was the time he sent John Miller, a friend and naval officer who wore his hair razor-short, a gag gift of a cap with an attached ponytail. Drew knew when to be serious and when to be playful. His sense of humor ultimately contributed to his charm.

But beyond charm, Drew worked harder than most people, sitting up and clocking in ten- to-fourteen-hour days at the office, and then some on weekends. His wife, Cheryl, shared a story Drew told her about counting on the incompetence of others.

> He said that most people are pretty lazy, and that he had overcome his disability and succeeded by working harder than most people are willing to work. When he arrived at Harvard Law School, he found himself in the company of other bright people who were equally motivated and did not have his physical limitations. He said that was the first time he really felt the impact of his disability on his efforts to excel.

And then there was preparation. Drew found his true life's work helping the disability community, and I believe that he, more than anyone else on this planet, was best suited to carry out this mission because of his qualifications. His training in law, economics, and health policy research, and his experiences in government and as a wheelchair user, made it so. He became a juggernaut in the disability rights movement.

But whatever the ultimate reason for Drew's success, he seemed to evolve from an unassertive, bright, conforming teenager into a dogged, visionary, hyperconfident activist with a penchant for adventure after he broke his neck. Like a weakened dam yielding to torrential water currents, Drew exploded into his new disability world after his injury, helping to give his community options, more access to public spaces, more hiring protections, fewer health care coverage exclusions. But conditions had to be right. First Drew had to become a person with a disability.



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