Preface

I believe the key to happiness is to find a good mission in life, to make it your life’s work, to take that work very seriously, and not to take yourself seriously at all. Most people who publish autobiographies are self-important, self-serving blowhards, who take themselves much too seriously. With some notable exceptions, this is true whether the author is a sports hero, captain of industry, or even president of the United States. Publishing one’s private memoirs is, in a sense, the ultimate act of arrogance, in that it assumes that someone else would, or even should, be interested in the author’s existence.

So, this raises the obvious question: Why did I write and publish this particular memoir, particularly at the relatively young age of forty-five, without being famous yet, or possibly ever. One possible answer, of course, is that I am a self-important, self-serving blowhard. I cannot be objective about this, so I will leave it to you to make this judgment by the end of the book. Another possibility, however, is that a depiction of my life and my mission can make some unique contribution to our understanding of the world. I like to think that this is the case; yet, again, one’s ability to assess the uniqueness of one’s own life objectively while in the process of living it is limited. In fact, everyone's life is to some extent unique, and some of the most interesting and insightful life stories are those of the so-called “average citizen” rather than the rich and famous. I recognize that this is sacrilege in our celebrity-oriented society, in which those of us who are not on some Social Register A-list, and therefore have not risen to the public consciousness, do not exist, for all practical purposes.

However, there are reasons that my life may offer unique insights. First, for the last thirty years, I have not gone to a single public place or event in which I have not been part of the show. People appear infinitely interested in watching me racing down the street in my chin-controlled, motorized wheelchair. Often I would be accompanied by one or both of my beautiful children, whom my wife and I adopted from Russia; one would be standing on the back of the chair and the other sitting on my foot plates, and we would be weaving in and out among people at full speed.

Living one’s life without the use of arms, legs, or hands presents some interesting challenges and appears to be inherently intriguing to many people. I suppose some are wondering what my life is like and whether they could survive under similar circumstances; I am sure that most could, in that we humans have a remarkable capacity to adapt to almost any conditions. I have never resented this voyeurism; as a person who was not disabled for the first sixteen years of my life, I am certain that I would have been similarly curious if I had not severed my spinal cord in 1973 and if I were in the same room as someone with my current disability.

Yet this still does not quite answer the question as to why my life warrants the sacrifice of trees necessary to publish this book. Although my disability—high-level quadriplegia—is relatively rare and was even more so thirty years ago, there have always been a fair number of people with quadriplegia who had survived back in the 1950s, and there are other disabilities that are far more rare and debilitating than
mine. However, there have been very few people with my level of disability who have studied in, worked in, lived in, or even visited the places I have been, such as Harvard Law School, Stanford Medical School, the US Attorney General’s Office, the White House, the Senate, and the top of the Great Wall of China.

These particular experiences do not make my life more important than those of my colleagues with disabilities who have not experienced these places. I remember, when I was in rehabilitation at the famous Rusk Institute in New York, that virtually every one of my fellow inmates with a recently acquired disability had a story that was sufficiently interesting for a book or a motion picture. In fact, years later I watched the movie *The Waterdance*, which brilliantly told the story of a person with quadriplegia adapting to his disability. Much to my satisfaction, it was told in a refreshingly honest manner, warts and all. Although this film was based on a particular individual, it describes well the general experience of many of us becoming rehabilitated. I recommend it strongly.

One of the reasons that such stories are so interesting is that they deal with a very intense situation—going through the transition from being a “normal, able-bodied” person to a “cripple,” “invalid,” “gimp,” “handicapped person,” or “person with a disability,” depending upon how you are addressed, where you live, and with whom you interact. My experiences have been particularly intense, in that they have taken place in some of the most competitive and respected institutions of our society. I believe that such intense experiences often offer great insight for those who survive them, much as Viktor Frankl derived remarkable insights from his horrible personal experiences as a survivor of the Holocaust and John McCain gained a unique perspective from his five and a half years as a POW in Vietnam. This is not to compare their horrendous experiences with the experiences of quadriplegia (although the permanence of quadriplegia does provide some similar intensity); the purpose is only to indicate that all such experiences offer the promise of wisdom to those willing to learn their lessons.

The title of this book may require some explanation. Generally speaking, very limited wisdom can be derived from inanimate objects, such as chairs. A notable exception is the wisdom that can be gained from a wheelchair. Wheelchairs are among the most vilified objects in human history. Even as we enter the new millennium, it is common to turn on the local news and hear some commentator talking about a person who is “wheelchair-bound,” “confined to a wheelchair,” or even “condemned to a wheelchair.” Those of us who use motorized wheelchairs do not find them confining, binding, or condemning; they expand our horizons and help us get where we want to go, often more expediently and faster than the legs of our colleagues.

Wheelchairs have been used in virtually every medium, including novels and films, to depict weakness, evil, and other negative traits. Their use in horror films, such as *Psycho*, is practically ubiquitous. In the final, ironic scene of the movie *Sleeper*, Woody Allen portrays the leader of the world as being a person in a wheelchair, apparently suggesting that such a thing would be impossible (despite the fact that FDR led us out of the Depression and to victory in World War II from his wheelchair). This particular negative portrayal does not offend me as much as it amuses me. A wheelchair and life in a wheelchair are not negative things in
themselves. A wheelchair is actually almost always a positive thing, as long as it is functional and affordable, and the life of a person with a disability can be very good or very bad, depending in part on the individual’s circumstances and what he or she is able to do with them. Although disability is often associated with adversity, it can also be a source of very positive things, such as wisdom, for those who are open to it.

Over the years, many people have told me that I am an inspiration. Although I have always appreciated such sentiments when conveyed sincerely and without pity, for a long time I found such compliments somewhat annoying. I always find “inspirational movies” about the lives of people with disabilities a little nauseating. My mission in this world is to try to ensure that all people, including people with disabilities, have greater choices in and control over their lives. I believe that achieving this mission will make the world a slightly better place than it was before I got here. Recently, I have decided that if this orientation, or the way in which I live my life, inspires someone, that is fine.

I imagine that there are some who do not share my view of a better world and who think what I do makes it a little worse, and there are some who will no doubt be offended by some of the things I say in this book. Although such offense is not intended, it is also fine. I pride myself as one of the early opponents of the notion of “political correctness,” even before political incorrectness was fashionable, and I believe first and foremost in honesty expressed in a sensitive manner, even when it does not please everyone. I take what I have characterized as a “constructively cynical” approach to life, and I leave few of our cherished institutions unexamined.

Finally, after hopefully having at least partially justified this book, I must answer the question as to why I am writing it now. On August 12, 2003, I will celebrate the thirtieth anniversary of my spinal cord injury. Every year, I celebrate another year of survival with my disability, and it seems that a thirtieth anniversary should be commemorated in a special way.

I have written this book primarily as a gift to my children, Joe and Katey, to whom it is dedicated. In writing it, I estimate that my audience will be somewhere between fifty close friends, relatives, and colleagues and a couple of million people who I know less well. This is a substantially larger variation than the readership of my two previous academic books, which sold a few thousand copies. I will be happy either way, though I will be particularly gratified if this very personal book reaches a large audience.

Several years ago, one of my close relatives indicated that she wanted to write a biography about me, apparently more impressed with my achievements than I was at the time. I told her that I would be ready to have my life story in print once I had achieved something of note. I did not tell her, but I was also concerned that, because she is too close to me emotionally, she would not be able to maintain objectivity and the piece would inevitably have been one of those inspirational things that make me sick. I needed someone much more critical of me to write such a book, such as me.

I am not certain whether my other criterion has been met, and the reader will have to judge whether I have achieved anything of note at this stage of my life. Irrespective of the satisfaction of this criterion, I am writing this now in part because one of the key insights I have derived from my disability is not to take anything for granted.
granted. Although I am very healthy generally, and few “able-bodied people” could keep up with me throughout my long workday, I have had several severe acute episodes over the years in which I came close to dying. Such occasional near-death experiences are part of the territory associated with quadriplegia. One of the reasons I am writing this book now is in the event that I do not have an opportunity to do so later. Accordingly, this book should be regarded as number 1 of volumes. Whether there will be subsequent volumes will depend upon how long I live and what I achieve in the process.

Andrew I. Batavia
August 12, 2003 [the planned date of publication]

Helping to Complete Drew’s Memoirs

Drew passed away on January 6, 2003, before he could complete and publish his memoirs, the target date for which had been August of that year. He had written fourteen chapters. I was approached to complete his work, but the writing was as perfect as it was unfinished. I didn’t want to touch it, lest I adulterate it. And several family members could have stepped up to the task. So why get involved, more than a decade after his death, dredging up past grief, opening healed wounds, and unearthing new ones? What would be gained? These thoughts hopscotched through my mind.

I rationalized, as his younger brother by two and a half years, that I was the person (except for our mother) most privy to his forty-five-year life, from early childhood, when we shared a bedroom in Bensonhurst, to our final visit at his bedside in the ICU at Miami’s Jackson Memorial Hospital in 2003.

But to be truthful, we were not particularly close as kids, and we did not interact except for teasing, rivalry, and physical fights. We did travel together on holiday trips to see our grandparents in Hallandale Beach, Florida, and frequented the same sleepaway camps, but even then I was never his confidant until shortly before his accident. Nevertheless, we had a common interest: We religiously tuned in to The Tonight Show starring Johnny Carson around bedtime on Drew’s black-and-white twelve-inch TV. Following squabbles, however, he would turn the set away from my view. I would return the favor by pulling the plug on my eight-track player when a fight ensued. Such is the rivalry of brothers.

But there was tenderness, too. One night, at a rented summer house in upstate New York, while our parents were out, Drew climbed to the top of the refrigerator to fetch me a banana, my comfort food, to console me during a raging thunderstorm. But our relationship really began to cement shortly before Drew’s accident. During Wisdom from a Chair: Thirty Years of Quadriplegia
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his training for the upcoming Yonkers Marathon, we pounded the Westchester pavement together. As a teenager, he rounded up his friends and circled the village bully (every town had one) with their bicycles, making it clear that I was off his menu. And at one summer camp, I became his confidant. In short, he became my older brother.

And following his injury—during Drew’s “mega-morphosis”—we kept in touch. I witnessed his rehab at Rusk, his move to Harvard, his parenting at “Bedlam,” his tenure at FIU. And I stood as best man at his wedding. His circumstances swayed my choice of careers toward physical therapy. And as our careers in higher education crossed, we published together. Perhaps we’re doing it once more.

Now, with more than a decade of distance since his death, I believe I have the clarity to offer a fair perspective of Drew’s life. In doing so, I have uncovered a surprising amount about Drew, his life, and my relationship with him. I would like to believe, though I am by no means certain, that I shared at least a shred of DNA with him, a twin-like connectivity that could offer some special insight into his journey. Perhaps, though we were miles apart on the day of Drew’s accident, the burning crater I felt in the lining of my gut wasn’t the mystery meat at camp.

In the end, what convinced me to finish Drew’s memoirs was his deathbed wish that either his wife, Cheryl, or I do so. When Cheryl approached me with the project in the spring of 2015, I was astounded by the captivating prose of Drew’s unfinished work, which had been found in his computer files. What a treasure of life experiences nearly lost. It must be published, I thought. And reading it is like having Drew back in our lives, as if I could turn back time, albeit temporarily.

Drew’s writing has not been altered except for minor edits, use of a few pseudonyms where indicated, and some phrasing to reflect current disability language when he refers to others; historical information (publication excerpts, speeches, letters with quotes) remains unchanged. I penned the final ten chapters and provided commentary on several others, pulling from his publications, eulogies, holiday letters, family anecdotes, photographs, interviews, tenure files, letters, and my own memories. My contributions are noted with the heading “Mitchell Batavia, Brother.” Cheryl, and my mother, Renée, were indispensable partners during this memoir project. They, along with other relatives and friends, provided anecdotes and documents for its completion. I thank my wife, Evgenia, and son, Michael, for their patience during this year-long project. To preserve Drew’s voice and get the publication out around the time of the ADA’s twenty-fifth anniversary year, the family decided to publish this work on their own rather than use a traditional publisher, which might have had competing commercial interests.

Drew’s memoirs are published as a lasting gift for his two children, his family and friends, and for a wider audience both within and outside the disability community, where Drew’s rich escapades might serve as a model for living fully, despite or perhaps because of his life in a wheelchair.

Mitchell Batavia
March 31, 2016