



## THE LONG ROAD TO ADVOCACY

PAUL JOHNSON

### AN INTRODUCTION TO AN AUTOBIOGRAPHY

The reason I wrote *The Long Road to Advocacy* is because it is not very often that a person with developmental disabilities writes an autobiography. For many years, people with developmental disabilities have been left out of the inner circle of education as we know it today. Because of this exclusion, it takes time for a person with developmental disabilities to learn all that I'm writing in this paragraph. In my own life, I was bullied and had to take myself out of junior high; I did not have the opportunity to learn about basic grammar until I took classes at a community college in my early thirties.

Not only is there lack of equitable education for people with developmental disabilities, there is also lack of encouragement. People with developmental disabilities have been segregated, bullied, and put aside because we are different than the average non-disabled person.

Fortunately, I had someone in my life who saw that I had the potential to learn more. Randi Moe, a mentor I worked with at a vocational skill-building center, went out of her way to encourage me to continue my education. Because of her encouragement, I was able to get my GED and attend community college later in my life. We need more encouraging and patient people like her. We must encourage people with developmental disabilities to study more about their interests. I would like people with developmental disabilities to be able to accomplish what they set out to do. I found this encouragement at South Puget Sound Community College.

Later in my life, I also found encouragement at The Evergreen State College Writing Center with the Kokua LEAD program. I started writing my autobiography by dictating my story to a job coach named Cori. As time went on, Randi Miller of Kokua got me connected with the LEAD program and set me up with Josie Jarvis, an intern from The Evergreen State College. As we were working on my book *The Long Road to Advocacy*, Josie helped me to develop different ideas on how my book could be written, organized, and revised. She also suggested that I go visit The Evergreen State College Writing Center. This is where Josie and I met and began working with writing tutor Haley Bea.

Working with the Writing Center has been a wonderful experience. Working with Josie and Haley has given me a different perspective on how to write my autobiography and make it clearer. It gave me an idea of what sentence structure should look like; it's also been a helpful and broadening experience in getting my ideas across. I thought that writing my autobiography was going to be simpler than it was.

I've learned that I have a long way to go and that there is more to writing than I thought. I would recommend collaborative writing, especially if you are a student at Evergreen or any other educational institution. It has given me new ideas and shown me that there is more I can do with my writing. I would encourage teachers of all walks of life to help students learn about writing what is on their mind, even if it's just a simple sentence. It is my hope that people learn how to work together on writing projects.

Community programs like the Kokua LEAD program are so important because people with developmental disabilities need a "hand up" to accomplish their education goals. They need inspiration so that they can believe in themselves and their potential and see the possibilities that are out there to read, write, and more. I think these programs are also important because they provide students, staff, and non-disabled people the opportunity to learn about and connect with people with developmental disabilities.

It is my hope that teachers and tutors make it a point to have their students with developmental disabilities learn about the writing process—perhaps this would encourage and empower people with developmental disabilities to write their own stories. I want to get people with developmental disabilities excited about writing their story and being heard. It is therapy for them to write their feelings down.

EXCERPT FROM *THE LONG ROAD TO ADVOCACY*  
CHAPTER TWO: SCHOOLING CHALLENGES

In 1963, when I was twelve, we learned that a new special education wing was being built onto John Rodgers Elementary just around the corner from my family's house. With the new renovation in place, I was excited to attend a new school in my neighborhood. That summer, before school began, we received a phone call saying that my new teacher, Mr. Monahan, was going to come to each student's home to get acquainted with the incoming class. I showed him my sports trading card collection. He was impressed; apparently he had been a football coach at one of the other schools.

As the upcoming year approached, some of the PTA members made it known that they disliked the idea of children with disabilities attending the same school as those who were not disabled. Despite their objections, I entered into John Rodgers Elementary School. The transition into the John Rodgers special education program was difficult, and I frequently found myself caught in between the two worlds of "regular" and "special ed." Although I was able to keep up with and understand the work in all other classes, the faculty and school frequently misunderstood my

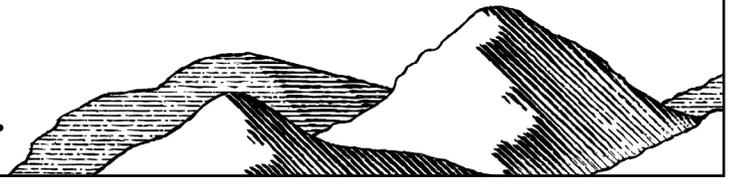
capabilities and wrongly thought my cerebral palsy was a mental or behavioral disability. Cerebral palsy is a neurological condition that mainly affects muscle function and coordination; it does not diminish my intellectual capacity or my ability to learn.

During my time in the special education program, the other students and I took Mr. Monahan's class in the mornings. He was a good teacher, although I often felt bored and isolated because the program was unable to accommodate all of my learning needs. For example, my reading level often excelled beyond what my peers were learning in the classroom. In the special education program I was the only student with a physical disability; most of my classmates in the special education wing lived with mental and learning disabilities. Although I was able to participate in a traditional reading program, I was not given many other opportunities to challenge myself.

The special education students were frequently segregated from many of our peers. For a while the teachers and school staff brought lunches to our rooms in the special education wing on a cart. Apparently, they were not yet ready to "mainstream" us into the regular population. It wasn't until later that year that people with disabilities were able to eat in the cafeteria with the rest of the students. Looking back, I feel cheated that we didn't get to join our peers for lunch.

It's sad for me to think that the kids without disabilities weren't able to experience and grow up learning about the lives of those with developmental disabilities. I would have liked to have seen more integration between the programs. People come from different places, and it's important that in public communities, such as public schools, we see what we have in common and come together.

Growing up in the '50s and '60s and having lived through the many dramatic changes in ideas and events shaped my relationship to politics and advocacy in America. 1963 was an especially charged year both for me personally and for the nation. It was the afternoon of November 22 when our teacher came into the classroom to announce the bad news that President Kennedy had been shot. The whole school was in shock, wondering, "Who would want to shoot President Kennedy?" This event, along with witnessing the Civil Rights Movement at this time, planted seeds that helped me become more aware of the social and countercultural movements happening around me. During this particular time in my life, I felt deeply segregated within my school, and it was moving to watch how others around me were fighting the injustice they felt. I would realize later that these acts of individual and community activism helped me see the potential for creating positive social change through self-advocacy.



## SUPPORTED INDEPENDENCE: NAVIGATING A NECESSARY PARADOX

JOSIE JARVIS

In the fall of 2012, I was approached by Randi Miller, the volunteer coordinator of the Kokua LEAD program. This program works to link Evergreen students with adults with disabilities who want support in accomplishing their learning goals. In our conversation, Randi told me about Paul Johnson, a person with cerebral palsy seeking support in his life goal to write and publish his autobiography. I was excited about the project and began working with Paul as a Kokua LEAD tutor that winter. I have been an active volunteer ever since.

Before I worked with Paul, I took many aspects of my life for granted. Society saw me and my body as capable of learning, and because of that, I was given access to people and resources who encouraged me to develop as a writer from a young age. I can sit privately in a room and put my thoughts to paper without having to show them to anyone. If I decide to go somewhere, I don't have to schedule it with public transit four days in advance and hope that staff is available to accompany me. I don't have to worry my plans will fall through at the last minute because of a scheduling error or staff cancellation. When in public I can go just about anywhere, move through any building, and have my needs met fully. I can live and work and socialize and write fairly spontaneously. As someone with a typically- mobile body, my life is rather blissfully free of constraints.

Although my writing is often bound by anxiety, deadlines, other projects, and page limits, I was not really prepared to understand the conflicts and challenges that would impact working with Paul on his writing. It is more clear to me than ever that ideals do not exist in a vacuum: when implemented, they come with real-world constraints and compromises. Seeing where my privilege, assumptions, good intentions, and goals got in the way of Paul's independence and voice ended up being one of the most challenging and rewarding lessons of my academic career. It was difficult; it was frustrating; it was challenging; it was imperfect; and above all, it was worth it.

Many of the goals of this project contained internal, unavoidable conflicts. My overarching goal was to effectively support Paul in his independence as a writer. This paradox created a line that was difficult to balance on: support and independence are not concepts that are usually paired.

In writing, Paul relies heavily on dictation and physical support to get his ideas down. In this role I found it easy to make assumptions about what Paul wanted to say and to influence the content beyond what was appropriate. There were many times when I would write down a sentence for Paul and inadvertently include words he had never heard before. I tended to encourage him to talk about personal experiences of oppression that went beyond what he felt comfortable sharing. I would often not give Paul the opportunity to put sentences together on his own. It was difficult for me to recognize and acknowledge when I was influencing the writing process in a way that denied Paul's agency as a writer.

It took a lot of practice, mistakes, and apologies to be accountable to Paul's voice. In order to walk this fine line of support and independence, consent became very important. I needed to ask before I offered help, and make sure that what was transcribed was what he wanted to say, even if it meant that the sentences did not sound the way I would word them. I still made mistakes, but I'm glad I did not give up. It is really important that Paul sees his voice, not mine, in his autobiography.



## PRESERVING THE SPLENDID MESSINESS: REVISING MYSELF DURING PAUL'S REVISION

HALEY BEA

### I. COMBATING MY BIASES

I came into this project later in the game. Paul Johnson's autobiography had already been six years in the making, and he and Josie had been working together for nearly a quarter on its revision. In the beginning, I applied a thick layer of professionalism to mask my nervousness and ignorance around tutoring someone with cerebral palsy. When I first met Paul, he had come into the Center to revise and eventually edit his autobiography, *The Long Road to Advocacy*, but I struggled to give him the honest or thoughtful feedback that I felt he deserved. Rarely did I stray from the "safe" and patronizing responses of "Good job!" or "You're doing so well." During these first few months, I wasn't sure why these phrases had left me feeling so confused and unsatisfied. I had used these go-to sentences many times before as a way to pad other awkward or tense tutoring sessions, but while working with Paul, these little words felt harmful—even caustic.

It wasn't until embarrassingly recently that I realized why cushioning our sessions was more destructive than helpful. Though I had thought at the time that my polite words were simply sparing Paul's feelings, by doing so I had assumed what so many able-bodied people do: that those with disabilities are incapable of the same physical or mental challenges as those of us who are able-bodied. These saccharine responses I had doled out so readily were just one of the many ways I maintained, rationalized, and even fueled my ignorance around disability.

Before Paul, I had never worked with someone whose range of motion was directed by a mouth-operated electric wheelchair. It had never occurred to me to check to see if a room was ADA accessible, and I wasn't sure how to interact with the caregiver who would pause our sessions to feed Paul water or adjust his glasses. One of my biggest hurdles was understanding why Paul's wheelchair intimidated me. During our sessions I struggled to know how (or even if) I could see Paul's body as separate from the complex machine that moved him forward. The sheer force and power behind Paul's movement was at times unnerving, as it challenged the cultural biases I held equating disability with frailty.

This last fall, during our revision process, I received a message that Paul couldn't make it to our session: his chair needed to be fixed. For three weeks, Paul's movement became severely limited, and the Kokua LEAD program struggled to get the appropriate people to respond in a timely manner for this urgent repair. Suddenly, I realized just how unruly every body is, and for the first time I could acknowledge Paul's body for what it is as a whole—both machine and flesh.

In my conversations with Evergreen professor Chico Herbison, he discussed how those with disabilities can challenge those who are, in his words, temporarily-abled: "I think people's fears around disability and those with disabilities are rooted in mortality. People with disabilities are a reminder of what we could be one day after a car accident, a slip... anything at all." As a response, he says, many able-bodied people infantilize or dehumanize those with "unruly bodies" as a way to convince themselves that this person is not a mystery or a challenge, but rather "pet-like" or even nonexistent. The more I worked with Paul, the more conscious I became of this phenomenon. Quite regularly, I noticed two very distinct ways people chose to convey information to Paul. The first was communicating through other able-bodied people in the room, typically Josie or me. The second was a shrill and sing-song cadence usually accompanied by slow and basic sentences, a combination usually reserved for children and small dogs. Though both were pervasive, the latter became almost expected.

One of the most destructive moments I witnessed came several months into the revision process, when Paul's twenty-year-old caregiver pinched his cheek while feeding him water. "You're just my little Gerber baby, aren't you?" she cooed while wiping the spoon on a napkin. Unsure of what to do, I watched as the moment unfolded. Within ten seconds, Paul's six decades of life had been downsized. Paul's sharp mental faculties, language skills, and the sheer fact we were there to edit and hone his autobiography seemed to mean nothing during this moment.

## II. THE REVISION PROCESS

If you don't preserve a person's splendid messiness, you silence or modify their voice: you change their voice. When you change or modify a voice, it's just as unforgivable as silencing a voice.

– Chico Herbison

Before working with Paul, I had an established tutoring system. I developed certain patterns and assumptions about how I greeted people and interacted with their written piece. Typically, I would begin a session by asking the writer to find a seat in an area of the Center they felt comfortable. Once we were both seated and the writer had picked up a pen and filled out an author's note, we would eventually begin our conversation about their writing. Despite the whirlwind of noise that can easily scatter throughout the Center, we would work until the writer felt that they had enough raw materials to take home and knead back into their piece. After the session, hopefully both of us satisfied, the writer would walk out the door.

After I began working with Paul, I had to rethink and revise my original system. First, Paul already has a seat far superior to any plastic chair I could offer him in the Center. Second, Paul cannot move his hands without assistance, so his mind and our conversations were his pencils and paper.<sup>1</sup> Last, Paul's voice, though eloquent and sincere, needs amplification in order to be heard in a busy room. Though it took me a relatively short amount of time to figure out that my "foolproof" system was flawed, it took me far longer to figure out why.

Looking back, it terrifies me to think about how easy it could have been for me to negate Paul's voice in the midst of my own ignorant clamor. From the moment Josie and I began working with Paul on his autobiography, we struggled to understand if we were capable of supporting and amplifying Paul's voice without silencing it. Eventually, to combat this fear, Josie, Paul, and I decided to enact a revision process based mostly around dictation. When Paul communicated his ideas, Josie and I dutifully incorporated them into the piece. Every word or idea that we transcribed was meticulously reviewed by Paul. It seemed silly at times to be talking for fifteen minutes about four or five words, but it was what I needed to feel that our sessions revolved around agreement and consent.

Even after a year of this specialized revision process, I never found a magic answer. Usually, I just found more questions. Like many Evergreen students, I consider myself fairly conscientious and familiar with anti-oppression work. Also like many, I still battle my biases around disability. Even during the first edits of this article, the *Inkwell* editorial board helped me to become aware of my words and intentions when writing about this revision process. Without realizing it, my previous drafts had spoken for Paul, and in many ways had left him peripheral and voiceless. Becoming aware of this, as you may guess, was a hard blow. As a person who has dedicated over a year to supporting Paul's revision, I had felt entitled to my opinion on the do's and don'ts of what I had experienced. I had assumed that because I had been working with Paul for quite some time, I had the ability to accurately speak about my experience as well as our experience.

Working with Paul on his revision process has made me keenly aware of both my humility and humanity. As my work with Paul and the Kokua LEAD program winds down and he prepares to self-publish his book, I realize that the most challenging and unflattering experiences I have faced during Paul's revision have helped me to find my voice. Whatever my abilities, disabilities, or perceived disabilities are, I am messy. By choosing to embrace this splendid messiness, I was able to approach both what I needed to revise, and what I needed to accept, honestly and wholly.

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1. Eventually Paul began to use a tetra-mouse, a mouth-operated device that enables him to compose pieces of writing on the computer.