



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

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### 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.