



SUPPORTED INDEPENDENCE: NAVIGATING A NECESSARY PARADOX

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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.