

Fall 2019

# Cybernetics, Cyborgs, and Bionics, Oh My!!: Counterstories of the Intersection of Disability + Technology and Its Impact on Identities of Adults with Disabilities

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CYBERNETICS, CYBORGS, AND BIONICS, OH MY!!:

COUNTERSTORIES OF THE INTERSECTION OF DISABILITY + TECHNOLOGY AND ITS  
IMPACT ON IDENTITIES OF ADULTS WITH DISABILITIES

by

ELLEN HOTCHKISS

(Under the Direction of Ming Fang He)

ABSTRACT

In this dissertation inquiry, I explore the counternarratives of adults with disabilities relating to their identities and how their identities intersect and change with regards to technology and assistive technology. Theoretically building upon critical disability studies (Goodley, 2017; Davis, 2013, 2017; Erevelles, 2011) and posthumanism (Haraway, 1985/2016; Snaza & Weaver, 2015; Weaver, 2010) and methodologically drawing upon counternarrative or counterstories (Bamberg & Andrews, 2004; Carmona & Luschen, 2014; Delgado, 1989; Glenn, 2012; He & Phillion, 2008; He & Ross, 2012; Sandoval & Davis, 2008; Smith, 2006; Solazano & Yosso, 2002; Tuck, 2009), I explore the stories of seven participants with shifting and intersecting identities and disabilities. I also explore the possibilities for individuals, schools, and society to push towards action, advocacy, and social justice to remove societal barriers that envelope disability as a group identity in the furtherance of independence and fully experienced lives.

Seven adults with disabilities participated in my study. They are Eli, Silas, McKenzie, Liz, George, Leila, and Paul. These seven participants use technology and assistive technology to navigate their life. Their ages range from 19-50. Five of them are white men, and two are women with one South Asian American and one white. All participants have physical disabilities that stem from a variety of medical impairments such as degenerative muscle diseases, cerebral palsy, or impairment from injury and

subsequent infections. All of the participants are working in professional capacities with a college education. Some of them hold postgraduate degrees or certifications.

Eight findings have emerged from this inquiry. People with disabilities experience disability as a social reconstruction rather than medical deficits and physical impairments, which fails to capture the multiple abilities and complex aspects of their identities. Technology is a path to independence and connection. Technology is both a tool and an integral part of the lives of people with disabilities. Disability has informed and shaped pieces of these adults' lives, livelihoods, communities and even their leisure. People with disabilities want to be viewed as who they are with many dimensions and intersections but not as a person with a disability as the main or only aspect of identity. Living a life as a person with a disability engenders advocacy for other people with disabilities. Working with people with disabilities through teaching, research, and life helps develop critical empathy and engenders strong advocacy for people with disabilities. Listening to and learning from the counternarratives of people with disabilities fosters urgency to develop a curriculum for social justice that helps create equal opportunities for all to reach their highest potential (Siddle-Walker, 1996) in an unjust and contested world.

INDEX WORDS: Disability, Identity, Critical disability studies, Posthumanism, Counternarratives, Technology, Assistive technology, Intersectionality, Disability studies, Curriculum studies, Social justice

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in Partial Fulfillment of the Requirements for the Degree

DOCTOR OF EDUCATION

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December 2019

## DEDICATION

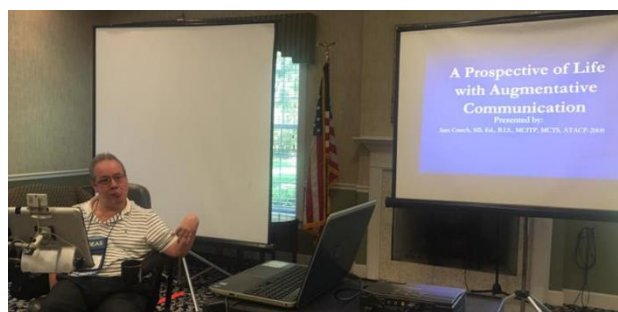
This study is dedicated to my friend Sam Creech. He was one of the first people I thought of interviewing for this study. His life and work live on in his friends and the programs and people he helped.



“Mr. Samuel Marvin "Sam" Creech, 50, of Belvedere, SC entered into rest suddenly and unexpectedly on Monday, April 2, 2018.

A lifelong resident of the CSRA, he was a 1986 graduate of Midland Valley High School and furthered his education by obtaining his Bachelor of Science from USCA and his Master of Science from Nova Southeastern University. He was a former Professor at Georgia Tech, Augusta Tech, and the University of South Carolina at Aiken.

Sam was born with cerebral palsy; however he never let his disability stop him from achieving anything he put mind to. He devoted his life to helping others with disabilities, especially children so that they would never have to face the challenges that he did as a child. The word "I can't" was not in his vocabulary. As stated previously, Sam was an advocate for people with disabilities. He often traveled the country doing so, which was something that he truly loved. One of Sam's greatest accomplishments was when he recently developed a device that allowed a child to speak for the first time. Her first word was "MaMa."



(<https://www.legacy.com/obituaries/augustachronicle/obituary.aspx?n=samuel-marvin-creech-sam&pid=188640497&fhid=5949>).

## ACKNOWLEDGMENTS

There are many people that have supported me throughout the process of my doctoral studies and growth of myself as a teacher and researcher and doctoral student and candidate. My family, of course, has been tremendously patient with me as I pursue my passion for learning and sharing that learning with others. Joe, Daniel, and Tess: Thank you for putting up with me. I hope I have inspired you to keep learning, growing and sharing your passions to make the world a better place. To my parents Mike and Becky; sister and brother in law, Carole and Tim; my grandmother, Mary Ellen, my aunts and uncles and extended family: You have always been there to support this nerdy, curious girl that loves books and conferences as much as she loves technology, sci-fi and helping others. To my in-love family: Mike & Betty, Amy, Barbara, Amanda, Rachel, you have loved me almost my whole adult life. Thank you for your support. My academic life would have been austere and bare if there are no shared meals, discussions, questions, and challenges from my academic mother, Dr. Ming Fang He, and my other wonderful professors at Georgia Southern University. To Dr. John Weaver, Dr. Daniel Chapman, and Dr. Nirmala Erevelles: thank you so much for all of your time, attention, and insight throughout this process. I am so grateful for the inspirations you have brought into my life. Dr. Sabrina Ross, thank you for allowing me to be the first guinea pig in the Certificate in Curriculum & Pedagogy for Social Justice program. I think it is a very valuable program. To my cohort, shared Mexican meals and group texts got me through this process and I cannot wait to see what brilliant works you will produce. To my friends at Tools for Life: Carolyn, Liz, Dan, Ben: your work inspires me every day to work for practical solutions for people with disabilities. Finally, to the participants in this study, all my current and former students, friends, and family members that know what societal barriers the world has put up in your way: thank you for sharing your life and stories with me. You are valuable. Your stories are important. I appreciate you entrusting me with such an important task to share parts of your life with the world.



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## CHAPTER 1

### INTRODUCTION

When we think of the TV show, *Star Trek* and one of the Federation's enemies, the Borg, we see a human face in half, and machine covering the other half. Cybermen of the world of *Dr. Who* were on a mission to assimilate humanity into automatons. The world of bionics, on the other hand, is not science fiction but the medical progress that is happening on a molecular scale, not at all the same way we envisioned the Bionic Man in the 1970s. But in our daily life, there are people who are a combination of full humanity with the supplement of the machine, and/ or technologies to assist in what is considered "normal" functions of the human body and mind.

Marginalized groups often are silenced in a variety of ways by society through the use of linguistic, political or economic power differentials. People are labeled disabled, who do not meet society's view of what a normal body, a normal intellect, a normal speech pattern, a normal amount of focus. These people often have their words, thoughts, and feelings spoken for them by caretakers, Medicaid, teachers, and others who think "they know best."

Speaking for students who need other ways to express themselves, or other ways to mediate their interactions with the world is a form of control. Nirmala Erevelles (2000) strongly expositis "the voices of disabled students as oppositional subjects or agents have remained conspicuously absent in this diverse array of counternarratives. In fact, I would argue that the continued exclusion of the social category of disability by critical theorists of education demonstrates that disability serves yet again to mark off the theoretical limits of critical educational theory" (p. 31). The counternarratives of what schooling and society are like for people with those "unruly bodies" is an important contribution that needs to be made not only for disability studies as a field, or even curriculum studies, but schooling and society in general.

## Context of the Study

According to a 2012 U.S. Census Bureau report, using a broad definition, 56.4 million people have a disability, equating to 19.4 percent of the total population (308.7 million) (US Census Bureau Public Information Office, 2012; Yan-Tang Institute on Employment and Disability, 2016). Of this population, over 6 million students in the year 2012-2013 were served and labeled with a disability category, totaling 12.9% of the school population (U.S. Department of Education, National Center for Education Statistics, 2016). The National Institute of Health does not have exact numbers on how many people with disabilities use assistive technology, but in a FAQ webpage they describe many of the various low tech and high-tech solutions for people with disabilities including mobility aids, hearing aids, cognitive programs including software, closed captioning, descriptive texts, and switch technologies with links to other sources (National Institute of Health, n.d.). The Center for Technology and Disability points out that Assistive technology (AT) devices are tools to help to overcome those challenges and enable people living with disabilities to enhance their quality of life and lead more independent lives” (2015). For children served by individual education plans or 504 plans, the consideration and evaluation of technology needs is carried out by a team of educators, parents, and students along with evaluators in their educational plans. For an adult with a newly acquired disability or one that has transitioned from school population to adulthood in the United States, the Department of Vocational Rehabilitation is the service provider with a network of support from multiple agencies, along with Social Security disability insurance and Medicaid to secure funding for technologies that encourage independence and the entry into the workforce. According to Erevelles (2011), “disabled people rank among the uninsured at a rate slightly higher than the 14 percent national rate” (p. 18).

Schools, along with medical industries, work often from a deficit view of patients, clients, or students to evaluate how someone is not meeting a norm or standard, and prescribe a “fix” be it medical, technological, or educational in order to bring people closer to the societal norms. In *Disability and Difference in Global Contexts*, Erevelles (2011) looks at the intersection of disability and difference in a

world-wide context with its implications and intersections, often pointing the finger at transnational global capitalist impulses to define disability in its lack: lack of productivity and lack of workforce.

Disability has to be more than that. It is a function of identity for tens of millions of people in the US and 15% of the world population totaling more than a billion people according to the World Health Organization (n.d.). Which incidentally was one of the few government/NGO sites with a variety of accessible formats for their report. Who are these diverse people that cross class, race, and gender lines? Though disability appears in multiple strata of society, it is often skewed to the most vulnerable end of our population spectrum due to poverty and health concerns.

The numbers are important so that issues can be raised to world leaders regarding the barriers of a good and healthy life for 1/6 of their populace. What is also important are the words and ideas of people with a disability and what their lives are like. How technology, assistive or otherwise, adds to the quality of their life is an important consideration in today's fast-paced technologically-oriented world.

What are the stories of the people living in this duality of a socially constructed life, while the physical reality of an imperfect body or brain brackets them with additional barriers to life fully lived? How does technology impact people with disability in their daily life and as part of their embedded life experience?

### **Autobiographical Roots of My Inquiry**

My passion for my dissertation research is derived from my personal experience of growing up with people with disabilities. My cousin Nancy lived in Florida with my grandmother's sister, so I suppose she was my second cousin. We were the same age, however, as my father was the first of nine children, and I was born when my dad was 19. Nancy was the youngest born when my great aunt was older.

We were told we were going to Disney World. I was so excited! I had never been and like all little children couldn't imagine a better vacation. We went to Kissimmee where Great Aunt Rose lived. Upon visiting we were "warned" about Nancy. She was clumsy, and looked a little different, gave great

sloppy kisses and didn't understand things quite the same way we did. Nancy was almost 6 months younger than I was but there were a lot of differences compared with my 8-year-old self. I didn't quite understand why Nancy still had school to go to when it was summer vacation. I knew she would have been difficult at Disney world though. I now know that her Down syndrome would have probably qualified her for a moderately intellectually disabled classroom. This was my first up close and personal experience with someone with learning and living differences, a label of a disability. For family, we had just a label of love and sloppy wet kisses on the cheek.

Growing up, I felt I was destined to be a teacher. I was teaching third grade Sunday school at the small Roman Catholic church in Milledgeville, Georgia with an older friend of mine, while still a sophomore in high school, after several years of working in the church nursery and babysitting in middle and high school. I was drawn to teaching. When I enrolled in my undergraduate program, I started as an elementary education major. That quickly changed after several conversations with my assigned advisor for the Bell Honors Program and coordinator of the Regent's Testing Center for learning disorders. My focus was turned toward majoring in special education.

My additional interest in technology grew over time. I have always liked gadgets and I suppose being a child of the 80s and 90s, made it easier for me to figure out computers and software. Several years into teaching I was asked to be part of the assistive technology team for my county special services department, which met on a semi-regular basis at state consortium meetings for the Georgia Project for Assistive Technology. This included a way to assess and get into the hands, the technology students needed to progress, such as augmentative communication devices, software, and low-tech solutions such as slant boards. I have had several students over the years that used wheelchair trays, communication devices, and the difficulty inherent in being able to show what they knew and express themselves through mediated means.

Through discussions in my doctoral program, I realized that I really wanted to understand the experiences of people with disabilities and the technology used to interact, experience, meditate and express themselves to the world and society. The critical questioning nature of the doctoral program in

curriculum studies was important for me to examine my role as a teacher working with teenagers with disabilities and the voices and stories that were not represented in traditional accounts of disability in textbooks or in lived teacher lore. In the curriculum studies program, we looked at a variety of perspectives including critical race theory, posthumanism, feminism, postcolonialism. We only briefly touched opposing views of ability that countered the ideal man perspective of the scientific revolution. I began to ask myself what are the voices of the marginalized and silenced? Where was disability in these countered perspectives? I began to think I wanted to hear the stories and other viewpoints that could turn special education as an educational viewpoint on its side. I wanted to know if the silence of people with disabilities came from purely physical means something that technology could overcome, or does that a mediated system of technology create a further chasm of difference.

Then change happened to deepen my commitment in unexpected ways. I was offered the opportunity to work at the high school my children would attend and teach with students labeled with a severe intellectual disability. It was a difficult year. I felt like I was a first-year teacher all over again. In the previous eighteen years, I had been working with students labeled with mild disabilities fighting tooth and nail to achieve the same educational content standards as nondisabled peers to get a “regular” diploma. My class now was completely different, which made me question and think deeply about the purposes of education and the praxis between reaching for full intellectual potential and working through the pragmatism of a functional life skills-based curriculum.

Two of my students use wheelchairs, two were ambulatory; all four have to use alternative forms of communication to get their intentions across such as of behaviors of grabbing, throwing, touching, making noises and sounds; a few ASL signs such as “please” or “food;” and occasionally communicating by touching picture language. For once, I couldn’t ask what my students were thinking. I couldn’t ask “Where do you need help?” “Why did you do that?” I was dependent on others views of my students and experiences, my observations of their behaviors, speculations, and trial and error. I was arrested in my thoughts and plans. I was forced to live in the moment. When I sat with one of my students while others’

needs were being met by my paraeducator, I had to stop. Pay attention. Live in the moment. REALLY, focus on that student at that moment.

When I taught high school students with learning disabilities, my focus was always on “What is next?” As students worked on remediation and tried to finish tests using extended time accommodations, I was wondering what next assignment we were going to work on and what skills we needed to solve the next problem. As the students were working on a problem, my mind skipped ahead to the next item on the agenda. We were running parallel tracks of thought weaving apart and together.

In my current classroom labeled Severe intellectual disability/Profound intellectual disability (SID/PID), I had to *be* in the moment. Did I want my students to practice skills of matching or identifying? Sure. That was the surface lesson/objective. The greater skill for my students was not matching pictures to words, but being able to sit with a caregiver and to interact without distracting or aggressive behaviors, to participate in something that the students enjoyed, to extend physical, emotional, and communication skills that would in the long run, give my students a sense of agency in being able to express a choice, a preference, a skill. Interaction and relationships that would improve the quality of their own life along with the community that would continually be caring for them for the rest of their lives.

This was not the world of preparing graduates for the workforce. To become worker bees in a capitalistic society. By society’s standards, my students would never achieve that. And to some people that was reason enough to consider their presence at best quizzical, at worst a waste of taxpayer funds. Many would consider, especially looking from the outside, my current position, little better than babysitting students. These students who according to IQ tests, would place them on age equivalent between 2-4 years old. Though many would consider those same IQ tests questionable given knowledge of their history and purposes, in a world of numbers and boxes, it helps others make sense, sort and categorize my students.

Creating a quality of life, giving chances of choice, self-advocacy, and agency using whatever means necessary of knowledge, skills, communication, technology, and dialogue is now what I consider a useful, purposeful education. Learning to slow down, to allow them time to respond and communicate in



their own modality, even if it is pressing a large switch with a picture of a choice of two items for lunch, these are things that have been hard truths for me. I have always lived in a world of words since I was very young and still do. Books are still often my best friends.

Lastly, as a final bit of inspiration on this journey for me is my friend Sam. Sam was an adult with cerebral palsy that for many years worked for Walton Options in Augusta as their technology director. He had a bachelors and masters degree and used a power wheelchair and a communication device. Sam helped people get the large and small technology they needed to improve their lives. In the summer of 2017, I talked to him at a state DOE conference about being one of my dissertation participants. He was excited about the possibility. He also told me he just changed jobs to work with Georgia Tools for Life to continue to do what he had for Walton Options with a bigger impact. We kept in touch through brief emails and Facebook. He wanted me to keep an eye out for doctoral programs that were online as hybrid programs. The one I was currently in would be difficult for his physical needs and issues. In April 2018, before he could find that type of program, he passed away.

I didn't get a chance to gather his story, and I know it would have been an amazing one. Now I want to learn the stories of those we do not slow down and listen to often enough. I want to experience their stories and just be present.

### **Purpose and Key Research Questions**

The purpose of this study is to delve into the lived experiences of people who have either been identified by the medical or educational community as having a disability and their relationship with technology, either assistive or otherwise, in context with the identity of disability. I want their counterstories of being disabled to help clarify and expose to others the inherent ableism in society by offering a countervailing view of what it means to claim the identity of disability and how technology shifts perceptions of that identity marker. I have research interests in areas of technology and special education and disability studies. I would like to explore several questions or ideas relating to technology and disability.

1. How does the intersection of identity and life experience with assistive technology and technology shape the lives of people with disabilities?
2. How does technology, either as a tool or integrated part of their lives, change the perception of being a person with a disability?

### **Theoretical Framework**

My theoretical framework consists of two strands of Critical disability studies (Goodley, 2017; Davis, 2013, 2017; Erevelles, 2011) and posthumanism (Haraway, 1985/2016; Snaza & Weaver, 2015; Weaver, 2010). Using critical disability studies, I explore views relating to oppression, and exploration of disability against the dominant view of ability as the “norm” using a variety of scholarship (Bayton, 2017; Berger, 2013; Blanchett, Klinger, & Harry, 2009; Chen, 2012; Cushing & Smith, 2009; Davis, 2013, 2017; Dolmage, 2017; Erevelles, 2011; Erevelles & Minear, 2011; Ellcessor, 2017; Gabel, 2009; Garland-Thomson; 1997/2017; Goodley, 2017; Liasidou, 2012; Linton, 1998; McRuer, 2017; Meekosha & Shuttleworth, 2009, 2017; Neilsen, 2012; Reaume, 2014; Siebers, 2008, 2017; Shildrick, 2012; Sullivan & Bal, 2013; Vehmas & Watson, 2013; Williams, 2006). I also draw upon posthumanism to explore the use of technology and assistive technology as a tool or an integrated aspect of our everyday lives, our everyday selves (Birkerts, 2015; Harari, 2017; Haraway, 1985/2016; O’Connell, 2017; Plant, 1998; Snaza & Weaver, 2015; Weaver, 2010). I also explore the applications of this work through lens of work done in social justice through curriculum and assistive technology (Edyburn, 2000; Freire, 1970/2000; Hackman, 2005; Harro, 2018; hooks, 2000; Jaeger, 2015; Johnson, 2018; Kirk & Okazawa-Rey, 2013; Peterson & Murray, 2006; Pharr, 2018; Schubert, 2009; Swain & Edyburn, 2007; West, 2018).

My positionality of being temporarily abled-bodied, means I need to explore the counterstories through collected interviews of varied life experiences. This is different than what I have come across in most of the work of critical disability studies. My exploration of the current narrative work in disability studies lays the groundwork, foundation and is an access ramp to my study, my methodology, and my work.

## Methodology & Introduction of Participants

This study, *Cybermen, Cyborgs and Bionics, Oh My!!: Counterstories of the Intersection of Disability + Technology and Its Impact on Identities of Adults Labeled with Disabilities*, explores the difficult topics of identity, and the intersection of categories of identity that often limit people labeled disabled. By exploring how technology modulates the category label of disability, I hope to challenge myself and others to see how fluid while rooted in realistic pragmatic lived experiences, the identity of disabled is. I am using the plus sign not only to indicate a shorthand for the word “and” but to also indicate the idea of intersection, both perpendicular and skewed between many of these themes. The language of technology is often one of Zeros and Ones (010101) in binary. The ideas of intersection is much more than additive but interweaving. And while the + symbol does not convey that complexity, it does start to move us beyond the binaries of identity that are hallmarks of a divisive and inaccurate representation of people that can be represented by a slash. (Black/white/other, Male/female, Dis/Ability, Rich/poor, etc.) These slashes of division do not represent the rich complexity of humans multiple identities. The whole (human and possibly human + tech) is much more than the SUM of their parts.

I explore the rich work being done in disability studies narratives to give foundational context of what methodological being done currently to express disability as identity. Much of the relevant literature in critical disability studies is being done in theoretical, historiographic, autobiographical methodologies and fictional work (Clare, 2015; Dick, 1968; Haraway, 1985/2016; Linton, 2007; McCaffrey, 1969; Mooney, 2007; Piepzna-Samarasinha, 2018; Sequenzia & Grace, 2015; Thousand, Diaz-Greenberg, et. al, 1999; Taylor, 2017). Many of these works often by scholars self-identified with various disability categories, share the work being done in counternarrative methodology against hegemonic ideology of ableism.

I also explore the importance of counternarrative in the work of social justice and why I chose this as an essential methodology for my study. I briefly review some of the work being done in counternarrative or counterstorying work (Carmona & Luschen, 2014; Delgado, 1989; Glenn, 2012; He &

Phillion, 2008; He & Ross, 2012; Solazano & Yosso, 2002; Tuck, 2009). I explicate the procedures, including profiles of these participants, and questions I use in the interview and data collection process, and my process of data analysis. Then, I write about the significance of counternarrative and the current literature surrounding counternarratives. Finally, I explore the challenges of this work with the unique challenges of the participants and how the interviews and data collection might look different than a traditional qualitative study.

In this study, I interviewed seven adults with disabilities that also use technology and assistive technology to navigate their life. I explored their thoughts on identity and technology and asked them to share those stories of growing up or current experiences. These adults range in age from 19-50, including five white men, and two women: one of South Asian background and one white. All participants have physical disabilities that stem from a variety of medical impairments such as degenerative muscle diseases, cerebral palsy, or impairment from injury and subsequent infections. All of the participants are working in professional capacities with college education some with postgraduate degrees or certifications.

### **Significance of Inquiry**

Why is this important to me personally? In my vocation as a special educator, I have always been focused on the minuscule sections that make up a person's ability. Things we measure, things we compare to a norm, a check-off list of achievements or not progressing. Interventions, strategies to ameliorate "deficits" is what my job is surrounded by, defined by, and measured by, as I measure the students in my care. Individual education plans need to show progress or we should amend them. The implication is that given the right methods, strategies, technologies, curriculums, we can for the most part "fix" what is wrong with students and make sure they are productive, job-producing or job-working members of a taxable society. Often, in my work with secondary students, our focus was to be realistic about skills so we could find appropriate work or school and transition appropriately. This is indeed important, and to some extent, the idea of having no goals to work toward is antithetical to the idea of a meritocracy of

achievement that the dominant homogeny presses as an American ideal. We do need a roadmap of learning. But the question is who gets to create the roadmap. The government, teachers, students? A mix of all? A chaos of none?

Nel Noddings (2005) reminds us in *The Challenge to Care* that “disabled people may be thought of as “at a distance” because we have difficulty in either eliciting or recognizing forms of response with which we are familiar”(p. 124) She discusses among other things where dialogue “connects us to each other and helps us maintain caring relations” (p. 23). This idea of the whole child stretches back as far as Dewey and probably farther. What do I really know about my students, their lives, their struggles, successes, and how our forms of education that label and box into labels so we may “fix”, “remediate”, “accommodate” them into a productive citizenry? Am I just looking at numbers and scores on the page or do I understand the experiences of my students, people labeled with disability, and the wider social construct and community surrounding the disabled community?

Whether someone has acquired an impairment from a genetic abnormality, a mutation, or through some tragic circumstances at birth, or at aged 4 or perhaps did not experience “disability” until many years post-retirement when Alzheimer's robbed them of their memories, we have a community of people we need to understand and fight for the right to live, work, play without barriers. We can only create a community of allies for social justice by hearing the stories, the lives of the people we are championing. We are not called to be a knight there to save the day but to labor shoulder-to-shoulder sharing the fight. This is why understanding the counterstories of people + technology and hearing their voices is so significant.

### **Chapter Outlines**

My dissertation consists of five chapters. In Chapter One, Introduction, I explain my purpose, preview my theoretical frameworks, methodology, participants and significance of this work. In Chapter Two, I explore the relevant literature through the lenses of two theoretical frameworks to examine themes of (1) disability +identity; (2) intersectionality; (3) cyborgs + intertwining culture; (4) technology +

history; (5) technology + critical disability studies and finally (6) technology + schools and curriculum. In Chapter Three, I review the importance of counternarratives to social justice work and share information about the participants and the procedures of my study. In Chapters Four and Five, I share many of the stories of the participants and analyze their lived experiences in light of the themes relating to disability as an intersecting identity with technology. This merges into themes of analysis relating to action. Social justice themes will be explored in both the microcosm of individual teachers in their pedagogy, practice and curriculum, but also in broader terms of what it means to improve access to needed technologies through program capacities and local, state and federal laws that break down disabling barriers to all society has to offer. Finally, in Chapter Six, I conclude my study with my reflection of the inquiry. I dive into the eight findings that I have discovered through my analysis of the counternarratives of the participants.

## CHAPTER 2

### LITERATURE REVIEW

When I contemplate the main themes I am exploring in this study, several important words should be explored: technology, disability, and assistive technology. Technology according to an online dictionary search is the application of scientific knowledge for practical purposes, especially in industry (Oxford dictionary of English, 2010). The word origins are Greek: *tekhnologia* ‘systematic treatment’, from *tekhnē* ‘art, craft’ + *-logia* (study). That word seems to have appeared in the early 17th century. Disability can be defined as a physical or mental condition that limits a person's movements, senses, or activities or a disadvantage or handicap, especially one imposed or recognized by the law. There is no word origin for disability listed but it is noted as the standard term for lack of ability during the second half of the 20<sup>th</sup> century (Oxford Dictionary of English, 2010). *Dis-* means not; and *-ability* is having the capacity to do. A word defined by its lack.

Interestingly, there is no dictionary entry for “assistive technology” in Oxford’s dictionary, nor Merriam Webster’s website (<http://m-w.com>). Dictionary.com based on Random House Unabridged dictionary DOES list a definition of assistive technology as: adaptive tools, as prosthetics or computer programs, designed for and used by people living with a disability to engage in everyday activities. With a word origin/first recorded 1985-1990. (<https://www.dictionary.com/browse/assistive-technology>, Accessed March 1, 2019). As you can see this term has only been coined in the past 35 years.

The interplay of these words, labels, and ideas of disability, technology, and assistive technology are important to several areas of diverse disciplines and gives a foundation to my study of the intersection of these words, labels, definitions in the lived experiences of people who inhabit, and expand beyond the labels of “disabled,” “AT user,” or if you are taking up Donna Haraway’s metaphor, “Cyborg.”

I draw upon several major bodies of research: (1) disability and identity, (2) technology and assistive technology and (3) intersectionality through the narratives of disabled identity both in

autobiography and fiction, and (4) work being done in advocacy and social justice. These themes of research are based on two theoretical frameworks of critical disability studies and posthumanism.

### **Theoretical Framework**

My theoretical framework consists of two strands: critical disability studies and posthumanism. Critical disability studies and disability studies have a wide range of scholars working in the field looking at various aspects of how disability is viewed and theorized (Bayton, 2017; Berger, 2013; Blanchett, Klinger, & Harry, 2009; Chen, 2012; Cushing & Smith, 2009; Davis, 2013, 2017; Dolmage, 2017; Erevelles, 2011; Erevelles & Minear, 2011; Ellcessor, 2017; Gabel, 2009; Garland-Thomson; 1997/2017; Goodley, 2017; Liasidou, 2012; Linton, 1998; McRuer, 2017; Meekosha & Shuttleworth, 2009, 2017; Nielsen, 2012; Reaume, 2014; Siebers, 2008, 2017; Shildrick, 2012; Sullivan & Bal, 2013; Vehmas & Watson, 2013; Williams, 2006). Posthumanism is also a varied field that looks at divergent theories and ideas surrounding the interaction of humans and the world around them, through either machines, animals or even objects (Birkerts, 2015; Harari, 2017; Haraway, 1985/2016; O'Connell, 2017; Plant, 1998; Snaza & Weaver, 2015; Stevens, 2013; Weaver, 2010). I explore the lived experience of people with disabilities who have been silenced, ignored, and coerced to be invisible in segregated spaces, places, and consciousness. As a special educator for more than twenty years, I experience a variety of personalities bounded by the label of "special education" students. Part of that experience is the realization that there is beauty and good in what many would label as grotesque. These experiences have led me to have a deep abiding interest in how disability fits as a marginalized population, in the same way, we address race, gender, and sexual orientation and other markers of identity. My research interests coincide with one of the newer "qualifiers" in curriculum strands. In *Understanding Curriculum* (Pinar, Reynolds, Slattery, & Taubman, 1994), politics, race, gender phenomenology, poststructuralist, autobiographical, aesthetic, theological, institutional text as curriculum are all addressed. Nevertheless, disability is not mentioned, neither is posthumanism.

The main theoretical lens by which I operate is in the critical disability studies framework. According to Reaume (2014) critical disability studies (CDS) "view[s] disability as both a lived reality in



which the experiences of people with disabilities are central to interpreting their place in the world, and as a social and political definition based on societal power relations” (n.p.). Just as Critical race theory (CRT) provides a critical analysis of race, and feminism does the same for issues and power differentials surrounding gender, critical disability studies casts a critical eye not only on representation of disability, but also at ways of looking at disability through the critique of ableism. People of color are not inferior to whites. Women are not inferior to men. People with disabilities are not inferior to temporarily abled-bodied individuals. Ableism rejects the mode of thinking that the norm is superior. Disability is just another way of being on the continuum of humanity. If you ask some animal rights advocates, they might say just another way of being for all living things, rejecting an Anthropocene outlook of human-only variation. I will discuss more in depth critical disability studies later in this chapter.

Interest in science and technology has filled my education journey and sometimes intersected with my interest in disability studies. Donna Haraway’s groundbreaking work in 1985 explored the nature of science and feminism and is extremely important to the work that evolved into posthumanism. In *Cyborg Manifesto*, Haraway prompted me to explore ways of looking at the world differently in society’s interactions and changing views relating to the tools of technology. She also muses about the idea of the severely disabled as the ultimate cyborg. This is a prominent inspiration for my exploration of disability and the intersection of technology. This exploration of technology and its relationship with all variations of humans not only changes society in its outlook, but also ourselves and even how our brain is “wired” differently. In reaction to this interest, the second theoretical framework I use in my research involves the interaction of technology and humanism: posthumanism.

What is posthumanism? According to Weaver (2010) there are “almost as many ideas and definitions of the posthuman as there are people writing about the subject” (p.10). Snaza and Weaver in their introduction of the edited book *Posthumanism and Educational Research* (2015), point out “it is about how one relates to that present and to the enormous, almost crushing weight of several millennia of humanist thought” using “posthumanist reconceptualizations of human/animal/machine/thing relations to diagnose how humanism ignores, obscures, and disavows the real relations among beings and things that

make up the stuff of the world” (p. 1). The work is divergent and interrupting to the forward progress of humanism claimed by multiple disciplines and thinkers across multiple centuries. In my dissertation research, I focus on the relationship of those beings we call disabled and machines. In the narrower scope of this work, I am focusing on technology and assistive technology.

Posthumanism theory has important implications for how people labeled with disability can interact and be viewed in the world, as something more than just a human body that has some “deficit” or “disorder” or “defect.” According to John Weaver (2010) in *Educating the Posthuman*, the “posthuman condition implies the merging of humans and machines in order to enhance or improve human capabilities” (p. 11). Whether it is a motorized wheelchair, an app that reminds a person with autism what is the probable proper response to a social interaction in a grocery store, or assistive augmentative communication (AAC) devices, technology creates a mediated experience for people with disabilities both to enter more fully into the social world, and paradoxically to create another area of separate identity that could now be shared and articulated in the world as another important community of diversity.

### **Critical Disability Studies**

According to Goodley (2017), critical disability studies (CDS) is a complex theory that has emerged from disability studies and is marked by eight things it IS, and six items it IS NOT. Goodley reports that CDS: (1) analyzes materialism and social model of disability, (2) is aware of income inequality and globalism, (3) views contexts from local to global, (4) is culturally relative, (5) is relational, (6) is a reflection of “dismodernism”, (7) is critical, and (8) is politically active (2017, p. 191-192). Goodley (2017) goes on to say that critical disability studies is not:

- (1) a futile exercise that simply adds the word ‘critical’ to disability studies to suggest that all previous examples of disability studies have not been critical;
- (2) just another approach to sit alongside traditional approaches like materialist social model perspectives;
- (3) the insertion of a discursive preoccupation with culture that ignores the material realities of disablism;
- (4) simply the study of disability (or ability for that matter);
- (5) an academic exercise without political

commitment, only constructed to keep academics in their jobs; (6) incapable of having values and ambitions that it wants to share with the world. (p. 192)

This expansive list shows how complex this theory can be encompassing many different perspectives of looking at disability. At its most basic level, I feel *critical disability studies is a critical way of looking and theorizing ableism encompassing several approaches leading up to political or material actions that improve the lives and wellbeing of people with disabilities*. Ableism, much like critical race theory and feminism is a civil rights fight, but in this case against discrimination of people with disabilities in favor of the hegemony of “ability” or a norm. What Garland Thompson calls the “normate.” She reports it is the “constructed identity of those who, by way of bodily configurations and cultural capital they assume, can step into a position of authority and wield the power it grants them” (1997, p. 8).

By being critical of the idea of a normate population and of the power differentials that ableism brings to light, critical disability studies is the fight for recognition of the needs and voices against oppressive social and institutional structures that make the well-being and well-lived lives of people with disabilities difficult. By embracing this critical view of disability studies, and disability/special education in general, I have come to be much more expansive in what I consider important values and ideals for my students and the people with disabilities in my own life. My cousin Erica, a young adult in Ohio, isn't just a list of symptoms that equates to a diagnosis of Autism and all of the things she struggles with doing in her daily life. Erica is a joyful, obsessively family oriented young lady that loves to help in the church kitchen, and ask about how each person in our large family fits in the family tree. She writes card and letters to family and friends, a practice all but disappeared in this current society. Erica's talents are not valued in this capitalistic society, so her parents have to spend a lot of time finding good places where her talents can shine, and wade through beauracatic red tape to get the supports she needs and has been promised by our government. What makes her talents less useful and important in our society? Is it an appropriate model of society that devalues and dehumanizes large groups of people and creates larger and

larger gaps of equality in power, livelihood and leisure? Critical disability studies has given me to tools by which to analyze the world around me.

How did the idea of critical disability studies evolve? Disability has been theorized and addressed in a variety of ways over the course of history. In this section, I briefly discuss the historical trend of how disability has been viewed through medical/deficit models and special education, to disability studies beginning in the 1980s, to critical disability studies (CDS) just in the past ten years. After reviewing briefly the historical context of disability in light of the medical/deficit model and the work in disability studies, I explore the work of Helen Meekosha and Russell Shuttleworth (2009), then Shildrick's work in 2012 in which she felt CDS needed to have a postmodernity bent. I then turn to critiques of Vehmas and Watson (2013) of Sheldrick's 2012 work. Finally, I look at Dan Goodley's research (2017) summarizing the state of CDS. His work focuses on finding common threads of this research to create a working definition. He also looks at areas that critical disability studies can grow in future work to include more directions and voices. By exploring the context and foundations of critical disability studies, I can explain why this is an important theoretical framework within which to seat my current study.

Beginning with the scientific revolution of the 1700s, disability when compared to a "standard" norm, most often with the norm of white, male of European descent middle or upper-class, was relegated to a medical model of the deficit. Disease, disorder, and disability were things to be cured, controlled or rehabilitated. This medical model influenced schools in how they addressed difference and disability. Throughout the 1950s and following *Brown v. Board of Education* (1953), advocacy for inclusion and specialized training of teachers followed the civil rights fight for policy and law changes of the 50s and 60s, federal court cases such as *Pennsylvania Association for Retarded Children (PARC) v. Commonwealth of Pennsylvania* (1971) and *Mills v. Board of Education of District of Columbia* (1972) culminated with the passage in 1975 of P.L. 94-142, *The Education of All Handicapped Children Act* by the federal government. This was reauthorized, amended and renamed in 1990 (P.L. 101-476) and 2004 (P.L. 108-446) as the *Individuals with Disabilities Education Act*. Throughout most of this push and pull between the forces in society to fix and remediate what was considered deficit and the forces of advocacy

to include children with a free and appropriate public education, the deficit model dominated the view of what disability was defined as for most, if not all of society. Only with a grassroots effort for the passage of the *Americans with Disabilities Act* (1990) is there an acknowledgment as disability being marked by barriers in society that individually, structurally and institutionally should be removed. For the first time this acknowledgment in law pointed to disability not as just an individual “problem” to be cured or rehabilitated, but an issue of society’s barriers that need to change to allow all Americans full access to public buildings and institutions.

Part of the change in this view of disability also coincided with the beginnings of change in how we think and theorize disability. In the 1980s, there was emerging work being done in what is now called disability studies primarily in the UK, US, and Canada. In 1986, the Society for Disability Studies was renamed from an earlier organization (<https://disstudies.org/index.php/about-sds/mission-and-history/>) and the first academic programs in disability studies started appearing in the mid-1990s. In 2009 Cushing and Smith reviewed the growth of disability studies in research and programs in post-secondary institutions in several countries. Their distillation of various program definitions of disability studies (DS) from colleges and universities along with the Society of Disability studies a definition of DS can be summarized by the common threads of: (1) challenging the dominance of medical, individual, deficit-based models of disability (while not dismissing their contributions); (2) considers disability part of the continuum of human experience; (3) examines the environmental and social barriers; (4) interdisciplinary; (5) inclusive: participation of disabled people and their families is essential; (6) accessibility in DS courses, conferences, journals, websites and buildings; and (7) accounts for cultural and historical context (Cushing and Smith, 2009, *Disability Studies Quarterly*, Vol. 29, No 3, <http://dx.doi.org/10.18061/dsq.v29i3.940>).

Even after over thirty years of discussion, in 2009 Disability studies research and programs were just beginning to have some commonality about what disability studies is or is not. The past forty years have seen growth in scholarship in disability studies with multiple models of disability explored. In the past fifteen years, one area of exploration of disability studies that aligns well with my exploration of

disability in this study is that of critical disability studies. As stated at the beginning of this section, it is a way of theorizing and researching ableism leading to material or political actions that contribute to improved lives of people with disabilities.

In 2009, Helen Meekosha and Russell Shuttleworth mention the emerging research of critical disability studies with citations starting in 2005. Meekosha and Shuttleworth point out that the social model of disability studies “argued for a conceptual distinction between 'impairment' as a functional limitation and 'disability' as a socially generated system of discrimination” and that “using the term 'CDS' is a move away from the preoccupation with binary understandings- social v medical model, British v American disability studies, disability v impairment” (p. 50). The authors point to an influx of “postmodern leaning and decentering of subjectivity during the 1990s” (p. 50), concerns of the “cooption of the language of disability studies by institutions of government,” (p. 51) and identification with critical race theory, critical legal theory, critical criminology and critical queer studies sets up the factors for why critical disability studies is different than the disability studies movement that dominated the 1980-1990s. This isn't to say the work in disability studies was transmuting into critical disability studies. The authors envision that CDS will open up new lines of inquiry-based on critical social theory to an “expanded understanding of disabled people’s place in the world” (p. 66). This decentering was an important theoretical movement away from binary to continuum, or some might argue even a divergent rhizomatic growth of theorizing in different directions along a continuum of what disability is.

Whereas, Meekosha and Shuttleworth examined the role critical theory had on CDS, Shildrick (2012) continued to develop work she did in 2007 through her exploration of the postmodern view of Critical disability studies. By using a postmodernist lens she views CDS as “underlying each of those inherently resistant discourses is a retheorization of the question of difference that entails a radical shift from the modernist privileging of an autonomous and stable self to the postmodernist contention that the self is always embodied, dependent on its others, unsettled, and always in process” (p. 37 Location 1483, Kindle edition). In other words, disability is far from a stable identity, in that we could view everyone as on a continuum between temporarily abled-bodied to severely disabled. That there are multiple ways of

being human that the postmodernist approach embraces. She points to the diversity of the disability as an identity group as problematic to the social model of disability studies. She points out that “where mainstream disability studies has relied on a narrative of progressive transformations of meaning – from early Judaic biblical models of impurity to a dominant biomedical approach that pathologizes the disabled body, and more recently to the SMD analysis that has politicized the problematic – CDS works with a far more messy, disorganized and insecure set of indicators” (pp. 37-38, 2012). I appreciate the deep theoretical work done by Shildrick, but I along with Vehmas and Watson discussed below, am concerned that this theoretical focus of trying to fit critical disability studies in a postmodernist lens avoids the material barriers people with disabilities face.

To illustrate the unstable nature of thoughts on what CDS could be defined as Vehmas and Watson (2013) critique Shildrick’s postmodernist lens by asking how CDS approaches ethical and practical day-to-day events in a person’s life in respect to disability and health and well-being. Vehmas and Watson argue that “CDS often makes normative judgments about policies or about the current understanding of disability or how contemporary social organization is morally wrong, it offers no evaluative arguments on impairments or on the implications of living with an impairment” (pp. 640-641). They point out by accepting postmodernisms view that there is no single mode of embodiment, there are “some forms of embodiment are preferential to others, they are ultimately referring to ideas about human well-being” (p. 641). Vehmas and Watson (2013) critique CDS as not engaging with ethical issues that is the work of taking disadvantage to improve health and well-being of all people. They proffer a capabilities philosophical theory that is the basis for practical policy development at the United Nations and a number of national governments such as the United Kingdom. Vehmas and Watson (2013) defined:

The influence of CDS and its challenge to the assumption that disability is a uniform condition have enabled the emergence of new ideas on disability. In particular, this has enabled the development of a theory that can take account of not only impairment effects but also can include class, ethnicity, sexual orientation or cultural identities. It has also argued for the re-emergence of a new political identity, one where a solidarity that was previously built on a common single

identity is replaced by one that incorporates multiple voices including representatives from across the range of constituencies. The politics that it seeks to develop will be the ending of the single interest group identity of the disability movement to be replaced by single-issue groups campaigning for different social issues. (p. 646)

They want to point out that often the “the problems disabled people face require more than ideological change, and ideological change is of little use if it does not result in material change” (p. 647).

As the field of critical disability studies grows and matures, the gaps pointed out and differing viewpoints about what the field should look like probably grow in different divergent ways while maintaining several commonalities. Dan Goodley (2017) devotes a chapter at the end of his book *Disability Studies an Interdisciplinary Introduction* to critical disability studies as “a location populated by people who advocate building upon the foundational perspectives of disability studies while integrating new and transformative agendas associated with postcolonial, queer and feminist theories” (p.191, Kindle Edition). He does not share the view that CDS is without an ethical and material reality that Vehmas and Watson feel CDS lacks. In using an overview approach Goodley identifies eight factors he considers part of disability studies and six factors that are not. These are the factors I delineated at the top of this section. To me it is the most comprehensive definition of the complex perspective of critical disability studies. It considers the maturing of this theory over the past 15 years. He goes on to explain how CDS can be broken up into four approaches or perspectives: (1) Crip studies, (2) critical studies of ableism, (3) global south disability studies, and (4) dis/ability studies. These perspectives all disrupt the idea of what it means to be called disabled or be disabled. They are the ways current scholars continue to expand the ideas and translate those ideologies into actions to help the wellbeing and material reality of people with disabilities. Those four approaches to critical disability studies all can address themes in CDS in different ways. Goodley identifies three themes of CDS to close out his chapter on Critical disability studies and his book on disability studies as themes to move forward with this scholarship. The three themes (pp. 201-208) are: (1) Question of the human, (2) Bodies that matter, and (3) Global biopolitics of dis/ability which gets into discussion of both the global south but also of biopower and complex problems



NGOs (nongovernmental organizations) face in improving the health and wellbeing of all people. These themes Goodley brings up are currently on the leading edge to which critical disability studies can continue to question, critique and ask for action from society and governments across the world.

Williams (2006) shares that:

there are multiple ontologies of disability. These ontologies exist in the biomedically constructed body. In the person's relationship to the "lived," between the person and the people with whom he or she comes into contact, and between historically formed society (encompassing political economy, social welfare, culture, and ideology) and the person as a member of that society.

(p.129)

More exploration of these relationships between people, society, and in my opinion, objects such as technology help to define these ontologies. If you cannot understand the history of society, if you do not examine the current relationships between people with disabilities and with whom they inhabit society, or the role in which they inhabit in society, are you looking deeply enough to critique and demand change to eliminate dehumanizing barriers in society.

In the next two parts under this theoretical framework of Critical disability studies I examine how scholars, whether through the lens of disability studies or more recent work in critical disability studies, have explored the themes of disability identity and disability intersectionality.

Davis (2017) tells us that critiques of normality are being explored "as disability studies progress along with postmodernism and posthumanism" (p. 13). In the past thirty or so years, theorists have begun to explore the boundaries of what has been termed "ableism" as a parallel to the work done with regards to racism and sexism. The exploration of identity is a complex one shaped by historical factors, and often linked to the story of critical race theory and feminism in the ultimate form of "othering." The power structure of denigrating others as weak, disabled, and unable to contribute meaningfully to society plays a large role in the suppression of many of these categories of identity. This intersectionality "makes complex the general rubric of disability itself" (p. 13). American Educational Research Association's special interest group in Disability Studies in Education focuses on ways to "promote the understanding

of disability from a social model perspective drawing on social, cultural, historical, discursive, philosophical, literary, aesthetic, artistic, and other traditions to challenge medical, scientific, and psychological models of disability as they relate to education.” (Disability Studies in Education SIG 143, n.d.). Work of participant-scholars along with temporarily able-bodied scholars pepper this field and have many intersections of curriculum studies and theories which will be explicated throughout my discussion of CDS, posthumanism and social justice work in society and the classroom.

### ***Disability + Identity***

Kirk and Okazawa-Rey (2013) point out that “identity formation is the result of a complex interplay among a range of factors: individual decisions and choices, particular life events, community recognition and expectations, societal categorization, classification and socialization, and key national or international events” (p. 8). But identity isn’t just a personal signifier, it is also a social category where often others “think they know who we are and how we should behave” (p. 9). I would also point out not addressed by Kirk and Okazawa-Rey, but by many other scholars in the fields of critical race theory, feminism, and disability studies that identity is historically situated and embodied. How society forms labels and categories is embedded in the political, economic and social milieu that makes our history. Much of the beginning scholarship in disability studies, following the steps of Critical race theory (CRT) and feminism, explore those historical underpinnings (Nielsen, 2012; Dolmage, 2017; Garland Thomson, 1997; Erevelles, 2011; Davis, 2013; Bayton, 2017; McRuer, 2017).

Disability as an identity is complex. It is rooted in physical and mental barriers of societal oppression and history. It is conflated with other identity categories to strengthen reasons for oppression. It is rooted in the daily lives and civil rights struggles and embodiment. Disability, as an identity is at once both individual, claimed proudly at times as cultural (deaf culture in particular, and in recent times Autism community), and other times prescribed by comparison to a societal-chosen “norm” as a deficit defined by the medical and educational communities.

Disability is so complex that scholars in disability studies use a multitude of theoretical lenses and theories by which to examine it. Examining what disability is through the lenses of history, minority

models, social constructivism, historical materialism, post-positivist views, economics, postmodernism, posthumanism, metaphors in literature and media, social justice movements, embodiment, and the roots of scientific normalization and data to label and categorize people are some of the facets of research explored by disability studies and CDS scholars. Linton (1998) points out that a disability studies perspective adds:

a critical dimension to thinking about issues such as autonomy, competence, wholeness, independence/dependence, health, physical appearance, aesthetics, community, and notions of progress and perfection -issues that pervade every aspect of the civic and pedagogical culture.

They appear as themes in literature, as variables in social and biological science, as dimensions of historical analysis, and its criteria for social policy & practice. (p. 118)

For every modern mode of exploring the lived and/or cataloged experiences of humanity, so do those modes apply to how disability fits in the idea of a variegated, diverse human experience.

Since the 1980s disability studies began to grow out of the civil rights and social justice activists of the 1970s disability rights movements. Growing out of the civil rights struggles regarding race, gender, and sexuality fomenting in the 1950s-1970s, disability rights activists claimed their identity in the name of justice and access and the fight against dehumanization. The idea that the social justice actions to make people's daily, material, and embodied life better, is followed by the theoretical study of the concept of disability and identity following those same historical patterns. Linton (1998) succinctly reminds us through her own personal lens of lived experience in a wheelchair and through her scholarship that "the question of who 'qualifies' as disabled is as answerable or as confounding as questions about any identity status. One simple response might be you are disabled if you say you are. Although that declaration won't satisfy a worker's compensation board" (p.12). Disability is both a claimed personal experience and identity but also parallel to society, through government, educational, and medical institutions' labels by which checklists, tests, and hoops are jumped through, whether you choose to claim the label or not. Just fill out an application for Social Security disability insurance to verify that claim. As a service provider, I have personally filled out disability adjustment service paperwork for students turning 18 that were 15-20

pages long “proving and documenting” their disability to the Social security administration even if the severity of their physical and medical impairments have been part of the government’s records at birth, or very close to that.

The questioning of the medical/educational deficit model of disability in scholarship slowly gathered steam in the 1980s and 1990s. And with other young fields of scholarship, the interdisciplinary nature of disability studies created those many windows and choices and frameworks by which to explore the subject. As the scholarship has grown, tendrils of different intersections, interests, and a sharpening of focus and questioning current homogenic beliefs about disability and people labeled disability have rhizomatically grown. One important offshoot is critical disability studies that was discussed previously in this section. Meekosha & Shuttleworth (2017) feel that a “critical, emancipatory orientation” (p. 181) is the main reason for disability studies as a mode of social transformation. Since critical theory explores power dynamics, whether it be rooted in the Franklin school scholars, or Foucault, this basis of criticality has us “examining the power dynamics and hierarchical social relations of gendered disabilities” (p.185). Chen (2012) discusses why language and labels matter in their (*chosen personal pronoun*) work on animacies where “discussions of dehumanization and objectification depict persons actively subordinated to structures of authorities” (p. 45). For example, Chen recounts an anecdote from Lennard Davis that Terri Schiavo been considered a “severely disabled woman” rather than a “vegetable,” different politics--even different legal consequences--would have ensued” (p. 42). This brings in questions of the intersection of disability in the light of an anthropocentric human cognition that many scholars across multiple disciplines are beginning to explore (Chen, 2012; Despret, 2016).

This also applies to us currently in a critique whereas “disability been a concretizing metaphor, used to illustrate abstract theories and not interrogated for its own political baggage and relation to lived experiences and identities (Ellcessor, 2017, p. 1763). The lived experiences of students either with claimed identity or the assigned identity of disability has only been strengthened in its deficit model in the educational context. Liasidou expositis that “the ideologies of the market has given rise to contemporary versions of ‘ideal students’ who regarded as ‘Human Resources’ rather than ‘resourcefully human’”

(Liasidou, 2012, p. 174). This intersection of neoliberal forces on schools in service to the market hurts students with disabilities and reinforces that disability is the *lack*. The tension between test scores and pressures of the business, career-oriented views of schooling are at perpendicular cross-purposes with the civil rights-oriented inclusion models. Inclusion is “reduced to a special education artefact that creates and consolidates fixed and essentialised understandings of students’ ‘disabled identities’” (Liasidou, 2012, p. 174). This is a lived experience of mine. I have taught in a high school setting for over twenty years. As a coteacher or sometimes termed interrelated resource teacher, I had dual goals of helping students improve on deficit areas and weaknesses listed on their Individual education plans, but also to “get them across the stage.” The market orientation of secondary schooling makes every “why” of every student be answered “So you can get into a good college and get a good job and have a good life.” Yes, even if the logical thinking created by Algebra will not be explicitly used by many students in their daily adult life. Special educators are asked to stand on two tightropes at cross angles from each other in the purposes of educating our students. The focus on what students lack can often be demoralizing for both student and teacher.

Is disability a social model, a postmodern model, a minority, or a historical materialist model of identity? Depends on who you ask, or study. The exploration of these lenses by scholars have often been seated in the qualitative and theoretical areas of research, complicated by expression of personal narratives intersected with theoretical musings. Before I delve briefly into a few of these lenses of identity, I want to point out that even in research studies that use quantitative methodology the work grouping or categorizing identity in the context section or conclusion section are being eroded by the ideas that identification factors beyond “students’ medical, developmental, or cognitive functioning.” This widespread concern stems from outside factors that can lead to subjective disability categories (Sullivan, & Bal, 2013, p. 476). The call for more research on intersectional factors to refine if it is truly a function of disability or other social identity factors, poverty, or differential treatment and “differential opportunity to learn in an economically stratified society” (p. 490) complicates the educational and medical deficit model of disability and the research being done with disability as a category. Do we truly know which

part of a student's person is due to their societal view of a lack of disability or is it a reflection of the supports the students need in their early life due to not having enough to eat, or their parents working two or more jobs to keep the family afloat financially.

Exploring disability through critiques of majority identification is one way of teasing out a nuanced view of disability. Siebers (2017) points out that identities most frequently in the analysis of minority identity- only people of color, Jews, Muslims, gay, lesbian, bisexual, and transgendered people, women and people with disabilities seems to possess unhealthy identities” (p. 137). But that minority identity discovers its “theoretical force” (p. 319) by representing similar stories, and experiences of oppression of different minority identities but also to “increase the chance of political solidarity” (p. 319).

Erevelles (2011) complicates social construction of disability through a historical-materialist view of disability that argues the social construction of the disabled body emerges from “the specific ways in which society organizes its basic material activities (work, transport, leisure, domestic activities)” (p.181). She advocates that we look at the real and intersecting components of race and economics that devalue the economics of care and point out the work of Sara Ahmed as another way we can look at the value of people with disabilities outside of a capitalistic worth/non-worth of labor and economic productivity. She also looks to a more nuanced explanation of disability than what posthumanist analyses have focused on “that of the bourgeois self” (p. 196) and argues for a dialectic that “foregrounds in searing reality the actual violence of economic exploitation that produces difference that refuses to disappear” (p.196-197) even in light of posthumanism “most transgressive discursive imaginaries” (p.196).

Rosemarie Garland Thomson's work *Extraordinary Bodies* explores another way disability is shaped: through representation strategies in books, and performance such as freakshows that gained popularity in the United States in the 1840s. Work that intersects examining literature and how disability is represented has been done in individual books and stories and broad analyses over the years by various authors from disability studies backgrounds, to literature and historical fields. In the introduction to the 20th anniversary edition of the book, Garland Thomson points out that “disability is an almost clichéd

representational strategy through which to achieve the grit of naturalism and realism, the affect of sentimentalism, the irony of modernism, and either clueless or transgressive humor (Garland Thomson, R., 1997/2017, p. ix). Her exploration of freak shows interrogates parts of our history in America's growth and expansion years up until the 1940s casts a critical eye on the representation of women and disabled people in both historical events and literature examples such as work by Harriet Beecher Stowe, Rebecca Harding Davis, Elizabeth Stewart Phelps, Ann Petry, Toni Morrison, and Audre Lorde.

Disability can be viewed from another angle if individuals identify positively with disability, akin to feminism, black and red power movements and gay pride according to Siebers (2008). He argues that it can garner tangible benefits of freeing them from violence and hatred but also shared community (Kindle locations 339-343). The social justice, civil rights focus uses identity as a point of pride to fight against the dehumanization of oppressive tactics and laws. He points out the example of the Deaf community on Martha's Vineyard during the 1700s where "one in twenty-five residents was deaf and everyone in the community knew how to sign" (Kindle locations 1483-1484). I would also interject that the Autistic community has begun to also position their lives and work by acceptance of 'Neurodiversity' as an important, pride-filled part of their personal community, and the 'neurotypical' community gets named as such by them, claiming and flipping the script of labeling. Siebers feels that the most important objective of disability studies is to "make disability an object of general knowledge and thereby awaken political consciousness to the distasteful prejudice called 'ableism'" (2008, Kindle locations 1628-1630).

Susan Gabel (2009) points out and reiterates the difference between the social interpretation of disability and typical educational views of the deficit model and how it tends to 'pathologize difference and rely upon expert knowledge' (p. 2). Gabel looks through a Freirean form of praxis and emancipatory research model that "brings about equity, social justice, and full participation in a society where the work toward social change is led by those who are, themselves, oppressed" (p. 9). Though Siebers' work does not specifically mention a Freirian outlook, the parallel tracts of the positive identity of disability and praxis, as expounded on by Paulo Freire in Gabel's discussion shows the movement of research and work as a means to connect to the real experiences and problems and solutions in the disability community.

One interesting component Gabel (2009) brings up is the tension and “methodological dilemma for educators” of how “to balance the need for improvement of function (often the school’s concern) with the refusal to pathologize the reticence to “cure” difference (two concerns of social interpretations)” (p. 9). This is the dilemma of the educator in work and practice, this is similar to the dilemma of researchers who pursue a Frerian position whilst being part of the dominant class, in the case of disability, of being temporarily able-bodied.

The history of disability is an interesting bridge between disability as identity and the intersectionality of disability with other social or identity categories. By exploring where disability is historically situated, you begin to understand the points of intersectionality touching and diverging between disability, race, gender, and sexuality. People, society, civic/governmental institutions all have used disability as a reason for oppression and conflated it with other categories to explain the oppression of African Americans, women, and people with different sexual orientations and genders opposed to the heterosexual white male who was a productive member of middle class or upper class, i.e. the “everyman.” To understand the current theories of identity of disability, and how it is entangled and related to intersectionality and diversity research many scholars have begun to unpack historical events through a “crip” lens. Much like the idea of “queering” theory to bend perspective of historical analysis, a “crip” lens does similar: bending, breaking, crippling the traditional historical accounts.

This important aspect of disability studies that is also echoed by curriculum studies historians involves the idea that you have to understand history in the light of your topic in order to contextualize the present and theorize the future. Scholars interested in the current state of disability as a marginalized population, often turn part of their focus on how history can be seen in a new light through the lens of how dominant populations treated people with disabilities and often conflated disability with other marginalized populations in an effort to discredit their experiences and humanization.

Lennard Davis (2013) feels the explicit bias against people with disabilities and the raising up of ability dates back to the Scientific revolution and more specifically “the nineteenth century concept of “the normal person (*l’homme moyen*) by Adolphe Quetelet and of the bell curve by Sir Francis Galton



[which] acts as both scientific and cultural imperatives socializing people to find their comfort zone under the reassuring yet disturbing concept of normality” (p. 1). Davis theorizes that Galton used the concept of a normal curve to “camouflage what he actually wanted, which was a bigger, smarter, stronger, more dominant human being that corresponded with the putative traits of the dominant social and political classes in a racialized and sexist society” (p. 2). Under the guise of objective science and statistics, we have buried racist and sexist oppression under the traits of ability as a rationale for “rule by elites” (p. 2).

Bayton (2017), Dolmage (2017), and McRuer (2017) all in different chapters in Davis’ *The disability studies reader*, either take readers through various and explicit time periods such as Ellis Island or Eugenics movements of the early 1900s to reinforce the inter-linkages of oppressing race and gender using the metrics of “normality” or “ability.” Bayton (2017) tells us we need to historicize disability as “one of the most prevalent justification for inequality, has rarely been the subject of historical inquiry” (p.19). He elucidates that disability has been “used to justify discrimination against other groups by attributing disability to them” (p. 18), implying it was perfectly acceptable by society to discriminate due to someone not meeting another’s version of normal or fit. Dolmage (2017) repeats this idea by pointing out “the categories of the physically and mentally defective were created and used in service of racism as a means of darkening a group of ethnic others with the stigma of disability” (p. 51). In an enlightening look at the records and observations of how immigrants were sorted at Ellis Island, Dolmage uses words of the historical record to show how within 6 seconds per person inspectors would judge the fitness of immigrants entering the country and not being a “burden” to the community-based on observation and bias. For example, “the moron [was] designated as a high-functioning feeble-minded individual, yet capable of passing as normal, being attracted to normals, highly sexualized and thus an even greater menace to the gene pool” (p. 56). This “threat” was used as justification and “created the need for greater diligence and surveillance, and inspection and worry in the whole population and on the borders” (p. 56).

In the 1840s, racism conflated with disability was used in service of justification against the abolition of slavery. In the “U.S. Census of 1840, for example, free blacks were inaccurately reported to have an incidence of mental illness that was 11 times higher than slaves and six time higher than whites”

as statistics to justify slavery (Berger, 2013, p. 60). At the same time in the 1840s, freakshows in Europe and the U.S. were on the increase as entertainment and control of the “other.” Rosemarie Garland Thomson spends a chapter of her 1997 book exploring this phenomenon in the light of oppression and exploitation of race, gender and disability. Burger (2013) tells us that “as a social institution, the freak show helped reinforced the curious of their own normality and superiority, and helped construct disability as the ultimate form of deviance” (p. 62).

Nielsen (2012), a historian, tackles looking at disability in the United States from pre-colonial times to the passage of the Americans with Disabilities Act (1990). She points out interesting events, particularly in the lead up to the Civil rights era. I had personally never heard of the activist “Paul Strachan and the American Federation of the Physically Handicapped (AFPH), a cross disability activist organization” (p. 151) or his work that called for “policies and programs that focused on social structures and what’s in which they excluded people with disabilities. Disability, he argued, was a class and labor issue” (p. 151). This was the 1940s, not the 1970s.

Disability advocacy between the 1920-1970s often intersected with labor movements. I speculate why it isn’t as well known in schools today. In current U.S. history textbooks publishers have a conflicted outlook on sharing positive aspects of labor unions and laws outside of child labor laws. Nielsen tells the story of Robert Payne and the “Disabled miners and widows (1960s-1972) [as] a story of class, labor, race, and place; it is also the story of the social movement that culminated in President Lyndon B. Johnson’s Great Society” (p. 159). The work of disability advocacy and labor unions is closely intertwined culminating in the Vocational Rehabilitation Act of 1973 where many of our current initiatives for disability work adjustment and funding of research and dissemination of assistive technology comes from.

As do many scholars, Nielsen reminds us of the coalescing of the disability rights movement in the late 1960s and 1970s from “previously disparate elements” much “like the movements for women’s rights, lesbian, gay, bisexual and transgender rights, the environment, and racial freedom” (pp.161-162). The disability rights movement was built on a history of oppression from ancient times and the Age of

“Enlightenment” to the disparate movements of war veteran’s rights and post-war adjustment, to labor movements and finally civil and human rights. If we have no grasp of this history in how disability was used to conflate and justify racial and gendered oppression, we cannot theorize and understand the real intersections of those oppressions and the lived experiences of people living in between and amidst the intersections.

This walk through historical analyses by various scholars is an important component to understanding disability as a historical artifact, and so we can theorize under multiple lenses in the work of current scholars. Much of my historical knowledge over the years has come from traditional textbook accounts taught in school. These surveys over the years have been critiqued for being a Euro-centric, male, capitalistic and militaristic view of history. Marginalized groups such as women, African Americans, Asian Americans, and people with disabilities are notably absent with the exception of the “exceptional minority” side bar. Reading these accounts by Dolmage, Neilsen, Berger, Bayton, McRuer was like shining a light on a long neglected and dusty corner of historical accounts for me. Personal accounts, field notes and historical documents bringing the stories of the Eugenic movement or Ellis Island was transformative for me. It also created in my head and heart room to be critical of majoritarian accounts in both history and current events.

### ***Intersectionality***

If my work in this study is to explore the intersection of technology and disability and its impact on disability as an identity, I need briefly to explore what intersectionality is and how it has been used to theorize other experiences of faceted identities. Part of this study is to suss out ways in which people view the integration of technology into the lives of people and people with disabilities in particular. Is technology and assistive technology just a set of tools or has it become an integrated part of the identity of people. If so, is it something in need of viewing through the lens of intersectionality?

In contemplating these questions, a Biblical and hymn quote popped into my head. “We are many parts, but are one body.” (Marty Haugen, 1980 song based on 1 Corinthians 12:20). While this refers to how people fit into a working healthy community, the analogy can be applied to how intersectionality is a

sort of fluid- mosaic model. Similar to this model in Biology regarding cell membranes, this makes up the components of someone's personhood into a varied but unified whole. The different identity markers or categories all have their own history in a society that influence how people treat an individual and how it impacts the self-concept of the individual. The worldview thrust upon them. Highly individualized.

Collins and Bilge (2016) remind us that "intersectionality as an analytic tool gives people better access to the complexity of the world and of themselves" (p. 2). The analyses of intersectionality began with feminist theorists and refined into intersectionality of black feminist theorists in the 1970s, often attributed to Kimberlee Crenshaw opens up this theory to the constant motion of action and reaction of many parts or "major axes of social divisions in a given society at a given time, for example, race, class, gender, sexuality, dis/ability, and age operate not as discrete and mutually exclusive entities, but build on each other and work together" (Collins & Bilge, 2016, p. 4). The focus on how the different parts of societal markers work internally and externally represent a focus on relational thinking which moves beyond an either/or binary and "embraces a both/ and frame" (p. 27) which leads theorists, practitioners in social work such as education, social work, policy advocates to examine the relational and interconnectedness. The applied fields, such as education, grounded in a history of praxis not only "tackle questions of how interactions between social inequalities...shape educational experiences and outcomes" (p. 39) but also shape educational scholarship in areas that were before considered distinct.

Not only is the examination of intersectionality important on a micro-level of an individual's self-concept and action/reaction to their world, but it is often the bridge from theory to applied field scholarship to actions. Collins and Bilge (2016) report "working for social justice is not a requirement for intersectionality. Yet people who are engaged in using intersectionality as an analytic tool and people who see social justice as central rather than peripheral to their lives are often one and the same" (p. 30). These workers in social justice and intersectionality are often the ones who "have taken aim at government agencies with an eye toward changing the terms of public policy itself" (p. 45). Even turning inward toward critique, intersectionality can give purchase for scholars in critical disability studies to "criticize the whiteness of the canon and epistemology of the disability studies field" (Meekosha & Shuttleworth,

2017, p. 101). Many of the disability scholars take aim at much work that points out “the absence or perfunctory use of disability in intersectional scholarship” (p. 102). Meekosha and Shuttleworth (2017), point out “intersectionality has been important in critiquing these rather simplistic approaches to identity, and politically it assists in the process of building coalitions” (p. 187).

One important example of this critique of the field has come from Erevelles and Minear (2011), where they take to task a call for papers in a special issue of the *Journal of Educational Foundations*, in asking critical race theorist to address educational inequalities and disparities listing other categories of identity and glaringly absent the one of disability (p. 97).

In addition, Erevelles (2011) provides a concise summary of McCall’s work (2005) of the three ways to theorize intersectionality. McCall discusses an (1) *anticategorical* framework based on poststructuralist argument that social categories are “merely social constructions/fictions” (p.100); an (2) *intracategorical* framework providing a middle ground that focuses on social groups at “neglected points of intersection of multiple master categories” (McCall, 2005, p. 1782) to explore and reveal “the complexity of lived experience in those groups” (p. 101); and finally (3) an *intercategorical* framework that McCall (2005) says can use existing analytic categories to document “relationships of inequality among social groups and changing configurations of inequality along multiple and conflicting dimensions” (p.1785 cited in Erevelles, 2011, p.101). The frameworks examine how society erects barriers for individuals in a variety of dimensions. A person who has a physical disability, is LGBTQ+ and white looks different than an African American woman who has a cognitive disability. In both cases, the configurations of inequalities and oppressions might be different and conflict, but both have relational connections that can be explored for comparison, contrast and coalition building.

The important points of contact between these conflicting and multiple intersections between people involve what Erevelles (2011) calls points of contact (p.103). She points out both “being with critical assumption that race and disability are, in the face, social constructs,” are both “theorized as relational concepts” and finally, both “use stories and first-person accounts to foreground the perspectives of those who have experienced victimization by racism and ableism firsthand” (p. 103).

In my work, not only are the stories of intersectionality to be explored as these participants are of varied ages, races, types of disability, classes, but also in the type and ease of use of different technologies that are integrated into their lives. In my limited study I am discovering the stories of people who are disabled but many of the participants have had some advantages through intersecting dimensions of their personhood. Most of these participants are white, and a majority are men. All are currently working or attending school to work in a technical or professional class. There are some variability as these dimension intersect. The nature of the impairment that caused the initial marker of disability could also affect how these dimensions interact in the participant's lives, including the ability to work through the beauracractic systems to get the assistive technology or just buy it outright. Is assistive technology another point of intersectionality that these accounts can foreground both stories of victimization but also stories of success and pride in disability? Siebers (2008) writes that "identities, narratives, and experiences based on disability have the status of theory because they represent locations and forms of embodiment from which the dominant ideologies of society become visible and open to criticism" (Kindle location, 402-403).

If we can be critical about society and about disability studies and take the next step Siebers (2008) recommended nearly 10 years ago, where "disability studies is to develop a theory of complex embodiment that values disability as a form of human variation" (Kindle location 603-605) and we can eschew for good the medical model which labels individuals as defective.

This interaction of identities and the intersection of identities does enter a complex model. Davis (2013), points out "if identities are theories about the world, then you would, of course, say that a theory is real when it enters the realm of action, as in, the theory of the social model is real as it interacts with policy decisions and political acts. But because it is a 'theory' it is also disprovable and therefore can't be an absolute sign of the real" (p. 25). How we think about intersections and theories of identity become real when we enter into action. The praxis of theory and action is what Freire (1970) places the apex of his arguments in *Pedagogy of the Oppressed*. Davis (2013) also points out that other disability scholars are using points of intersection and other theories to examine disability. Like a multi-point, large carat

diamond, the facets from which to explore such a large idea abound. Davis summarizes the work of Derrida, Lacan, Butler, Deleuze in discussions of “fragmented, incomplete bodies, deafness, and the like” (p. 27). He discusses Sara Ahmed work in feminist materialist returning to a “qualified sense of ‘the body,’” and Victoria Pitts-Taylor and other aestheticians, philosophers work on now neuroscience has reintroduced the materiality of the body (p. 27). He also gives a nod to Jasbir Puar and Mel Chen who explore the intersections of queerness, postcolonialism and disability studies (p. 27). These scholars and others he calls “dismodern” in their seeking to “find points of connection among identities and thus change our conception of identities” (p.27). “Lenny Davis” according to Goodley (2017), points out “disabled people are the ultimate intersectional subject, the universal image, the important modality through which we can understand exclusion and resistance” (p. 45). Goodley (2017) exposit that Helen Meekosha “fills the feminist silence” as disabled women occupy a specific site of exclusion (p. 45) and are denied equal access to education with a “literacy rate, worldwide, is probably under 5 percent” (p. 47). This is a perfect example of how intersectionality impacts people in their daily lives. If you are a woman, you have more barriers to being literate. If you are a disabled woman, you have even more barriers to education and literacy across the world. “Race and disability share a tangled history” Goodley points out David Conner’s work on the subject (p. 47) as I have also in brief, in the section above on identity and disability history.

Using the knowledge of where we have been as a disability studies community and knowing the various routes, we can go to theorize intersectionality and disability can give multiple pathways to explore in a critical study of ableism. Goodley reminds us “unpacking the ideology of ableism invites us to contest the ways in which only particular formations of humanity are deemed worthy of fighting for” (p. 57). How we examine the subject of disability and intersectionality has an impact in the day to day world of interactions and the work we do in education. For example, special education has been the model to provide separate services based on deficit. We have it encoded into law on how to write a “diagnosis” in an Individual Education Plan, i.e., through the present level of performance section listing of needs and strengths, and a “prescription” in the forms of quantifiable goals and objectives of progress. This led

Blanchett, Klingner and Harry (2009) to point out that “it is not far-fetched to say that special education and civil rights movements were actually on a collision course” (p. 393). My experience tells me this is true. I feel my purposes in my work as a special educator in public k-12 schools and research in critical disability studies are often on a collision course.

In this section I have explored the framework of critical disability studies through the history of disability studies and models of theorizing disability as identity and intersections of identity. Now, I turn to my second theoretical framework, posthumanism, to add the ‘components’ of technology and assistive technology to our disabled identity ‘operating system.’

### **Posthumanism**

The work of posthumanism informs and proffers a lever to counteract the hemogenic narrative of ableism as it explores how humanity and technology interact and inform on each other into a new and more complex view of the identity of humans. It could also be the key in leaving the normal *Homo sapiens* behind in evolutionary leaps through the intersection of human and machine. According to Snaza and Weaver (2015), “we don’t know yet what a body can do, nor do we know what we beings who are used to thinking of ourselves as “human” are capable of” (p. 4). This use of the word *body* is very important to disability studies and posthumanism. The questions of where a body ends and begins, where a mind ends and begins and what the “form” that we need to “conform” to in the politics of control. Both theoretical frameworks use the foundation of Donna Haraway's “Cyborg Manifesto” (1985/2016) to push ideas inside and out ideas of embodiment. The work of posthumanist theorists are wide-ranging but have an integral impact on the work of the oppositional situatedness of disability studies. Embracing the identity of disability while exploring the potential and pitfalls technology which offers an enhancement of quality of life is important work. It also addresses and questions the practicality of the hemogenic medical model of disability to “fix” what is wrong in the reality of daily life.

One of the ways that using posthumanism as a theoretical lens can be exciting is the fact that posthumanism looks at humans in relationship to objects, animals or technology. Humanism often falls



into the trap of binaries such as trying to sort what education or characteristics make someone human.

Posthumanism, on the other hand, has the theoretical freedom to look at relationships. How are humans in relationship with animals? How are humans in relationship with technology or objects? Just like critical disability studies, it is interested in breaking the binaries of ability/disability and looking at people with disabilities in relationship to other people and things of this world in order to challenge the traditional view of “human.” Posthumanism gives us a bridge in how we as a species relate to technology and through technology.

In the following sections, I explore the themes of cyborgs and how technology intertwines in our life. Then, I examine several authors’ overview of technology and history. Finally, in this section, I look at how posthumanism interacts with critical disability studies and the discussions surrounding why many curriculum workers (scholars and teachers alike) are resistant to technology and further melding of technology with humans.

### ***Posthumanism, Cyborgs & Current Intertwining Technology***

In Donna Haraway’s 1985 critical feminist essay “A Cyborg Manifesto,” she uses the metaphor of the cyborg to critique feminists’ focus on identity politics and to explain her theories revolving around the boundaries of gender and politics. This metaphor points to breaking of boundaries also fired the imagination of those in other areas of critical studies and critique in later decades, including the work in critical disability studies. She begins her irony of humor as “a rhetorical strategy and a political method” (1985/2016, p.5), discussing modern medicine’s cyborgs “conceived as coded devices, in an intimacy and with a power that were not generated in the history of sexuality” (p. 6) and with a nod to Foucault’s “biopolitics [as] a flaccid premonition of cyborg politics” (p. 7). In very generative word play, pregnant with meaning, she shows us the birth of cyborgs are already ‘crowning’ and among us. She urges feminists and humans in general to recognize that the “boundary between physical and nonphysical is very imprecise for us” (p. 12). Her poetic “cyborg myth is about transgressed boundaries, potent fusions, and dangerous possibilities, which progressive people might explore as one part of needed political work” (p. 14) where the “dichotomies between mind and body, animal and human, organism and machine,

public and private, nature and culture, men and women, primitive and civilized are all in question ideologically” (p.32).

This is one of the ideological spaces on which other ideas of posthumanism in the swirl of postmodernism, poststructuralism emerged. The fight against dualisms (Haraway, p. 60) hallmarks postmodern thought and in the relationships between human and animal, human and machine, and human and object posthumanism scholars work to detangle the threads or even re-entangle the boundaries of where humans end and the rest of the world’s organisms and objects begin.

Cyborgs as a cultural icon have permeated and changed from the self-evolved human in space idea and mythology of broken liminal boundaries of human identity to incremental and bounding scientific advancements which necessitate the refining of the definition. Weaver (2010) point that posthuman condition is a merging (p. 11) falls right in line with the idea of a cyborg. Weaver uses the idea of technology progress to exposit that this merging is an enhancement. He doesn’t specifically say evolution, but other theorists such as Harari (2017) does. Additional theorists and scholars in intervening years expand on this discussion through boundaries-crossed between relationships of humans and animals and humans and objects (Snaza & Weaver, 2015).

As to a more expanded view of cyborgs, Weaver defines two types of cyborgs. Cyborgs “describe any human who is permanently connected to a mechanical devise [sic] such as a prosthetic limb, an organ transplant, a pacemaker or altered gene sequence” and fyborg (a functional organism)

describes more effectively humans whose lives are enhanced because of some form of biotechnology. A fyborg maintains an intimate relationship with technology but unlike the cyborg the mechanical intersection is not permanent. A fyborg is someone who undergoes regular kidney dialysis, has a hearing aid, wears eyeglasses and perhaps in the near future benefits from some stem cell procedures. (p.11)

I would deem that the recent interest in “wearables” such as Fitbits, Apple watches and rise in interest of VR goggles are a recent innovation of “fyborgs” that we as developed society are choosing for ourselves not out of medical necessity but out of our fascination with technology, measurement, and need to “stay

connected” at all times through Bluetooth technology to our smartphones. This is technology that while not medically necessary, most teachers and education workers are expected to be able to understand, master and use in service of the changing dynamics of teaching and learning inside and outside of the schoolhouse through BYOT (bring your own technology) policies in public schools. Brad Petitfils points out that “as we purchase more technology, and as we spend more time with that technology, we become more cybernetic” (in Snaza & Weaver, 2015, p.30).

These technologies create a mediated life where “this mediation shapes the reality we interpret. It does not shape our interpretations or usurp our primary function to frame reality, but the mode of mediation whether it is the television screen, film frame, painting, photograph, or some other filter, shapes but we refer to as truth” (Weaver, 2010, p. 16). As cyborgs, we are mediated by our medical intimacy to machines and our “wearable” technology. This is not science fiction or fantasy of the future. This is the medical work of today. In Hallam Steven’s work *Life out of sequence: A data-driven history of bioinformatics* (2013), we even see how the “code” of DNA, which in itself is just representation of data, a model, of how traits are passed along, humans are flattened into computer data. With the use of computers and science the questions of biology changed, according to Stevens, in that “the use of computers as tools of data reduction carried Big Science into biology- the machines themselves entailed ways of working and knowing that were radically unfamiliar to biologists” (p. 39). The push and pull of science to explore big picture patterns through bioinformatics opens up new questions for biology, and other sciences to explore regarding humans and nature. But this reduction of living things into zeros and ones, can obscure knowing something more complexly and richly studying through the microscope, or the phenomenologist opposed to the macroscope of bioinformatics. This “challenge is not just an issue of communication or language, but a struggle over whose modes of doing and knowing will persist in biology” (p. 50). This challenge is echoed in the work of all researchers and scholars in the false dichotomy of quantitative versus qualitative research methodology. It isn't a question of which is better, but what questions are you trying to answer. Are you looking for patterns in human behavior, education, where responses are reduced to data sets and patterns are looked for, or are you asking questions of

complexity that are not easily generalized to other populations in exactitude? We should know both modes of knowledge production are essential and important and not in opposition to each other. Harding (2015) agrees with this idea reminding us “sciences and their philosophies have never been value-free. They have always been deeply integrated with their particular social and historical contexts. If they weren’t, they would be irrelevant” (p. 2).

Where Weaver (2010) calls posthumanism a merging of humans and machines, expanded work (2015) connects the relationships of animals and humans, as companion species (Haraway, 2016; Morris, Miller in Snaza & Weaver, 2015) and connections to ecological web of the world (Jagodzinski, Wallin in Snaza & Weaver, 2015). Obviously the *rhizosemiotic* nature of posthumanism (N. Gough, in Snaza & Weaver, 2015) helps to make sure that posthumanism as a fractured area of research continues to reach out and help us avoid the “glomus body” problems of what “proliferates what bears the quite simple and unmerciful name of misery” (A. Gough quoting Nancy in Snaza & Weaver, 2015, p. 168).

Petitfils (2015) also points out a specific narrow segment of posthumanism that is called transhumanism. Transhumans are “biologically enhanced humans that take on more cybernetic characteristics. These entities (cyborgs) “operate” through nanotechnologies and altered biology — they might have bionic limbs, artificial organs, synthetic blood, and so on — and can (theoretically) live to be more than five hundred years old” (in Snaza & Weaver, 2015, p.32-33). Mark O’Connell (2017) describes the transhumanism movement as the “belief that we can and should eradicate aging as a cause of death; that we can and should use technology to augment our bodies and our minds; that we can and should merge with machines, remaking ourselves, finally in the image of our higher ideals” (p. 2). From a layperson and journalist’s point of view he asks the question “If a cyborg is a human body augmented and extended by technology, is this not what we basically are anyway? Are we not, as they say in the philosophy racket, *always already* cyborgs? These aren't rhetorical questions. I'm genuinely asking here” (p.146). To ask what a cyborg is, we are asking what a human is, or has become.

The eternal question of what it is to be human. The problem when you encounter many of those with transhumanist worldviews is that they divorce the human from the body completely in that “its

conception of our minds and bodies [are] as obsolete technologies, outmoded formats in need of complete overhaul” (p. 11). This is an extremely problematic view in terms of disability studies and much of its scholarship rooted in the relationship of the body, lamented broken, or celebrated as variation and the stark materialism of flesh that is part of being human. To most critical disability scholars you cannot divorce the mind/spirit/soul/ethereal from the material/flesh/body.

Weaver theorizes that the “most important question any actor can ask at the biosciences is what kind of manipulations should we tolerate and how did these manipulations embody the values that matter most in the posthuman condition? What type of monstrous offspring do we aspire to be?” (p. 50). This question of values is the one we should be asking not just as curriculum theorists, but as bioscience ethicists and the average citizen in a technology-laden democracy.

### ***Technology + History***

Technology is often not viewed through a separate history. Technology as viewed as tools of humanity, is embedded in our military and economic and civic histories that explain the “progress” of inventions. In trying to examine technology as a topic unto itself, several authors and scholars have approached the topic in three ways: technology and history, technology and the present and technology and the future. Additionally, some writers have looked at technology through the people who are considered the innovators of today. These three ways, and additional “profiles of innovators” style of approaching the interaction of technology all have interesting angles with which to view humans’ relationships with tools and technology.

In *Zeros + ones: Digital women + the new technoculture*, Plant (1998), weaves back and forth in vignettes and musings that wind from stories of Ada Lovelace and Babbage’s counting machine, to the idea of women and weaving as the first types of programmable code. She points out that “digital machines of the late twentieth century weave new networks from what were once isolated words, numbers, music, shapes, smells, tactile textures, architectures, and countless channels yet unnamed” (pp. 11-12) but that “weaving was already multimedia: singing, chanting, telling stories, dancing, and playing games as they work, spinner’s, weaver’s and workers were literally networkers as well” (p. 65). In her

often poetic musing back and forth like a shuttle of a loom, Plant (1998) reminds us that technology's rationale "has always been the effort to secure and extend the powers of those whose interest they are supposed to serve" (p. 77). But today that is increasingly hard to control because quoting Deleuze and Guattari's *A Thousand Plateaus* she points out "man and his tools exist 'only in relation to the intermingling that they make possible or that make them possible'" (p. 90). Her observation of parts of the history of technology and the missing components of women's contribution to technology are "complicating orthodox western notions of what it is to be a human being" (p. 177).

Other authors look at technology through a lens not of history, but of present. Many pieces that explore new technologies make the assumption that new + progress = good for us. Instead, Birkerts (2015) feels that technology and the internet in particular, is a place where "the immediate present is undermined, perforated by a sense of elsewhere" (p. 16) and that it "slip[s] still another layer between us and the world, another source of lightness, and not an agile, balletic lightness, but something more like the metaphysical disconnectedness Milan Kundera evoked in his phrase "the unbearable lightness of being" (p. 16). His concern is one of an artist and writer. That our ability to appreciate the present is constrained in particular by a mediated existence through the internet. He evokes the Pandora story and posits that it "seems cynical to ponder the fact that Apple's logo is the fabled fruit with the bite already taken" (p. 57). His concern is an important one for the present and current age. In his work here, though, the cautionary tale is not balanced with the experiences of those that experience richer interactions with the world through the use of technology, such as assistive technology and people with disabilities. His position of caution is from an ableist standpoint, that is bemoaning, and possibly rightly so in many people's experiences, the diminished influence of art, music, writing and the humanities. His question of "do processed screen stimulants have an eroding effect on a child's- or anyone's- interaction with the unmediated world?" (p. 120) is a valid one for debate and discussion, which is his purpose.

A third way to examine technology is through the eyes of the future. Harari (2017), in *Homo Deus*, does that among other wide-ranging questions of the future and which direction we should explore as a human race. He points out that "acknowledging our past achievements sends a message of hope and

responsibility, encouraging us to make even greater efforts in the future” (p. 19). This is the *modus operandi* of science and technology and the idea of progress equals betterment of humanity. He posits that the point of “modern science is to defeat death and grant humans eternal youth” giving the example of Ray Kurzweil, who after creating communication technology for people with disabilities in the 1970s, is now “director of engineering at Google” where they have launched a sub-company “Calico whose stated mission is ‘to solve death’” (p. 24). Harari’s look into the future philosophizes “the upgrading of humans into gods may follow any of three paths: biological engineering, cyborg engineering and the engineering of non-organic beings” (p. 43). He reports that “cyborg engineering will go a step further, merging the organic body with non-organic devices such as bionic hands, artificial eyes or millions of nano-robots that will navigate our bloodstream, diagnose problems and repair damage” and where “paralysed patients are able to move bionic limbs or operate computers by the power of thought alone” (p. 44). He does paint this as a cautionary tale of the future. He explains that “no clear line separates healing from upgrading. Medicine almost always begins by saving people from falling below the norm, but the same tools and know-how can then be used to surpass the norm” (p. 51). The concern for the poor and marginalized to fall further behind in the human “race” is one both of the alarmist but also of concern to social justice workers. I would problematize as I said earlier in this chapter, if we view technology as a way to “fix” and bring people up to the norm, this medicalization and scientific view of humanity, we are at risk of and do dehumanize those that are deemed “below the norm.” His fear that the “regular humans” would fall into the same dehumanized position in relation to superhuman types that those labeled disabled have had to deal with for all of humanities' history. He asks the question “will elites and governments go on valuing every human being even when it pays no economic dividends?” (p. 311). I would point out, that question assumes elites and governments have valued every human being, which we have examples along racial, gender, and ability lines that they do not and never have. Technology could widen that gap, as easily as it could close that gap. The crux of that problem tips along lines of power and how advances of science and technology are distributed among humankind.

### *Cyborgs + Critical Disability Studies*

Technology to assist people with disabilities has been around in a “low-tech” manner since variation of the human body necessitated crutches or mechanical work-arounds for people to “do and work.” After the 1800s and major wars of Civil and World War I and II, governmental action related to veterans injured in war began slowly to spread the idea of low and high technology solutions for people with disabilities. (Bryant and Bryant, 2012). The slow steam momentum of empowerment progressing from 1800s until 1970s followed behind the Civil rights movements for African Americans in the United States part of the various movements of the 1960s and 1970s.

The movement of workplace and school access for people labeled with disabilities blossomed in the 1970s with The Education for All Handicapped Children Act (PL 94-142, 1975) and the Vocational Rehabilitation Act of 1973. Making schools, public institutions and workplaces accessible continues through fits and starts of federal law tied to the civil rights of people with disabilities most recently culminating with the American with Disabilities Act of 1990.

Throughout these events people worked toward ameliorating the impairments that caused disability through both mainstream technology solutions and assistive technology. As noted before, Haraway (1985/2016) points out that “perhaps paraplegics and other severely handicapped people can (and sometimes do) have the most intense experiences of complex hybridization with other communications devices” (2016, p.61 note 35). People such as Ray Kurzweil worked in the field of Optical character recognition and created The Kurzweil Reading Machine, the first machine to convert books and other printed materials into synthetic speech, introduced in 1978 (Candela, 2004). Incidentally, Kurzweil is also part of a transhumanist movement with his focus on “Singularity” and now is working with Google, leading a team of about 35 people whose code helps you write emails which offers three suggested email responses you can select with one tap (Simonite, 2017). Predictive speech and replying has extended into our daily email barrage.

This connection between improving the biological form is fluid. One that many scientists and futurists are wildly and divergently relating too. It is an important idea that for many people with



impairments, especially severe impairments of speech, mobility and gross and fine motor functioning, technology that is melded is a necessary combination of the biological and the mechanical/technological. Rosemarie Garland-Thompson in the preface to the twentieth anniversary edition of her 1997 book *Extraordinary Bodies*, reminds us that “this most unstable of identity categories visits us slowly over a lifetime or in a second. Superman becomes quadriplegic with the stumble of his horse. We grow old if we are lucky. We become disabled not through the inevitable failures of our flesh, but by using the material, technological, and legal apparatuses our liberal democracy offers in its steady aspiration to assure equality among citizens” (1997/2017, xvii). The social construction theory of disability is a key point for many disability studies scholars, one that would support the pragmatic goal of using technology to create cyborgs of necessity and function in an effort to minimize disability but not deny the impairments of the material flesh.

Tobin Siebers (2008) critiques Haraway’s view of prosthesis as overly optimistic calling Haraway’s cyborgs “spunky irreverent, and sexy; they accept with glee the ability to transgress old boundaries between machine and animal, male and female, and mind and body” (Kindle Edition location 1289). He accuses, albeit mildly, that she is “so preoccupied with power and ability that she forgets what disability is” that her cyborg “is always more than human- and never risks to be seen as subhuman” (Location 1289). Other scholars such as Stone (2009), extend Haraway’s work through own musings and scholarly pursuits. Stone (2009), in “Split subjects, not atoms; or, how I fell in love with my prosthesis,” views prosthesis in a traditional material sense but also a philosophical one where she “could send a whole part of myself out into the ether. And extension of my will, of my instrumentality” (p. 394). Sandy Stone is the founding Director of the Advanced Communication Technologies Laboratory (ACTLab) and considered a founder of transgender studies. Her work extends from technical to the artistic and everything in between. She points out in the case of Stephen Hawking “in the absence of prosthetic, Hawking’s intellect becomes a tree falling in the forest with nobody around to hear it. On the other hand, with a box, his voice is auditory and simultaneously electric, in a radically different way from that of a person *speaking* into a microphone” (p. 395). This isn't just a mere use of technology of a tool but

intertwining and blending of the human physical and the assistive technology that helped him communicate with the world.

The tensions between the materiality of the body and technology is inherent in communities that identify as disabled and those that do not. Articles and arguments over electronic books versus paper, or speech-to-text and text-to-speech in our phones mirror the discussions in assistive technology circles for the learning disabled, blind, hard of hearing communities in the 1980s and 1990s. Rarely, the AT specialists fall on the side of materiality, but almost always for the progress of technology to make life better for those living with impairments. Sieber's point is a nuanced but important one. It relates to representation of difference and idea that disability scholars embrace or repudiate the normal forms of representation as something to ameliorate through technology or to be proud of who you are, through the discomfort, or pain of impairment.

The cyborg represents the myth of the New Man/Adam from its earliest days of Čapek's 1920 science fiction play "R.U.R." For some transhumanists, and some disability studies advocates cyborgs represents the New Adam. The broader milieu of posthumanism and disabilities studies is much more varied than the thirteen conditions recognized as disability by Individuals with Disabilities Education Act (IDEA). To some the cyborg is inevitable, the next generation of what we should become and progress to. To others it is just a tool to help express the diversity of humanity and democratic citizenship. To valorize the inevitability of disabled and abled alike becoming "more" risks and according to Siebers (2008) "contribute to ideology of ability, marginalizing people with disabilities and making their stories of suffering and victimization both politically impotent and difficult to believe" (Kindle location 1309).

The relationship is complex and complicated as it should be. Just as posthumanism rejects the binaries and dualities of modernism and positivist traditions, the complicated field of disability studies is as individual as the impairments that create difficulty in the lives of people labeled disabled especially when it intersects with posthumanism through technology, assistive or otherwise.

### ***Cyborgs + Schools: The Difficulty with Curriculum***

There are two major reasons why many curriculum workers (scholars and teachers alike) are resistant to technology and further melding of technology with humans.

Pragmatically, teachers, technology, timing, set-in ways, lecture-based and the ingrained idea that learning is consuming knowledge to repeat are barriers and reasons teachers resist technology in our schools. The constraints from “above,” be it federal, state, local or in-building governments such as school administration often hamper a teacher to not think beyond what is required. Technology integration, the topic *de jure* in education is most often the type that is manipulation of tools of repetition, and electronic ways of reproducing same knowledges and content as could be with paper, pencil and lecture. Ask practicing teachers in K12 settings and often in higher ed and you will find the technology tools are often one of presentation in a variation of PowerPoint, or of repetition and review such as flash card games or programs like Kahoot. Programs that use technology for problem solving and creating new knowledge and products are reserved for special STEM days, programs or Makerspaces. Being able to give students the freedom to interact and use technology in novel and new ways would make predicting “achievement” difficult and often at odds with state curriculum maps of “consuming” knowledge already created. Truly tapping into the rhizomatic learning idea of technology would have students step outside the “course” take the meandering trail with his/her chariot and horse to forge their own path.

More philosophically, the connection of reproduction of knowledge and of a “docile body” of workers (Foucault) feeds into the political climate of “meeting industrial needs and contributing to economic productivity” (Giroux, H, 1988, p.1) Giroux goes on to point out that in case of curriculum packages created commercially, and I would argue, curriculum standards in general, “is a limited and sometimes crippling rationality. It ignores the dreams, histories, and visions that people bring to schools” (p. 6). His view is that education should be transformative and “any viable form of schooling needs to be informed by a passion and faith in the necessity of struggling in the interest of creating a better world” (p. 9). Those “people” are not just the adults in the building but the “human capital” of the students and their situated complex views and ideas of how and what they should be learning and why, and what is valued.

Nowotny (2016) points out “fear arises then and now as a reaction to, or anticipation of, perceived threats, whether they are unleashed by the forces of nature or stem from the social Other” (p. 19) and I would add forces of technology and unpredictable nature of creating another social Other through melding of technology with humans. Nowotny makes an argument that there should be caution to the seductive nature of embracing technology as the only solution and that it

lends itself to the fantasy of omnipotent control. Only slowly does this fantasy yield to a humbler realization that in coping with the complexities and challenges of the present, a sole reliance on technological improvements, let alone on technological fixes, will not suffice. (p. 26)

Her point here leads to the second way that curriculum workers warily view technology and melding with the idea of human from a side eye as they use it in day-to-day life. Whereas, the pragmatic problem of teachers in formal education settings of K-12 and higher education, view technology with trepidation through comfort of the secure, what they know, the expeditious; Nowotny’s caution is based in the quest for balance between the tendency of technological and big data solutions to embrace an instrumentalist view of the world as a problem to solve, much like the transhumanist do with the “problem of death” (O’Connell, 2017, p. 179). Nowotny’s view that embracing uncertainty “is the dynamic balance between what we know and do not yet know about the world and about ourselves...opens the cracks in the wall to let the new in” (2016, p. 172).

Noel Gough’s exploration of “in a world of increasingly complex information / communication / knowledge technologies, the space of educational inquiry is also becoming a “rhizome space” more hospitable to nomadic than to sedentary thought.” (in Snaza & Weaver, 2015, p. 157). This idea of the rhizome that is far from the hierarchical knowledge of traditional courses of study, curriculum is how makerspaces work. It is connecting of divergent plans and thoughts that do not fit neatly into boxes of schooling. This is the second reason of fear of the merging of humans and technology. It is this uncertainty of where that rhizome’s tendrils would go, the meandering path off of the circus on the curricula, the *currere*, the curriculum. Something not easily controlled. Knowledge in a cybernetic era is the uncontrollable of science’s serendipity.

Foucault (1977) in *Discipline and Punish*, addresses the idea of schooling as a way for power to discipline unruly bodies into social reproduction of what those in power need to mold. By moving from an idea of mastery “supervised by the master alone, authorized by a single examination” (p.159) into training through control of time in a progress of hierarchies, “whole analytical pedagogy was being formed, meticulous in its detail (it broke down the subject being taught into its simplest elements, it hierarchized each stage of development into small steps) and also very precocious in its history” (p. 159). Moving past the industrialized age of society into a cybernetic, rhizomatic age necessitates changes in how learning, education, creation of knowledges are fostered. This change would remake the type of education we as educators, curriculum workers have relied on for the previous 150 years. This is the underlying basis of the fear. How scholars, CDS theories, technology and AT (assistive technology) specialists can overcome this resistance is a much more complex problem than an “intervention” or professional development module for an individual teacher or school can “fix.” It grapples with questions of what, and whose and what type of knowledge and learning we value in society.

### **Social Justice, Curriculum, and Assistive Technology**

In this last major section, I review the literature relating to social justice and disability. I discuss ways curriculum workers, both scholar-researchers and practitioners could use social justice perspectives to inform their work with and alongside children and adults with disabilities. Social justice informed educational practice asks we move from theory and ideas into creating spaces that promote equality. These places could be a classroom, a government conference room, or supporting a local agency that assists people with disabilities. I discuss how Assistive Technology (AT) is another practical pathway of action to create agency and voice in the lives of people with disabilities.

Curriculum theorists are a part of the world they reflect on. Culture, ideology, politics influences what happens in education, society, and the day to day lives of everyone. By using a critical gaze on parts of culture that influence the daily lives and institutions, they shed light on what is going on in the world, much like reporters do and then use critique to turn the lens and question and interpret much like opinion writers often do. What is a curriculum theorist to do when a problem is exposed? Why theorize solutions

and research of course. Freire's praxis included the essential element of theory to illuminate reflection. After we have seen what the world looks like we must theorize to illuminate before action can take place. "Human activity is theory and practice; it is reflection and action" (Freire, 1970/2000, p. 125). By stepping out of the lecture halls, and conference rooms into the communities, schools, and classrooms, curriculum theorists create praxis and movement from reflection to action; from theory to practice.

Many of the scholars working in social justice frameworks, use Freire as a foundational guidepost. Suzanne Pharr (2018) reflects that "this is the challenge for all of us. The work of liberation politics is to change hearts and minds, develop empathy with and sympathy for other people, and help each other discover how we are inextricably linked together for our common good and our survival on this planet" (p. 604). The challenging work of liberation politics includes working on building community in a "culture that glorifies individualism" (p. 606). The difficult part is "learning how to honor the needs of the individual as well as those of the group, without denying the importance of either" (p. 607). Several authors writing about "how to do" social justice work mention the importance of community or coalition-building as one of the facets of social justice work or even one of the steps in the process or cycle (Pharr, 2018; Collins Hill, 2018; Johnson, 2018; Harro, 2018).

Bobbie Harro (2018) creates a model of the cycle of liberation, repeating and mirroring what others write to share in their own work as the "steps" we go through in this work. His model of the cycle of liberation includes: (1) waking up, (2) getting ready, (3) reaching out, (4) building community, (5) coalescing, (6) creating change, and (7) maintaining. While this example from Harro is the most explicitly sequenced version of a cycle of liberation model of social justice, other authors have these same components in various forms (Pharr, 2018; Collins Hill, 2018; Johnson, 2018; Harro, 2018). For example, Patricia Collins Hill (2018) shares that "the coalitions that I have been involved in that lasted and it worked have been those where a commitment to a specific issue mandated collaboration as the best strategy for addressing the issue at hand" (p. 618). We can see that in today's political climate over concerns of Medicaid/Medicare cuts that would affect several types of groups in different ways, building a coalition and "fostering group solidarity" through the "presence of a common enemy" (p. 618).

A.G. Johnson (2018) simplifies Harro's model into four actions to push against systems of privilege imploring others to (1) acknowledge that privilege and oppression exists, (2) pay attention, (3) learn to listen, (4) little risks: do something (p. 623-627). He *does* point out the very important fact that privilege will not go away through an individual changing consciousness, but we have to understand systems in order that we can do the work of changing the systems themselves (p. 622). This is why social justice involves many of our social systems: health & medicine, law, social work, education, and community activism. Each of these disparate facets of society has different ways of looking at the multiple oppressions people experience because they are working through different systems. Many of these systems cross over or coalesce through the law, governance and policy along with the requisite component of money and resource allocation.

Cornel West (2018) in "Courage" tells us "it takes courage to cut against the grain and become non-conformist. It takes courage to wake up and stay awake instead of engaging in a complacent slumber. It takes courage to shatter conformity and cowardice" (p. 635). In current social media parlay, West might say "It takes courage to be woke."

Harro's reflection on liberation is beautiful, almost poetic:

Liberation is the *practice of love*. It is developing a sense of self that we can love, and learning to love others with their difference from us. Liberation is *finding balance* in our individual lives and in the agendas of our coalitions. Balance keeps us upright and oriented, moving toward our goals. Liberation is the *development of competence*, the ability to make something happen consistent with the goal. Liberation is the *belief that we can succeed* in a sense of confidence in ourselves in our collective efforts.... Liberation is *joy* at our collective efficacy and at surviving in a world that is that sometimes tries to kill us. Liberation is the knowledge that *we are not alone*.... Liberation is *commitment* to the effort of critical transformation to the people in our community to the goal of equity and justice into love. Liberation is *passion and compassion*, those strong motivating feelings that we must live by our hearts as well as our minds (p. 634).

Pharr (2018) reminds us of “why we do this work of social justice: *it is because we believe every person counts, has human dignity, and deserves respect, equality and justice*” (p. 605).

How does this play out and connect in my life and the lives of other teachers and people that ally and work with folks with disabilities? As said before the social systems of education and community intersect with systems with law, governance and policies. By becoming aware, awake I gather knowledge to be able to share with other people to build empathy for the issues surrounding spheres of oppression. There are micro- meso- and macro- layers of action I can take and view situations of oppression, privilege and social justice. In Kirk, G., & Okazawa-Rey, M. article “Identities and social locations: Who am I? Who are my people?” (2013), the authors use the micro-, meso-, and macro- levels of analysis to tease out discussion of identity and social relation. These same levels of analysis are important in reflecting on the actions one individual can do in furtherance of social justice work. What can I do to reflect on my individual daily practices and interactions to be more just and humane of others? (micro-) What can I do in relationships in my community to make lives better for people with disabilities or to make others aware of ableism and build empathy and coalition in those that are temporarily abled-bodied? What groups need hands and feet of action to do the pragmatic work of improving someone’s existence and lessen structural inequities? (meso-) What can I do to influence state or national laws, regulations, or policies through political activism, writing letters, emailing or calling my congressperson? How can I make others aware of how national policies have a direct and indirect deleterious effect on people with disabilities, and other oppressed groups? (macro-)

I hope that my dissertation opens up several levels of analyses for those to examine my research. By sharing the counterstories, I am exposing the lived experiences of people with disabilities that might open doors for others to examine their own beliefs regarding disability as an identity. I am also exploring technology as another identity facet but also as a practical exploration of tools that improve the lives of people with disability. The level of access people have or do not have to assistive technology, or technology, in general, can be enabling or disabling as a part of the civic and social life of today’s society. The work community and state-supported organizations do to get solutions of technology, training,



education into the lives of people most in danger of isolation, is difficult work. And finally, by being aware of the participants' counterstories and issues surrounding disability and technology (and assistive technology), I can open my own eyes and others to holding accountable government and corporations to policies that are not damaging but empowering to people with disabilities.

One area in my own work-life that takes careful examination is in curriculum studies and public education in light of social justice and equity issues. How can my exploration of critical disability studies and posthumanism influence my daily thoughts and actions in my classroom?

### ***Social Justice: School + Community***

In my daily practice of schooling, it is all about interactions with people using a social justice framework. Social justice for education framework is very similar to the work discussed above in community building and coalitions regarding awareness and action. If I was in a position to directly infuse social justice, diversity, and Freire's problem-posing process, I feel I definitely would. In the position, I am in currently, my influence in changing how people view disabilities as an identity and the importance of social justice actions is informal. It is in the interactions and discussions I have with fellow teachers, people in the community I interact with, in the students that come through my room as part of Buddy club, my Communication Buddies program or as friends of my own children.

Critical disability studies and technology through a posthumanism lens, intersect in the actions I take in my classroom and community interactions. Hackman (2005) reminds us "working in chorus with the goals of other educational theory bases, social justice education encourages students to take an active role in their own education and supports teachers in creating empowering, democratic, and critical educational environments" (p. 103). There isn't one right way to do this and social justice for education (SJE) is more than about appreciating diversity. Hackman points out SJE work "pays careful attention to the systems of power and privilege that give rise to social inequality, and encourages students to critically examine oppression on institutional, cultural, and individual levels in search of opportunities for social action in the service of social change" (2005, p. 103). The Southern poverty law center has offered standards for social justice in teaching (<https://www.tolerance.org/frameworks/social-justice-standards>,

accessed July 2019), along with other resources for k12 teachers While this is very important to give teachers ways to integrate into their daily lessons, often the work of a social justice educator also comes in the unplanned moments of discussion alongside the planned work of being focused lessons asking students to embrace other cultures, being critical of the world and media by which we see the world and problem-solving experiences that give students practice in taking action.

For critical disability studies, this could include talking about disability as a cultural identity and identifying ways social inequality is evident in the local community or state or national news and laws, policies and practices. It could be recognition of the stories of people with a disability that helps others confront their ableism, and work toward solutions of barriers people with disabilities exhibit. My work and research here is one example of those counterstories or counternarratives that not only confront individual ableism but help to ask us to explore the macro-analyses of institutional or structural ableism.

Assistive technology and the lens of posthumanism gives several ways we can examine issues in schooling, education and community building, and problem-posing. The work of curriculum studies often can examine schooling through the interaction of subject matter as curriculum, teachers as curriculum, students as curriculum and finally, milieu as curriculum. When using those different areas of interaction in a classroom we can ask a “question of worth includes: What is worth knowing, needing, experiencing, doing, being, becoming, overcoming, contributing, sharing, and just plain wondering?” (Schubert, 2009 in He, Schultz, & Schubert, 2015, p. xxiv).

Assistive technology can be a bridge of commonality between people and students with disabilities and their temporarily abled-peers. The iPad that can be used for music, games, reading, and also as a communication technology can be that bridge of commonality that is coalition building. One example in my own classroom involves a group I created “Communication Buddies” whose purpose is to have regular education students peer model using picture communication boards or AAC devices (augmentative alternative communication) for my nonverbal students and to “hang out” with them at lunch just like every other teenager gets to at lunch. This program is building bridges across the chasm of “other” between students who are considered very “other” due to the severe intellectual impairment and

nonverbal language to their typical peer group of friends, i.e. “regular education kids.” These peer buddies are future leaders, business owners, coworkers, health care professionals, and teachers that shape policy and social mores for my students as they progress through their adult life. This coalition building gives them a shared story, language and “teenager” identity with each other.

Another direction assistive technology can take a social justice educator is in actions of getting the correct AT in the hands of people with disabilities both as a school-based but also a community-based problem to solve through micro- and macro- pathways of analyses and problem-solving. This work legally falls to whatever state agency has been tasked with implementing the Assistive Technology Act of 1988, reauthorized in 2004 based on the Technology-Related Assistance for Individuals with Disabilities Act of 1988, or Tech Act. (Peterson, D. B & Murray, G. C., 2006, p. 59). In Georgia, that agency that administers the implementation of the AT Act is Georgia Tools for Life, based out of Georgia Tech’s (<https://gatfl.gatech.edu/>). They work with individual consumers, with state agencies such as the department of education and other AT resource centers to help schools, communities, and people with disabilities get access to the AT that breaks down barriers of access in multiple areas of a person’s life. According to Tools for Life wiki, the group “works to improve access to and the acquisition of Assistive Technology (AT) in the areas of: Education, Employment, Community Living, Information Technology & Telecommunications (<https://gatfl.gatech.edu/assistive.php>). For me personally, one of my goals is to apply to be on GATFL’s community advisory board as one aspect of action that is informed by the theoretical frameworks of this research. Peterson & Murry (2006) point out that “AT has the potential to help people with disabilities to live in the least restrictive environments and attain their personal and vocational aspirations” (p. 59).

Since assistive technology is often about putting the right solutions of low tech and high tech in the hands of people between engineers, app developers, and disability service providers, there is not a lot of theoretical work being done in AT. Much of what I have done is to approach AT as a part of the bigger milieu of technology and posthumanism to relate theory to practice. The few people that are writing about AT are writing about the pragmatic ways of addressing issues such as customer utilization, funding and

advocacy for funding (Edyburn, 2000) or the adoption of AT definitions and explanation of its importance to disability (Abbott, 2007). A handful of scholars do connect the theory-action praxis through the route of social justice or human rights and barriers that people erect around the use of assistive technology.

For Paul Jaeger (2015) looking at online accessible technologies, specifically relates to computers and online technology. Jaeger points out to meet this standard of accessibility a technology “must be usable in an equal manner by all users without relying on specific senses or abilities” and that it “must be compatible with assistive technologies that users may rely on” (html version p. 2 para 4). For Jaeger the connection of the pragmatic to a larger discussion is through the avenue of advocacy. He feels “advocacy for accessibility framed as an issue of equality, of human rights and social justice, may offer a better way to promote tangible changes in attitudes toward and implementation of online accessibility” (para 27).

In addressing the use of AT in school and the barriers students and service providers face, Dave Edyburn (2000) posits issues heard in classrooms about integrating daily AT use for people with disabilities into classroom contexts. One example is an oft heard comment “allowing a student with a disability to use assistive technology is cheating because the student really can’t do the task” (p. 26). Another example is “allowing a student with a disability to use assistive technology would not be fair to other students” (p. 26). These comments are heard often in the anecdotal memory of many special education teachers and other service providers over and over, thirty years after the AT Act of 1988 and forty years after IDEA was passed in the mid-70s. Edyburn connects these barriers and concerns in the daily educational life to the bias and ableism we have of “naked independence.” This form of bias “exults on the performance of able-bodied individuals and devalues the performance of others that must rely on external devices or tools” (p. 26). This value of making it on one's own merits without the help and interdependence of others is a hallmark of the mythos of American. This bias of naked independence feeds into the meritocracy ideal that the poor should pull themselves out of poverty “by their bootstraps” ignoring the systematic and institutional bias and oppression that makes generational poverty difficult to escape. This same meritocracy feeds what most able-bodied people feel is fair in regards to classroom standards and how all students might need to “show what they know” or even have equitable access to the

information and ideas to learn. Edyburn addresses this fairness argument by pointing out most people's definition of fairness "argues from the perspective of a kindergarten child who believes fairness means that everyone gets the same thing" when "actually, fairness means everyone gets what they need" (p. 26). He points out the social justice implications of this argument or barrier by many teachers is "the implication of naked independence and the desire to maintain the privilege and status held by non-handicapped students that complete a task without external aids" (p.26). Swain and Edyburn (2007) point out that "despite current U.S. educational goals and the documented effect of the achievement gap, little attention has focused on critical issues associated with the use of instructional technology as a social justice tool" (p. 15). Giving students and adults access to the supports they need through technology (low tech or high tech) provides the equity of access to both materials to learn and modes of expression to show what they know. The misconception many teachers and people in society often hold includes the ideas that allowing student with a disability to use AT would not be fair to other students. As we see in Edyburn's (2000) quote above fairness is not everyone getting the same thing. We must be advocates for students with disabilities and teach them to advocate for themselves in both accommodations and assistive technologies that make learning and living more accessible.

bell hooks (2000) reminds us that "love in the classroom prepares teachers and students to open our minds and hearts. It is the foundation on which every learning community can be created" (p. 137). This type of love is the love that accepts students and celebrates their many ways of being. If you have that foundational understanding of who your students are you are moved to do your best for them. Your actions in the classroom can be social justice in teaching students how to respect themselves and each other. We often hope that the lessons children learn from each other can be spread to the hard-hearted, cynical adults in their lives which in turn creates momentum in communities and across our nation. Reminiscent of 1 Corinthians 13:4-7 of the Christian bible in which love is patient, kind, not jealous, not pompous or inflated, hooks shares "love will always move us away from domination in all its forms. Love will always challenge and change us. This is the heart of the matter" (p. 137). This is the heart of the classroom where you do not teach curriculum, but students.

### **Summary of Literature Review**

In this chapter I have reviewed the lenses of critical disability studies and posthumanism as it relates themes of identity, intersectionality, the intertwining technology (cyborg technology) and the difficulty schools have with technology and assistive technology. I have examined the role of narrative in disability studies that provides an autobiographical and theoretical exemplar of counternarrative. I have recognized that my work would expand on this mode of writing through counterstories by the participants relating to disability and technology.

In examining these issues, I have linked the theoretical with the practical through the pathway of social justice in curriculum and AT and schools. Exploring the stories of people with disabilities + technology can inform and enlighten issues of identity, intersectionality, and technology so we can work for more just educational and community environments for people with disabilities against ableism. This is the work of a critical disability theorist, whether disabled or temporarily able-bodied. This is the work of a schoolteacher, professor, or curriculum theorist that needs to put into practice actions in their classroom and wider society to help eliminate barriers to education and fulfilling life in society. I hope that my study will open eyes, and give others a chance to cross ideological boundaries that constrain what they believe education, learning and the worthiness of people. The work reviewed here is important. By reviewing the state and history of critical disability studies, I have a lens by which to examine disability as an identity. By looking at posthumanism I can examine how assistive technology and technology can disrupt my view and society's view that disability is a static, stable identity that is defined by "lack of" worth and value.

## CHAPTER 3

### METHODOLOGY

Methodologically, I draw upon the work being done in counternarrative research (Bamberg & Andrews, 2004; Carmona & Luschen, 2014; Delgado, 1989; Glenn, 2012; He & Phillion, 2008; He & Ross, 2012; Sandoval & Davis, 2008; Solazano & Yosso, 2002; Tuck, 2009). I collect the stories from people with disabilities to explore how their interaction of technology and tools has shaped how they view themselves and the world. I used a variety of methods of data collection such as basic interview questions via electronic platforms. I used alternative methods to communicate with the participants to allow them to have time to think and craft their thoughts and answers. Follow up questions through personal interviews, with possible videotaping, especially for augmentative communication device users, or electronic video and text-based chat, emails, messages and in-person traditional interview formats were also used as varied data collection methods to match individual interviewee's best ability to communicate their thoughts, words, and counterstories. Counternarrative is a way "to illuminate the nuances of unjust, dominating, or hegemonic relationships" (He and Ross, 2012, p. 1). The persistent interest gives marginalized groups a means to "speak truth to power and in so doing, begin the task of moving from silence and marginalization to speech and liberation" (hooks, 1989 cited in He and Ross, 2012). Carmona and Luschen (2014) share that "critical stories are those stories that speak to the constitution of experiences within a sociopolitical context; that acknowledge their development within historically situated conditions and that recognize the gaps and silences in dominating ways of knowing and seek to illuminate counternarratives" (p.1-2). The diverse work of counternarratives in race, gender, class and ability gives it a powerful and wide-ranging foundation on which to continue to build this methodology (Delgado, 1989; Glenn, 2012; He & Phillion, 2008; He & Ross, 2012; Kridel, 2010; Solórzano & Yosso, 2002; Tuck, 2009).

#### **Counternarrative as Methodology**

When given the task of experiencing someone else's reality and truth, researchers turn to qualitative research. Dyson and Genishi (2005) point out "qualitative researchers are interested in the

meaning people make of their lives in very particular contexts” (Kindle location 270). The findings of qualitative research, whether case study, phenomenology, ethnographic research, self-study, narrative or counternarrative research, are “a concrete instantiation of a theorized phenomenon” where “‘truths’ or assumptions can be extended, modified or complicated” (Kindle location 1939, Denzin & Lincoln (2008) remind us of the “province of qualitative research, accordingly, is the world of lived experience, for this is where the individual belief and action intersect with culture” (p. 11).

According to Sandoval (2000) “when scholars transform their consciousness of objectivity into a consciousness of situated knowledges, they develop a different kind of relation to perception, objectivity, understanding, and production that is akin to... the middle voice” (p. 174). This middle voice a liminal boundary of identity both defines and defies our concepts of able/disable, human/inhuman and breaks the dichotomy into a continuum of strengths and weaknesses, stories and counterstories of what it means to be human. Methodology is “not politically impartial” (Collins & Bilge, 2016, p. 113). In being aware of the thorny issue of shifting, prismatic intersectionality, scholars including myself, need to be aware intersectionality not as a social theory that explains data, but “opens the door to the many narrative works, e.g., autobiographies, auto-ethnographies and ethnographies, which are inspired in some fashion by intersectionality” (Collins & Bilge, 2016, p. 113). In one example of what is described as duoethnographic process, where two researchers write together reflecting upon each other’s work and experiences as they process through their reflections on abled-bodied normativity, Kathy Sitter reflects “I also think people communicate their truth and share their practical wisdom in different ways, and in these spaces, voices can take shape beyond the written and spoken word” (Nusbaum & Sitter, 2016, p. 311). Counternarrative research uses positionality taken from feminism research and “frame their stories in relation to the dominant cultural storylines which form the context of their lives, especially when those storylines don’t seem to fit” (Bamberg & Andrews, 2004, p. 1). This positionality relates directly into work on identity and intersectionality. Elaborating on Butler’s notion of performing identities in acts of ‘self-marking’, Bamberg and Andrews (2004) point out research and analysis “of how speakers actively and agentively position themselves in talk starts from the assumption that the intelligibility of their claims



is situationally and interactively accomplished” (p. 366). These counterstories are a stark relief and in tension connected to the dominant storyline of race, gender, sexuality, and ability. Bamberg and Andrews in editing a collection of counternarratives can explore as I hope to, from a “deep concern with power and hegemony” to the purpose of “mak[ing] headway in designing alternative strategies to public, institutionalized power relations, resulting in more egalitarian reciprocity and universal moral respect” (p. 353). This is a hallmark of the work being done in social justice research and action. This use of counterstories to challenge power is a focus of many researchers (Bamberg & Andrews, 2004; Carmona & Luschen, 2014; Delgado, 1989; Glenn, 2012; He, M. F. & Ross, S, 2012; Sandoval, 2008; Tuck, 2009). Tuck (2009) implores researchers connected to deficit models is “distinct and being more socially and historically situated” (p. 413). She asks that we “insist that research in our communities, whether participatory or not, does not fetishize damage, but rather celebrates our survivance” (p. 422).

In the work of social justice, sharing stories that broaden the reader’s experience and make them think in a different way is an important first step toward actions that will engage all minority identities focused on eliminating inequalities in a democratic and civil society. Carmon and Luschen (2014), in collecting work of critical stories and pedagogies, remind “us that we cannot depend on statistical data to illuminate experience and compel change, but rather, it is also in the crafting of narratives and sharing stories that social transformation happens” (p.2). They note that “among social justice educators, the call to narrate, craft, share, and explore critical stories” (p. 7) has gained urgency in recent years. For this reason, I have chosen counternarrative as a form of inquiry and mode of representation for the expression of my dissertation work.

The methods of counternarrative are very similar to narrative inquiry pioneered by Connelly and Clandinin (2010, p.216). The collecting of narratives and stories function as arguments “in which we learn something essentially human by understanding an actual life or community as lived” (Connelly & Clandinin, 1991, p. 136). While the ideas of narrative inquiry are powerful, they are not enough to lever the important work of social change and transformation. In narrative inquiry we focus on understanding something essentially human in the stories shared, whereas in counterstories we are dipping into the

stories of “outgroups,” as Delgado (1989) terms them, that “create their own bonds, represent cohesion, shared understandings, and meanings” (p. 2412).

By using qualitative methods of collecting the stories and counterstories of disabled people, we can analyze with an eye to broaden the horizons of society’s perceptions and create cracks in the idea of a monolithic dominant narrative of what it means to be “normal” and “human.” This is the transformative work of social justice that is a hallmark of counterstorying. This type of storytelling is particularly suited to the epistemically compatibility of uncovering the situated truth of these participants. Each story is unique and highlights the counter of the dominant stories of “normality” in this case, the mythology of the “average” man who is not disabled. By using counternarrative as a methodology, I can be a conduit to share an expanded or new way of looking at disability. It is a way of countering the official labels of disability and all that implies in a majoritarian or hegemonic way of looking at disability. Both Critical disability studies and posthumanism disrupt and blurs the boundaries of humanism and what we consider to be the “right” way to human. Disability by entomology meant a lack of, a lessening of what is valued through ability in a humanist worldview. Posthuman disrupts the narrative of a lone “everyman” that represents what it is to be human by looking at relationships between humans and technology or humans animals and humans. Critical disability studies questions the very foundations of what we consider disability to be. Work in social justice and social justice for education disrupts these majoritarian ideals of society through action and activism. Counterstorying shares those narratives and ideas that do not fit the mold of “the normal person (*l’homme moyen*)” (Davis, 2013, p.1). It disrupts what we think of when we think of the identity of disability. Technology creates the same disruption as we integrate it more and more in our lives.

### **The Role of Narrative in Disability and Technology**

Haraway tell us that “cyborg writing is about the power to survive, not on the basis of original innocence, but on the basis of seizing the tools to mark the world that marked them as other” (p.55) and that these tools are “often stories, retold stories, versions that reverse and displace the hierarchical dualisms of naturalized identities. In retelling origin stories, cyborg authors subvert the central myths of

origin of Western culture” (p. 55). I hope by looking at disability and technology and the melding of the two, I can share the stories and counterstories of our modern “cyborgs” to subvert the myth of the perfect, normalized human of Western culture. Are we bold enough to listen to the stories without mythologizing cyborgs in our midst?

How has intersectionality and identity been explored to bring about a fuller representation of disability? Often, through the narrative process. Whether it is through reviews of representations of disability in literature, movies, and media, or autobiographical accounts that cross the boundaries and interweave between autobiography and theoretical work or even through narratives of others along themes and commonalities. Siebers (2008) tells that “we of the tender organs need to think about ways of telling our stories that will communicate the truth of our existence as a group facing prejudices and other barriers, often physical, put in place by society at large” (Kindle locations 1012-1014). He makes the case that Judith Butler feels “constructionism is inadequate to the task of understanding material bodies, especially suffering bodies” (Kindle locations 1146-1147) making the disabled body “the best example and significant counterexample” for the theory of social construction to contend with (Kindle locations 1181-1182). Like Schrodinger's cat, we cannot unpack and unwind the social construction of disability without acknowledging the material bodies of disability also. It both exists and does not at the same time until we open the box to see and examine. But unlike the thought experiment paradox, disabled people live the both/and existence as do any of the social categories through how society thinks, perceives the other and the lived experiences that are real and solid and material.

The narratives of disability, intersectionality and in my work here of technology also, allow “people with different disabilities to tell a story about their common cause. The story of this common cause is also the story of an outsider position that reveals what a given society contains” (Siebers, 2008, Kindle locations 2040-2044). Even in more practical-oriented research, Thousand, Diaz-Greenberg, et al. (1999) felt “student consumer perspectives in special education indicated dissatisfaction on the part of these students and particularly feelings of not being respected, heard, or supported by the educators in their lives (p. 324). Thousand, Diaz-Greenberg, et al. were researching inclusive education and felt “voice

through dialogue is empowerment, which appears to be a common key principle of both critical pedagogy and inclusive education” (p. 324). So, not only are the narratives important for disabled people, or society as a whole, but much more manageable practicality of changing the practice in education for both students and teachers.

Many of the narratives that show the reality of the lived experience of either disability or posthumanism are expositied through either fiction or autobiography. There are few examples of narratives or counternarratives mediated through an outsider researcher/ally status. Some interview-based work in technology is available, but much of the scholarly work is observational of the cultural and social events of the world or theoretical.

There is a lot to learn from the autobiographical perspective of disability identity and intersectionality. Much of this work weaves personal anecdotes, with theoretical discussion and commentary of contextual forces in the lives of the authors. Disability is a very individualized experience, despite schools’, governments and societies creating broad categories of “sameness” through labels of disability. The autobiography is able to give that individual experience and lens. These are important stories. Whether it is Simi Linton’s *Body Politic* (2007) intercepting her story of disability with calls to arms on changing the policies and structural inequalities surrounding her life of becoming physically disabled as a young adult or Jonathan Mooney (2007) sharing his story of experiencing learning disabilities along with stories of others with disabilities in a cross-country exploration of guilt, acceptance and peace. With disability as identity, autobiography has an extremely important tradition in telling the stories of people with disability. Mooney’s musings include an enlightening comment of growth and angst in his meeting of a severely disabled person, Ashley. He said:

Ashley confronted me with my own deep prejudices about what it means to be a valuable human being. I didn’t know if I could truly value a body that was so damaged. Ashley also challenged some of my ideas about intelligence. If Ashley couldn’t hear, speak, or see, how could she learn? And if Ashley couldn’t learn, was she a fully functioning member of the human race?” (p. 113).

And on the other hand, Mooney's commentary on autism can exposit the complexity of issues of identity and disability. He points out "it is common in the field of autism to invert the traditional politically correct sorts of phrasing and claim that an individual does not have autism but is autistic- like a cognitive nationality" (p. 239) giving us insight through his lens on the shift politics of claiming and pride of disability as an identity.

Linton (2007) shared how after her accident on Interstate 95 she was to "become a marginal citizen, her rights and liberties compromised, and her economic advantage, white skin, and private school education weakened currency in this new world she inhabited" (p. 3). She shared the stories of the rehabilitation facility, apartments and inaccessible cities, apartments and universities. Her conclusion was that "the problem, as I came to understand it, was not that I couldn't walk; it was that the society was configured for those who do walk, see, hear, etc. It would take me a while longer to learn how entrenched the patterns of discrimination are, and how solid and purposeful the disability community was" (p. 54). Her disability changed the trajectory of her life and gave focus to her life's work. Sharing her story was a way to enlighten others and call action into justice. She closes her story by saying:

We can't wait for this century to unfold to reveal the truths in this forecast. We will have to act quickly to make the line- to state for the record who is and who is not part of the community, the public, and the citizenry. From there it will take affirmative actions of a new and as yet unwritten form to make inclusion, integration, and participation a given of the twenty-first century (p. 245).

Sequenzia & Grace (2015) edit a series of submitted works called *Typed words, loud voices* of people, generally autistic, that use typing as a primary form of communication, to counter nonverbal or semi-verbal status. The controversy of aided language communication has spanned decades but from the words of these various authors you get a direct connection and insight into their varied lives and perspectives. There is no theorizing or commentary from the editors except as an introduction and one of the author's own work in the work. One writer pointed out "people who are very disabled like I am, people who are non-speaking as I am, we are immediately graded as lesser valuable" (p. 10). Another writer shared "my status as an Autistic person who can't always speak means typing part time is the most

effective way for me to communicate. This adds up to what I sometimes think of as another exercise in activism by existence” (p. 23).

Eli Clare’s work especially *Exile and pride* (2015), delves into biography and theoretical musings across several areas of intersectionality: disability, queerness, environmentalism, rural geographic differences influencing all of these other topics. Clare’s work is a story of feeling at home, eventually. Clare asks early in the work:

How could I possibly call my body home without the bodies of trees that repeatedly provided me refuge? Without queer bodies? Without crip bodies? Without transgender and transsexual bodies? Without the history of disabled people who worked as freaks in the freak show, displaying their bodies: Charles Stratton posed as General Tom Thumb, Hiram and Barney Davis billed as the “Wild Men from Borneo”? The answer is simple. I couldn’t. (p. 11)

The wide-ranging work covers intersectionality of Clare as a beautifully flowing river, weaving in and out of sight of several shores of identity and witness. Without these personal narratives, the connection between the marginalized and dominant groups would be much more difficult.

Piepzna-Samarasinha’s work (2018) crosses boundaries too and shows her thoughts on intersectionality of the Crip culture, of invisible disabilities, such as chronic fatigue and the social justice work being completed in the disability and artistic communities surrounding her life. *Care Work* ranges around and flits to various topics as they relate to parts of her history and life and her work in disability justice. She says “disability justice centers sick and disabled people of color, queer and trans disabled folks of color, and everyone who is marginalized in mainstream disability organizing” (p. 22). Before her work, I was unaware of the striations of various types of disability organizations. I learned the important concepts of “spoons” which is the shorthand for expended energy due to fatigue and disability. She frequently had to calculate the “saving of spoons” to complete a task depending on a host of other factors in her body and life that day. She shares “I am, like many people, someone who remembers and fights to remember as an act of both resistance and changing the future, who has sought to record my stories and the stories of my communities when I write” (p. 80).

In mixing the work of autobiography, disability and animal studies, Taylor (2017) uses the weaving back and forth of her stories of growing up with a disability and her concern for animal rights and animal studies in *Beasts of burden: Animal and disability liberation*. She talks about ableism and expounds about what disability is, much like many scholars earlier noted here discussing social constructs and the “overcoming” mythos surrounding disability. Some of the very poignant points she makes includes the point that “there are countless ways that the lived experience of disabled people are replaced with metaphors and stereotypes: from pity-mongering charity drives and sappy “super cripp” characters in movies to representations of disabled people as scroungers, fakers, malingerers or burdens in common political discourse” (Kindle location 290). She contrasts that with her own view that “disability can be an identity one embraces, a condition one struggles with, a space one finds liberation in, or a concept that can be leveraged to marginalize and oppress. It can also be all of these things at once” (Kindle location, 368). She touches on questions of posthumanism through the lenses of asking who is human or non-human is not as clear cut in history as we would like to think we have as a definition today (Kindle location 404). She connects disability to animal studies with the intersection of a discussion of crippled animals and the conflation of disabled and animals in history. To counteract the idea that there is a hierarchical divide between the ways humans share information and the myriad ways other animals do (and I would personally add humans that are nonverbal), she reminds us of the call from disability studies and activism. That call is “for recognizing new ways of valuing life that aren't limited by specific physical or mental capabilities. Implicit in disability theory is the idea that it is not specifically our intelligence, rationality, agility, physical independence, or bipedal nature that give us dignity and value” but that “life should be presumed to be worth living whether you are a person with Down syndrome, cerebral palsy, profound intellectual disabilities, quadriplegia, autism, or like me, arthrogyrosis” (Kindle location 989). She celebrates the value in “the very embodiment, cognition, and experience that disability encompasses” (Kindle location 1035).

Autobiography is an important avenue of sharing the stories of the disability community. It is deeply personal, individual. It is also an avenue of work not particularly available to me. I am a white

woman and able-bodied (for now) with the exception of a moderately severe eyesight condition due to amblyopia in my left eye and ever-worsening nearsightedness enough to contemplate as I age if and how it will worsen to the point of true visual impairment and blindness one day. By working through collecting others' stories in areas of interest to me of disability and technology, I hope to gain and share insights of my multiple participants and make those connections for others to get a sliver of connection to these participants' lived experiences.

There are many examples of disability used as qualities equaling evil, ugly, broken in fiction theorized and explicated and critiques in fiction many authors such as Rosemarie Garland Thompson. Posthumanism is often explored through the fictional genre of science fiction in the world of robots, androids and human interactions. Few works address both. Two notable exceptions are Philip K. Dick's novella, *Do Androids dream of electric sheep?* which was the inspiration for the movie *Blade Runner* and *The ship who sang* by Anne McCaffrey. Dick's work (1968) shows the main character in pursuit and trying to determine if android are perfect mimics of human-ness. We also have the counternarrative of the "chicken heads" and one character, J.S. Isidore as a counterpoint to what it means to be human, or subhuman after World War Terminus. He says of himself he is "a special, a chickenhead; what do I know? I can't marry and I can't emigrate and the [radioactive] dust will eventually kill me. I have nothing to offer" (p. 70). The following year, 1969, Anne McCaffrey published a novella, *The ship who sang*, that is one of the only other instances I could find of disability + technology in fiction. In Haraway's *Cyborg Manifesto* mention is made of this story. The premise is that in this time of space travel, the severely disabled, have their brains trained and tested, and if eligible their brains/personalities are transitioned from their broken bodies into space ships as the control center for intergalactic travel. Helva's comments on her situation are ironic, witty and commentary on the view we have of the worth of those "broken bodies." She says "I'm a living example of the extremes to which they are willing to go to sustain a human life" (p. 67) and how even in this imaginary future "most of their (humans) original objections about "shells" were overridden by the relief that these hideous (to them) bodies were mercifully concealed" (p. 3) inside the control center of the ships. This short story and several others that followed



focused on Helva's adventures across space and finding the perfect "mate" of pilot in her extended aging process as a ship. These fictional and imaginative examples of disability and posthuman are interesting insights but do not get us to what people with disabilities are experiencing now, with the benefits and/or drawbacks of technology and assistive technology in today's society.

By providing a counternarrative perspective of the stories of several individuals with various disabilities and their interaction with technology and assistive technology, I hope I can look for commonalities and differences in the lived experiences of the participants around these two phenomena of disability and technology. This cannot be achieved by an autobiography or biography. This cannot be achieved through exploration of fiction and the lens it puts on history, or the possible future of science fiction. This can be achieved through the collection and analysis of counterstories of participants across disability categories and technologies.

### **Research Settings**

As I will discuss in the next chapter more in depth, I situate this study partly through a semi-autobiographical lens of myself as a special educator, as a family member of people with disabilities, and as a friend, and ally. Part of this study is a culmination of one stage of growth in my journey as a teacher and ally to the disability community. The participants in my study all entered my life in different stages of my growth and development as an adult and as an advocate. Three of the participants are former students. All now ages between 29 and 33, these young men are all professional adults in their communities and respective fields and will be highlighted in Chapter 4 of my study. Two of the participants entered my life as I was beginning to learn and work more extensively with Assistive technology as an outgrowth of my work as a special educator and my interest in technology. The final two participants have been part of my journey only in this last stage of this study and my growth after I had already began my work in Curriculum studies and my doctoral program. They represent my growth in advocacy and social justice in the community beyond the schoolhouse. The last four participants will be featured in Chapter 5 of this work. Subsequently, because these participants have arisen from various aspects of my life, there are

some interesting contextual elements of identity that have emerged. I live in a suburban county west of an urban node of Georgia. The school system and community I work and live in is not diverse a community as the community east in Augusta, GA. Six of my seven participants live in Georgia and live or have lived in the community in which I live and work. Because this study is also a mapping of my life and journey as a special educator and ally, it is not as diverse racially, or gendered as it could be. Also, all of these participants have physical impairments. This is an aspect of conscious choice as a researcher. Many if not most of the individuals that use assistive technology have physical impairments. Other exceptionalities that do use assistive technology, and a more diverse racial make-up of people sharing their counterstories is an important pathway of expansion of the work I have started here and I hope to continue in the future.

### Participant Profiles

These participants are all adults ranging in age from 19-50, including five white men, and two women: one of South Asian background and one white. All participants have physical disabilities that stem from a variety of medical impairments such as degenerative muscle diseases, cerebral palsy, or impairment from injury and subsequent infections. All of the participants are working in professional capacities with college education some with postgraduate degrees or certifications. All live independently in various ways, either married in their own home, or living in an apartment with a roommate or by themselves, or in their parent's home or in a college dorm with personal care attendants. As discussed above in the context of the participants, these participants were asked to be part of this study through their professional or personal relationship with myself as a special educator, researcher and advocate in disability issues and assistive technology.

Table 1

Participants Profile
<p><b>Eli:</b> white, male, single* Age: 33            + Lives at home w/ parents            + cerebral palsy</p>

+ counselor at state medical prison  
 + formerly certified rehabilitation counselor at state vocational rehabilitation agency  
 + BS psychology  
 + Appling, GA (rural Columbia County) west of Evans, GA

**Silas:** white, male, single  
 + Age: 31  
 + lives in apartment  
 + Cerebral palsy  
 + attorney at own law firm in injury and divorce proceedings primarily  
 + Law school in Georgia, \*History BA at large state university in Arizona  
 + passed bar in GA & SC  
 + Evans, GA (suburban Columbia County)

**McKenzie:** white, male, single  
 + Age: 29  
 + lives in apartment w/ roommate  
 + Cerebral palsy and a twin with more severe impairments  
 + dropped out at 16 took GED  
 + MA & post-graduate fellow in communications/Spanish at large Southern university  
 + Charlotte, NC from Evans, GA

**Liz:** South Asian American, female, married  
 + Age: 40  
 + lives w/ husband  
 + degenerative muscle disease  
 + program and outreach manager at a technology and disability service provider  
 + Greater-Atlanta area, GA (Urban-suburban)

**George:** white, male, single  
 + Age: 19  
 + cerebral palsy  
 + lives in dorm (summer with his father at home)  
 + sophomore at prestigious university in Atlanta  
 + studying computer science and intern at wireless rehab engineering center  
 + uses personal assistants for daily living and class needs  
 + uses personal assistants and iPad for verbal output of communication  
 + from metro Atlanta area, GA

**Leia:** white, Jewish-background, female, single  
 + Age: 32  
 + lives with a roommate  
 + Cerebral palsy  
 + screenwriter, disability advocate, PhD student in Disability studies

- + MFA creative writing
- + Orange County, CA

**Paul:** white, male, married w/ 2 children in thier 20s

- + Age: 50s
- + lives w/ wife in own home
- + acquired disability amputation in Afghanistan
- + military veteran and works with various Wounded warriors projects
- + studied nursing several colleges in the southeast
- + from Savannah, various military moves and now Evans, GA (suburban)
- + uses personal dog assistant
- + part of Team 43 (President's wounded warrior athletes)
- + promotes adaptive sports and rec programs for veterans
- + Evans, GA & often Washington, D. C. for months at a time

## Procedures

In trying to uncover the voices that are often silenced through marginalization of disabilities, I wish to use an array of methods to create counterstories that “allow participants to connect with characters across lines of difference” and encourage “them to reconsider assumptions that society and they hold and perpetuate” (Glenn, 2012, p. 326). By engaging in inquiry that is a large part of my work life and passion with people that are considered an oppressed group by critical theorists, this fits in the framework of participatory inquiry whose aim is “to work with oppressed groups and individuals to empower them so that they take effective action toward more just and humane conditions” (He and Phillion, 2008, p.13).

I used traditional qualitative interview methods (Kvale & Brinkmann, 2009; Merriam, 2009; Saldana, 2013; Wolcott, 2009) to create interview questions, and settings that will guide interviews into the generating of narratives and counternarratives. What might look different are the methods, dependent on the participants recruited and located to participate in this research. I use a set of basic introductory questions created to send to participants so they could think, discuss and share their experiences in the method that best suits their abilities and modalities of communication. If I have participants with verbal communication difficulties, having a written set of questions to work from in the beginning will ease the rapport and lower the stress level of waiting for a response. Computer-assisted interviewing in the form of

emails or correspondence or internet chat interviews could be a good start for some participants (Kvale & Brinkmann, 2009, p. 194). Some participants may have excellent verbal skills where a traditional interview with digital recorder will be appropriate, others with difficulties of expression videotape would be added to aid in transcription. Additional interviews and face-to-face settings might become necessary to follow additional lines of questioning and to probe into more of the story of their life and the story of their life with technology. Many traditional qualitative methods of standardization in questions and modalities of research tools are not appropriate in collecting the stories of people whose impairments are as diverse as the stories they will be sharing.

I sent the first set of pre-interview questions via a Qualtrics Survey through Georgia Southern University. These surveys have internal checks for Accessibility for items such as screen readers for people with disabilities. (<https://www.qualtrics.com/support/survey-platform/survey-module/survey-tools/check-survey-accessibility/>).

Table 2

Pre-Interview Survey	Question Type	Answer Choices
1) Demographic Questions: <ul style="list-style-type: none"> <li>• Full name</li> <li>• Pseudonym you would like me to use</li> <li>• Age</li> <li>• Race</li> <li>• Location/region of USA</li> <li>• Best contact (phone/email etc. for interview)</li> </ul>	Constructed response	N/A
2) What is the best day/time for your interview (Please select all that apply)	Selected responses	Weekday morning Weekday evening Weekend morning Weekend afternoon Weekend evening
3) What methods(s) would you be most comfortable for the format of your interview? (Please check all that apply)	Selected responses	Face to Face Skype

		Zoom Telephone Google hangouts
4) What accommodations will you need during the interview to make this comfortable and optimal for you?	Constructed response	N/A
5) Will you need a copy of initial interview questions ahead of time to process or use time/energy to think/construct some answers? (Like using AAC device or have verbal output weaknesses). There may be follow-up questions during a direct interview for clarification or elaboration.	Selected response	Yes No
6) Anything else I might have not thought about that will make this interview process enjoyable and comfortable?	Constructed response	N/A

The survey can be viewed here:

[https://georgiasouthern.co1.qualtrics.com/jfe/form/SV\\_9zPbPsQfEVltgQB](https://georgiasouthern.co1.qualtrics.com/jfe/form/SV_9zPbPsQfEVltgQB)

During the interview process I used the following questions to stimulate discussion and expositing of participants' recollections and experiences relating to the intersection of disability and technology. I recorded the interviews and transcribed them quickly from when the interview takes place to maintain accuracy.

Table 3

Interview Questions for Participants
<ol style="list-style-type: none"> <li>1. Tell me what you think of when you hear the word disabled or disability.</li> <li>2. Describe yourself to someone who doesn't know you.</li> <li>3. Tell me about the technology or the assistive technology you use in your daily life.</li> <li>4. Is your perception of yourself different when you're using your technology or after you began using your technology?</li> <li>5. Can you remember and share a story of using a new piece of equipment or technology the first time and how it made you feel?</li> <li>6. How do you feel other people view you with or without the technology that you use daily? Could you share a story to tell to explain that point?</li> <li>7. Do you consider your technology or assistive technology a tool to use or an integral part of who you are? How so?</li> <li>8. What would you like others to know about you?</li> <li>9. How do you think that your view of yourself is different from other people or society's view of what it means to be disabled?</li> <li>10. Do you have any questions for me or anything else you want to share about yourself and/or technology you have been using that we haven't talked about yet?</li> </ol>

11. Do you have anything else you would like to share such as photographs, or videos of you and your technology that would give others a better understanding of your life?

Just as Clandinin and Connelly (2000) tell and retell past and current stories, I also “share our writing on a work-in-progress basis with response communities” (p. 60). The research interview as field text (p. 110) was be my main source of information but I did not discount field texts of journal writing, field notes, letters, emails, and conversations or even photographs (Clandinin and Connelly, 2000, p. 110-115). Several of the participants offered to share videos from YouTube, and pictures of themselves. I want the participants to enter the conversation and tell their story to share what others might not understand as important about their identity not expressed in reductionist terms or as numerical data.

### **Analyzing Counterstories**

Seeing what welled up from the participants stories that fit into three broad themes of identity, stories of technology and advocacy and work in the community. Merriam (2009) shares that “the practical goal of data analysis is to find *answers* to your research questions” (p. 176). When using narrative coding and analysis to examine stories or counterstories is “appropriate for exploring intrapersonal and interpersonal participant experiences and actions to understand the human condition through story (Saldana, 2013, p. 132). Saldana reminds us that there is a wide breadth of ways to analyze using narrative or story structures in the literature but what is most essential for my work and analysis is what Polkinghorne (1995) calls paradigmatic cognition which “seeks to the inductive development of categories from the data, particularly if large collections of stories are available for analyzing patterns” (cited in Saldana, 2013, p. 143). According to Daiute & Lightfoot (2004, p. 2, cited in Saldana, 2013, p. 134) “the unit of analysis is often big gulps of text – entire stories.” Using these large “units of analysis”, e.g. counterstories, I employ what much qualitative inquiry engages is a loose type of constant comparative method (Merriam, 2009, p. 30-31) surrounding the themes of disability identity, technology and advocacy or social justice work. But instead of drilling down to small units of comparison, I am also

using a critical research perspective where I seek “not just to study and understand society rather critique and change society” (Patton, 2002, in Merriam, 2009, p. 43). This is entirely appropriate, given my theoretical frameworks of critical disability studies, posthumanism and social justice work are all critical perspectives that engage in critique of society and work toward change.

Surrounding the three main categories, I look to see what recurring themes or findings well-up within the highly individualistic stories and life experiences of these participants. I rely on these critical theories of CDS, posthumanism, and social justice to make meaning and draw out findings that disrupt the traditional, hegemonic, majoritarian views of what disability should look like in society, how technology intersects with both humans and disability as an identity and how society and schools should change.

### **Significance**

Through the collection of stories of the lived experiences of disabled people and their dialectical relationship with the technology they use for everyday living, I hope to weave together an image of the mosaic of lives and experiences this group of diverse people with one commonality of group membership into something those of use on the “outside” can connect to, and begin to understand and connect within our own lives. I want my audience to not only be sympathetic, or even empathetic but to become true allies through these stories and become aware of the social injustices and common daily life struggles people with disabilities undergo.

Counterstories of race, class, gender, geography have begun to be explored by researchers such as Delgado, He, Phillion and Ross. Tobin Siebers (2008) points out “the presence of disability creates a different picture of identity — one less stable than identities associated with gender, race, sexuality, nation, and class — and therefore presenting the opportunity to rethink how human identity works” (Kindle edition, locations 232-234). This identity is worth exploration as to add the body of work other scholars have started in counterstories, restorying, and narrative inquiry. Many of the work of scholars of disability studies that are functioning as an insider status often already use life stories, biography, and



autobiography throughout their theoretical and pragmatic work function as counterstories in practicality. I would be working in the role of an outsider researcher and scholar so I must be very aware that in the collecting of narratives, counterstories that these participants are part of the process through member check of data collected and through giving voice to their ideas of identity, political autonomy of naming and claiming disability in which to counter ideas of ableism. Because, “the ideology of ability is at its simplest the preference for able-bodiedness. At its most radical, it defines the baseline by which humanness is determined, setting the measure of body and mind that gives or denies human status to individual persons” (Siebers, 2008, Kindle locations 290-291). This ideology needs become a complicated conversation by the sharing of counterstories of both identity through labeling and the addition of technology as a part of the live, lived experience and personhood. Erevelles (2011) reminds us that “notwithstanding the emancipatory possibilities these studies (dynamics of class, race, gender, and sexuality) promise, the voices of disabled students as oppositional subjects/agents have remained conspicuously absent in this diverse array of counter-narratives” (p. 70). Hopefully, this work will start to assist in filling that gap and unmute the silenced voices.

### **Challenges**

There are many challenges to this type of research. Logistics of overcoming the very real, but also very socially constructed an idea of disability to “accommodate” from traditional interview protocols will be challenging. Having have to use multiple forms of field texts such as emails, letters, interviews with voice recorders or videotape of both the participant, or possibly any augmentative communication device is a challenge logistically. There are obvious limitations to the smaller number of participants having a narrower set of experiences. Disability labels cover a range that the federal government subdivides into thirteen different categories for educational purposes alone. The variety of my participant set will not be able to match the scope of life experiences of the varied types of difficulties people experience. Just as an IEP stands for Individual Education Plan, these interviews in a real sense are individual, but I hope also, communal and will capture some of the stories of this community that lives a mediated life between technology and their true inner (and outer embodied) selves.

My role is that of an outside researcher and ally. I know that “interpretive research is reflexive” and “made up of others’ experiences are mediated by their [researchers’] own lives” (Dyson & Genishi, 2005, Kindle location 1440). According to Brown & Ostrove (2013), “allies are generally conceived as dominant group members who work to end prejudice in their personal and professional lives, and relinquish social privileges conferred by their group status through their support of non-dominant groups” (p. 2221). I have caution as I move to collect and analyze these stories. I question my ally status asking “can my position of privilege as temporarily-abled, part of the normate, part of a socio-economic class not experienced by many people with disabilities.... Can I leverage what positions of power I do experience to help bring the voices, the agency the social justice of a group of people I have come to care about deeply in my life? Is that how I can negotiate that rocky road of ally scholarship?” (Hotchkiss, 2018, p. 3). Hopefully keeping these worries in the forefront and keeping the focus on the participants will show me the way to interpret, create commonalities among difference as I reflect and work reflexively even from my position of someone temporarily abled-bodied.

### **Summary of Methodology**

I hope that my dissertation research will encourage more exploration into both narrative voices of people with disability, and exploration of the posthuman critique of what makes human “human.” Does everything we have that makes us human have to be organic or biological? I hope this research will further encourage others to explore ways to help others make their voices heard and to challenge the distorted strands that a master narrative has for people who live life in relationship with others. I can only hope the counterstories collected and shared will move the participants and my audience into social justice action to eliminate inequities of ableism in both theory and in practice and policy. I hope these counterstories will broaden the definition of “normal” and “human” by creating bridges of connection across the continuum of disability. After all, Siebers (2008) rebukes that “only 15 percent of people with disabilities are born with their impairments” (Kindle locations 1224-1225), therefore we all have potentiality any day and as we age to become part of this minority group in the blink of an eye or over the long road of aging. It is in our best interests to share these counterstories, because any one day these

counterstories could be our story. By “connecting the personal with the political, the practical with the theoretical, and inquiry with social change” (He & Phillion, 2008, p. 15), I hope my work can help amplify the voices of those previously silenced or muted to engage fully in political, personal, and participatory life.

## CHAPTER 4

### COUNTERNARRATIVES: LOCAL

In the following two chapters, I will share the counternarratives of seven individuals that have the identity label of disability among their other intersections of identity. I will share their thoughts and stories of the disability as an identity and stories of technology and/or assistive technology. As I began to engage in my research with these participants, I realized that their stories are part of my stories and their lives are part of my life. I met the three people I highlight in this chapter when I was working in a high school in a suburban, fairly affluent county in eastern Georgia. These three young men all came into my life through my work in a special education classroom approximately fifteen years ago. All three of these men are now around the age of thirty and are all working in professional careers.

In the next chapter, I will highlight the stories of four individuals that entered my life as I began my interest in assistive technology and advocacy and social justice. I will share the stories of individuals that were part of my journey into advocacy, policy change and learning about technologies that might be solutions to make the lives of people with disabilities easier to navigate and break down societal barriers.

When I began to organize the stories of these participants, I realized that their stories are also the story of my journey of becoming a special education teacher. Seeped in the medical model of "fix and remediate" toward to the theories of disability studies and a much more varied perspective of disability. Not only are these counternarratives stories ones that you do not hear in a majoritarian discourse, but they also open up through the connection of narrative ways temporarily able-bodied people to learn vicariously through their experiences. Hopefully, this will enkindle a fire in others to join the fight against ableism in both attitudes, but also in policies and local actions. I am fully committed to the hope that these counternarratives will create allies in temporarily abled-bodied readers, but also an acknowledgment of validation from readers who may have an impairment or disability by connecting with the stories of these participants. Maxine Greene (1988) states that "human consciousness, moreover, is always situated; and the situated person, inevitably engaged with others, reaches out and grasps the phenomena surrounding

him/her from a particular vantage point and against a particular background consciousness” (p. 21). I am situated and I am reaching out to engage with others to grasp these phenomena of disability identity and technology to leverage myself and others to make changes for “access is the path to diversity, inclusion, and justice” (Garland Thomson, 1997/2017, p. xvi).

Often the work in counterstorying or counternarratives is centered on a particular geographic place and space. One school building, one rural or urban town, one region of a southeastern state, etc. My work is only centered geographically if you view place and space as one of several concentric circles. To explain the stories in this first section, all of these stories *do* start in one school, one town, one state. These stories begin at Greenbrier high school in a suburban area of Evans county, outside of Augusta, Georgia. The students have grown into adults and are now centered in Appling and Evans, Georgia and Charlotte, NC. My second group of participants expands that geographic circle. Two of my storytellers live in Atlanta and are heavily involved in the assistive technology community as both product users and creators that help others choose the right technology to help with their daily life. Then, I will turn to a friend I have made recently when I began studying and working in disability studies and advocacy. She lives in California and her work and story shows that my geographic center expanding nationally. Finally, my last participant is a military veteran who lost his leg through his work in Afghanistan. Even though he lives in Evans, GA, his work with veterans and his stories range to Washington, DC and across the world. The centering of the participants' stories goes from local and regional to across the state of Georgia to across the nation and global influences. I hope their influence has a similarly widening circle of influence on the readers that get to experience vignettes of their lives.

### **Keeping it Local: Educating the Teacher**

#### **Context of Evans, GA and Greenbrier HS & Myself**

I met Eli, Silas and McKenzie sometime when these young men were in high school in what was called an “academic elective class.” I had undergone quite a few changes already in my professional and personal life. I started teaching in the Fall of 1997, and lived in Covington, Georgia. Then, I moved back to Statesboro and in 1999 moved to Martinez, Georgia in Columbia County. This was all in my first 3

years teaching special education. Evans, Georgia is a suburban unincorporated area in the western part of Columbia County to the west of Augusta, GA (Richmond County). The high school I had gotten a job at in 1999 had just opened its doors three years prior. The special education department had several classes of “self-contained,” which were students with cognitive impairments that were working on a functional curriculum (now we term it low-incidence population with category labels of Mild, Moderate, or Severe/Profound intellectual disabilities). There were only three interrelated resource teachers, myself, the department chair and another teacher. Now, there are six interrelated resource teachers and several paraprofessionals supporting students in regular classes. To give you an idea of the growth in the twenty years I have been teaching in Columbia County, the population of Columbia County was 93,000 in 1999 while Richmond County’s was 190,000

([https://www.google.com/publicdata/explore?ds=kf7tgg1uo9ude\\_&met\\_y=population&idim=county:13073:13245&hl=en&dl=en](https://www.google.com/publicdata/explore?ds=kf7tgg1uo9ude_&met_y=population&idim=county:13073:13245&hl=en&dl=en)). By comparison, in 2017, Columbia County’s population is now 152,000 and Richmond County’s population has almost stayed the same at 201,000. The school population has increased from 1200 to 2100 in 2008 before a fifth high school was opened, to more current 2017 enrollment figures of 1673

(<https://www.schooldigger.com/go/GA/schools/0141001501/school.aspx?t=tbStudents>).

In addition to being in a growing school and community by moving near Augusta, I went from teaching elementary to middle school to my permanent k-12 home of high school in the Fall of 1999. This time period was also during the beginnings of the transition from teaching “resource” in small class settings for students with IEPs to the beginnings of coteaching as an instructional practice and setting. In the early 2000s coteaching was considered a best practice, but not mandated by the state or federal policy or implementation procedures. The No Child Left Behind Act was passed in 2001. When NCLB was passed, school districts were forced to prove at the high school level to have highly qualified teachers in all courses that awarded credit for a diploma. This meant that my special education degree did not qualify me to give high school credit to students I taught in PreAlgebra, 9th-grade literature or Physical Science. I would have to go back and pass teacher certification tests in 4-8 different areas to continue to teach in a

small group setting with my students with learning disabilities, emotional or behavioral disorders or other health impairments including ADHD or Orthopedic impairments. Needless to say, in those core classes, coteaching became the norm and baseline for the “least restrictive environment” for students with average cognitive abilities pursuing a general education diploma. We as special education teachers still worked with students in a small group setting called “academic elective” which was a sort of study hall where extended time on tests, and other reteaching and accommodation-related activities happened.

So during the years of 1999-2002, I primarily taught in my own classroom several classes that were dubbed “resource.” Starting in 2002 the high school I worked with began integrating coteaching in more and more classes until the NCLB regulations filtered down to the state and local level necessitating all of our district’s “resource” classes to be now “coteaching” classes with the exception of Academic Elective. At this same time, I had been married for several years and we were starting a family. In December 2002, I gave birth to my son. I was teaching part of the day in coteaching classes, part of the day in my own classroom. By the time I went on maternity leave for the birth of my daughter in the Fall of 2004, we were fully coteaching at Greenbrier HS. My classroom was given away, and I moved into an office. I was fully coteaching all day with the exception of one or two academic elective courses. By the time my daughter was born in 2004, I had passed the teaching milestone of five years. A milestone many new teachers did not, and do not make before leaving the profession. Tech prep and college prep diplomas in 2002 ([http://archives.gadoe.org/\\_documents/doe/legalservices/160-4-2-.47.pdf](http://archives.gadoe.org/_documents/doe/legalservices/160-4-2-.47.pdf)) have given way to just a high school diploma by 2008 ([http://archives.gadoe.org/\\_documents/doe/legalservices/160-4-2-.48.pdf](http://archives.gadoe.org/_documents/doe/legalservices/160-4-2-.48.pdf)). There were so many changes in special education during this time. It was during this constantly changing time in my life of my mid-20s and in education that I encountered the three young men I am featuring in this chapter of my study.

Each of these interviews and counterstories fall into three general categories that fit my three major themes of (1) disability identity, (2) technology and AT, and (3) ableism, advocacy and social justice. The stories will be arranged in that similar order for each participant to give some consistency for the reader as they learn about the lives of these individuals through these vignettes.



### **Eli (33)**

I am not sure when I met and worked with Eli during his time at Greenbrier. Eli was there from 2001-2005. I am fairly certain it wasn't his freshman year though. I had him for at least one year of the Academic elective class. He had a label of Orthopedic impairment.

Many of his accommodations were physical or related to the amount of classwork/homework due to fatigue, though I am fairly sure he often refused to reduce his assignment load. When we would talk about what he wanted to do for careers, I remember him talking about being either a preacher or a counselor. After a Bachelors in Psychology at a local college, he got a degree in rehabilitation counseling. This enabled him to work with a Vocational rehabilitation agency. This is a state agency that used to be under the state department of labor but is their own agency now as the Georgia vocational rehabilitation agency as of 2016. Its purpose is to help people with disabilities overcome barriers and find the right education, training or coaching needed to find work. He currently is a counselor at the Georgia Medical prison working with people with disabilities that are incarcerated at the medical prison instead of with the general population. Eli's positive attitude and spirit of advocacy for others have been influential to me from my experiences working with him in high school, and he continues to be influential to me today.

### **Disability & Identity**

*When thinking about the word disability*, the first thing that comes to my mind is, that is a label. And sometimes it doesn't always have to have a negative connotation to it. But in today's world, it tends to, and the *dis-* part in front of the word ability always has bothered me. Because the *-dis* is a prefix that denotes something negative and something that you can or can't do, or something that's going to take you out of the mainstream and categorize you in a way that you might not be comfortable with. But that doesn't always mean that that's the worst thing that could happen. Because sometimes, putting a label on something is the only way to identify that there's a problem. There's a need for intervention. There's some



kind of need for help. But me personally, I would rather you think of me as a person who just happens to need accommodations and assistance as opposed to the condition, from a medical standpoint. If you're getting to a point as a person, where you are proud of you of having that identity-- that, to me, says that you have accepted that as part of yourself. And many people at first glance when they see that word and use the word disability, that's not what they're thinking. They're thinking that there's something visibly different, or immediately different that separates you from me, or from somebody else.

I actually have a hard time with the word remediation, because that implies that there's a deficit that must be overcome or teased out or something that's got to be fixed in education. That's probably the best way to articulate that a goal needs to be accomplished, to move someone forward. But they don't put it like that. They put it in terms of deficit, you gotta overcome, something's got to be fixed --medical model of disability, right? If you go over to disability studies, it invites the whole thought of look at it, read it, digest it, think about it, and then apply it to the larger aspects of what you're doing. And that is the socio-political model of looking at disability. And I think, one, one of the issues is, it's such a higher-level process. But it's such a higher-level process that many people are not able to get there, because of how they were raised. Because of factors outside of their control, whether it be poor education, poor motivation to get outside of their comfortable little box. But for others, it's just simply they're lazy. They've got every opportunity. They've got good, good parents; good, good people around them that are trying to increase their tolerance and help educate them. And they just don't want to work for it. Yeah. Yeah, they don't want to do.

*How would I describe myself?* I'd like to think that I'm very positive, outgoing, intellectual, probably overly analytical at times. But I'm very gifted in a lot of different ways. And I tend to look at life as an adventure. Every day is something unique and very different. I actually think about this question quite a bit. Because as a young man out there in the social media world, you start to realize that you do have a presence out there, and how you communicate about yourself and about your situation counts in a lot of different ways. We're living in a time now that whatever you put on that profile, be it a dating site or Facebook or even a LinkedIn professional site, that's what people are going to gravitate to, not

necessarily take the time to sit down and get to know you across the table. But getting back to me, I like to have fun. And I'm probably like the same things. Most of the people in this day and time, enjoy, sitting around watching Netflix working hard and enjoying an adult beverage or two, here or there. But I want people to understand if you don't get to know me, how are you to know there's anything different between us? The beautiful little nuances that happen within a personal interaction. That's what really describes a person.

*How is my view of myself is different from other people's view or society's view of what it means to be disabled?* Okay, let's do society, because I think that's the bigger issue. Society. And I will say this, we've come a long way. And I'm very glad that we're getting we're getting away from so much of the medical-infused model of looking at the condition, as opposed to the person behind the condition. And I prefer, I like to say we're living in a post-ADA world. To be even more specific, post-ADAA, world. The Amendment Act of 2008, that kind of amped everything up a little bit. I think that, as far as even from a political socio-political standpoint, that galvanized a lot of things and really promoted inclusion and getting away from the label. But there's still some pockets of prejudice. There's still some \*sigh\* discrimination. And I'm even seeing it across different settings.

I've now held two different jobs for a similar agency. And you still see the, the glamorous, gilded rhetoric of "We're ADA compliant. We will accommodate those of you who have special needs. You will get this shot. You will be able to work in that shot." That's great. But the reality is, most of the time, that attitudinal barriers that you will run into when you're sitting in an interview across from a prospective employer, they're still sizing you up within 15 to 20 seconds. And I guarantee you if I walk in there with these crutches, and with this with this new brace that might not always be covered up by my pants, they're going to make that judgment. And *Lord help us* if they have come from an environment and a family background that sort of promotes this idea of ignorance towards persons with disabilities. Because if you're coming out of that environment, and you expect me to stand up to that and say, "Hey, it's not like that. You really need to give me an opportunity to tell you how it goes, what my life is." \*shakes head\*

I can't even tell you how many times I've tried to go out on a date with a prospective partner. And the first thing inevitably that comes up is "Is your disability, genetically transmitted?" First date, I mean, we can't we barely exchanged numbers, and we can't even get through the first course of the meal. And your first thought on your mind is "Are we going to be able to do this in the bedroom without fear of something being passed on?" In other words, "Are you are you contagious?" That's kind of how it makes me feel. But thankfully, we are getting away from that, but it's still there.

***Sharing my story is a Blessing.*** I want you to know that I'm one among many people that have long been considered by a lot of different folks to be disabled. But thankfully, through the help of a lot of others who are more inclined to give me a chance to give me an opportunity to say something, I am, I bet you, more uniquely able and more empowered than most others out there. And I know that some of my friends and my family members that also deal with unique challenges in their life, they are even smarter and more passionate than me. As you can tell, I don't mind telling you about it. I don't mind relating my story. And I actually love it , and actually have gotten very good at it over the years because of where my life has taken me. And I would love for you to just sit down and have a cup of coffee or whatever you prefer, and let us talk about it because I'm able to. And I think after we get finished, you're going to be blessed. I'm going to be blessed. And we will move together further this notion of incorporating everything into that socio political model of living with what most temporarily able-bodied people will call disability. Because eventually, we're all going to deal with something that comes with that label. And if you don't have some level of acceptance with who you are, before that tidal wave hits in your life, best of luck. Yeah, I'll give you my number come and find me and we can talk about.

## **Tech & Perceptions**

***The technology or assistive technology in my daily life.*** Well, one of the first things that those people will always notice about me, because I walk on fore-arm crutches, is that's part of who I am. I've gone through about six different variations of forearm crutches. From my very youngest days to now, I'm now sporting a pair of titanium, custom-made, forearm crutches that are a big part of my daily walk. I also have speech to text software, Dragon Naturally Speaking is something that I use in my professional

vocation as a counselor. I've also gotten back into the ankle-foot-orthotic (AFO) game, because I have a very unique drop foot on my left side that my left foot is actually starting to turn out more than it should. And thankfully, when I was evaluated, they said, you know we don't have to do surgery, but you're going to have to go back into an ankle-foot-orthotic. I'm actually trying to break that bad boy in and it looks cool. It's decorated in comic-book, comic-book garb. But it is heavy. It is cumbersome. And with as much walking as I do, up and down, at work, it's going to be a tough sell. I know that going in probably another piece of technology that people don't think of is right there on my smartphone. I love the voice activated Google Assistant features. Because sometimes my fine motor skills and being able to type in a text, type something out just takes too much time. And as you can tell, throughout the course of this interview, I can certainly talk much faster than I can type.

*Is my perception of myself the same or different with technology?* I really wouldn't say that my self-perception has changed, I would say that I can notice a difference between when I decide not to use my crutches at my home, because I'm more familiar with the environment. I don't have to. Sometimes I do feel literal wear and tear on my body that if I were to just walk around on and use my crutches like I normally do, it would make a difference. But to say that it changes how I perceive myself would probably not be accurate. But I can notice changes, especially with the speech software that I use. If I don't use that then I'm wasting a lot of my actual day being on the job, or when I go home and try to do continuing ed or something that's even just fun that involves typing and writing. If I'm not using that piece of technology, I'm pretty much dead in the water for the next three hours depending on how long it's going to be. Especially if I'm working on some type of report for work, or some which I'm not supposed to really do that at home, but I sometimes do. But I do think that I've noticed that there are some definite value-added features that that technology does allow me to experience in terms of making my life better. So, I guess anything, when I use the technology, like I'm supposed to, including this new, currently annoying AFO, it's going to be better for me in the long run. So really, it's kind of like a personal enhancement versus something that that takes away from who I am.

*First time with a particular piece of equipment.* I had been in physical therapy for less than, gosh, less than two years. We knew that I was going to have to use some type of device to get around, we just didn't know exactly what it was going to be. So being so young, they really didn't want to put me straight into crutches. They sort of wanted me to advance to that. So, I remember my first walker. And it was just one of those old fangled metal things that the whole thing was metal. It had very uncomfortable red plastic handles that kind of came around in front of you to where the rest of it was behind you. And being as young as that was, I was still trying to learn how to walk in my own way. First thing you learn in physical therapy, believe it or not, is how to fall, and then how to crawl. And then they start teaching you how you can walk in your own special way. But back to this walker. I was just so excited because this thing had wheels on it. And I knew that if I thought about it hard enough and had motivation. Usually, I was highly motivated by food, or by my mother who was frequently in the sessions. But I loved snack pack chocolate pudding, and applesauce. And I still eat applesauce every day, right now. But, if the therapist wanted me to get somewhere, and even if it was just a couple of steps, if you put that food on the table, you set me up my walker, and just gave me a little push, I was zoned in on whatever that food was. And the problem was, I would forget to breathe. I was so focused on trying to get from whatever point A was to point B for food was I would hold my breath. Because in my mind, it was conserving, I didn't have to think about it. And I remember one time in particular, I had turned, I was probably almost turning purple. And I didn't even realize it. And they had to literally take the walker away from me. And just give me the food so that I would open my mouth and start breathing again. But that was a very interesting time for me. And I know I was very young. But I definitely remember how, empowered, I thought because I had a walker now. I wasn't going to have to work so hard. And I did not do well with the initial..... They would get me walking. They would stand me up and I was just I was wanting to go. And they always wanted me to stand up straight, hold, , hold this pose and then put one foot in front of the other and stop. That was never my bag man. I was going somewhere if I was standing and walking by walker holding. It held a very special place in my life, because that was also the time that I felt a little bit of independence. Because my mom didn't have to hold me up. I didn't have to hold her hand. I didn't have to rely on

somebody else to pick me up and move me. Yet might take me a while and it might not look very pretty. And it didn't. But that was my way to get this job done. And I think I must have been probably must be probably five or six. But that was big for that was big for me. For sure.

*Do people view me differently with technology?* Well, it's interesting that you put it like that. And there's actually two different answers. Right now, what you typically get with me is these crutches and my dragging foot. And my very unique, I have a little bit of a shift and a twist. And one of my hips, that flexes a little bit differently, so it kind of creates a very noticeable gate that I have. Right now, where I'm currently working, I'm doing a lot more walking. Because of the crutches, because of the way that I look a little bit different, actually attracts more and more people. Now sometimes, most of the time, that's very positive, as I get a lot of questions. I actually have one client that I kind of see off and on, and he constantly just tells me what an inspiration I am for him. Now he's not, , he's not 100% all there, but I'm making an impact on him, because he's noticing that just like him for rapport building I'm different. And even with the guys that I work with on a regular basis, in my in my practice setting, they gravitate to the fact that I need a little bit of help, or I'm move different, or I'm a little bit slower, or they look at the crutches and they just, they light up in a whole different way. It gives me an opportunity to kind of invite that into the session and say, what, just like you've got this going on with your mental health need, I do deal with what I'm dealing with every day with these crutches. So, in that way, I think that that's how they perceive me in a positive way with these assistive devices that I have. But it's very interesting that in settings where maybe I'm going out to eat on a first date, or maybe I'm in my home, where I don't have my crutches immediately visible there's really no difference between me and anybody else out there. People don't, they don't even know, they would never even know. Luckily, because of my stellar personality and my ability to make friends with practically anybody, I've always kind of been able to grab people in and have that connection. When I'm out and they don't spy my crutches, they don't even really know anything's different until I get up, excuse myself or go to another room and I kind of have to grab onto the wall and swing from area to area. So, I think that they get two different sides of me versus when they see me with the crutches versus without. But for me, because I have gotten to the point where I know

who I am, and I know where my identity lies, it's the same. People often, and I'm sure you've seen this, and I know that anybody who's going to share in this study, they'll probably tell you, there's a certain stigma that can sometimes happen.

If someone's in a wheelchair, for example. And somebody hovering around the wheelchair here a little too close, and they touch that wheelchair, they start to just kind of rest on the wheelchair. The person sitting in the wheelchair sometimes treats that as a little extension of who they are. They kind of get a little offended, and rightly so, because that's invasion of personal space. But for me, I've never had that issue. If you want to play with the crutches, if you want to, I don't know where they've been, I don't know where they've been laying on the floor, but if you want to pick them up and move them around, or you bump into them and they fall over. It's amazing because people freak out as like, "Oh man. I didn't mean do that to your stuff. I didn't mean to touch you like that." I'm like, "you touched my crutches. My crutches fell over. I didn't." But see, for a lot of people, I don't think they feel that way. I think that maybe for them that assistive technology is so integrated into who they are. It might be very difficult to parcel that out. But for me, it truly is just a device. It helps me along and it's not part of who I am.

**Tool or integrated part of who you are?** I would have to go with option A. It is for me. But I will share this with you. It wasn't always like that. And if you look at if you look at everything that I've been through-- the types of supports that I've had, the education that I've had the opportunity to, to experience and grab onto, when I was younger, I had much more of an issue of pushing me touching the wheelchair, messing with the walker or mess with my crutches. Because when I was younger, I relied on that piece of equipment to really help define who I was, because you kind of got support perks, with it, , people wanted to push you around, and all the pretty girls wanted to hang out with you, because you were cool. But even on a more serious note probably once I got through high school, and got into college, and I started getting exposed to other people who had more complex and nuanced life stories that had unique abilities, so again, I'm getting away from that labeling. They were unique. They had some of the coolest stuff I've ever seen in my life. From somebody that could talk and do everything that he needed to do by using a computer screen to somebody that had one of those sweetest decked-out power-chairs I've ever

seen in my life that could move up and down those halls like nobody's business. And if you got to know these folks, you would just see that for them they really had become their own person. And the device was just there. And I just wanted to adopt that. Because one of these days, I hope to not have so many devices. And if I'm relying on this piece of equipment, to help build my self-esteem and get me through a day, or even worse, because I want to feel entitled to that stellar bathroom with the Super slick floor or because I don't want to. And I really would hate to admit this, but I've seen this too, because I don't want to work for it more. Because I want to sit on the couch and continue to watch Netflix and try to live off SSI.

### **Social Justice, Advocacy, and Politics**

I have to remember that, and thankfully, because of my education, because I'm a counselor, because I have been through ethics training, multicultural training, diversity, because I've had the immense pleasure and opportunity to be exposed to so many different amazing individuals that maybe have CP, like me, or muscular dystrophy, or especially those that are identified with the autistic spectrum. I mean, some of those guys, they perceive the world in completely different ways. And they are some of the most smartest, most amazing people whose voice will never really be heard unless you sit down and take the time to listen to them face-to-face, possibly using the technology that is comfortable with them to bridge that gap. But many people in today's world, and I'm getting kind of passionate, they missed that. Because it's safe. If we don't have to get involved, if we don't have to work really hard, maybe we won't get hurt, maybe we won't hurt them. But I think most of it falls back to maybe I won't have to deal with it. Yeah, maybe I won't feel uncomfortable because nobody likes feel uncomfortable. But how do you think that makes me? Or rather us? How do you think that makes us feel that you don't give us enough time to tell you and your friends about how we've had to experience life? And how these devices whether they be crutches, wheelchairs, or augmented communication, what have you how this is a special part of what makes us who we are.

It forces people to deal with it. And I don't just mean people on political level. I don't just mean a presidential platform to make everything equal across the board. I mean, from the community, to the



school system, to the church, or other religious organizations, and in the home. And part of what I've kind of become profoundly interested in and passionate about is, how can I educate you or your family, about you, about your uniqueness, about the things you can do about what might be different for you. But, if we put all this together, we put our minds together, and it's like, just like in an IEP meeting, that was one of my favorite parts about the IEP meetings, I got to have a voice. In my plan, it was a good, right, if it was a good IEP, if I was given the opportunity to say, to put my two cents, because many times, people just kind of forget that aspect. I mean you could have the biggest best plan on paper with the most compassion and heartfelt ideas as a teacher or as a mother, with the love for your child, but if you forget to include the child in what they want, good luck with that. Good luck enacting that plan, and good luck getting that kid out of out of school and moving them into the world of work or moving them toward family life. If you don't get their input, you're just you're hurting yourself and you're hurting the process right from the beginning.

I would just encourage whoever picks this up and takes a read that just to be creative and innovative. And remember that there are people out there that can't communicate exactly like I'm communicating. But if you give them an opportunity, and you give them the tools to do it, they've got even better, more exciting, more amazing story than I do.



### **Silas (31)**

Whereas, I cannot remember the exact year or grade in school I met and worked with Eli, I definitely can with Silas. He was a bright freshman in college prep Biology and I had him for a study skills/academic elective class. He didn't need any specialized instruction, just physical desk and visual accommodations when it came to grids, graphs and detailed drawings. My job ended up being an advocate and problem solver more than a teacher with Silas.

Figuring out how to educate and problem solve with his teachers and Silas himself on getting around problems that made curriculum less accessible to him. Before he graduated maybe even by his sophomore year, I advocated that we dismiss him from having an IEP and put him on a 504 accommodation plan. His

quick wit and determination were great characteristics for him to participate in wheelchair sports and on our school's track team using his racing wheelchair, while he used a walker in the classroom. He studied history and political science at The University of Arizona and played wheelchair rugby there. Silas returned home to Georgia and attended law school at Mercer in Macon getting his Juris Doctor and passing the bar exam in both Georgia and South Carolina.

### **Disability & Identity**

*When thinking about the word disability*, I believe in a way it's outdated. And still, stigmatizes. I don't know if you're familiar with the medical model and the social model? I feel like it deals more with that medical model still of like, there's something wrong with this person, we need to fix them instead of the social construct of this is just the person, how the person is how they live their life, they just live their life a little different than you and I. I think that, it doesn't have necessarily a negative connotation, but it just shows a difference that I really don't think needs to be noted. Because everybody's on the same kind of playing field. It's just like to me, I'm in a wheelchair is not a big deal. It's just the fact that , another fact along with the fact that I am, glasses and gray hair, sadly, the age of 31, distinguished hair.

This goes back to the question of hearing the word disability or disabled. I didn't think about it until I learned where I interned my second year of law school at the Georgia Advocacy Office, which is an organization that advocates for people with disabilities and mental illness and things like that. But a person first language is so important. Because if you say a person with a disability, that person is not defined by their disability. Where if you say, "Oh well, an autistic child," the first thing you hear is, boom, something's wrong with that child. That being said there's not a rulebook. There's not a handbook. it's whatever somebody wants to be called, they can be called. I hate to bring up the internet and memes. But there's a meme: it's a picture of somebody in a wheelchair, and somebody asks him, like, "What do you want to be called?" And he says "David's fine?"

*How would I describe myself?* Oh, boy, I've got a couple big questions here. Well, I'll just start from the beginning. I was born nine weeks early with cerebral palsy-spastic, God please you. And I had a litany of surgeries growing up. One being a dorsal-rhizotomy, which I can't really tell you what it does,

but Google does a fine enough job for me. And that gave me a lot of the function that I have now because my legs used to be sort of in a fixed position. Then in third grade, I had major hip surgery a femur-ostomy and hip-osteotomy, I guess. When I was in third grade, I spent the summer or part of the school year in a body cast from the chest down. And it was a trying time for everyone, mom, and Ken (his brother) got me stuck in the van one time. So that was always entertaining. And everybody just happened to be out washing their car that day, or walking along, so everyone saw. Then 10th grade, I had a heel-cord lengthening and that gave me a little bit more function in my feet. Then most recently, due to the fact of being disabled, and not very sturdy, I fell and broke my femur in two places. So now I have a rod and some screws in my knee. So, when I stand up I creak and pop a little more than I probably should. But all that aside I lived a-- I don't want to say normal life. So, I'm just going to say: a life. I went to college. I went to college very far away. My mother didn't particularly care for that, that I was 2000 miles away at the University of Arizona. I played wheelchair sports, growing up and in college, and sports has been a big part of my life. And wheelchair sports, in a way saved my life because it made me realize that, my life wasn't so bad because a lot of the people that I played sports with had catastrophic injuries and they had to pick themselves up, going from able bodied, to being really disabled was quite the task for them, but they were able to manage through it. I do the normal things that any normal 31-year-old does. Good movies. I drink. I go out and about do different things and am active in my church, all different kinds of stuff. So I'm very outgoing and I like to think I'm funny.

**What would I like others to know about me?** That I am not an inspiration. I absolutely hated, hated, hated, hated, hated, hated. I don't know if I can say hate it enough times. But I absolutely hate it when people call me an inspiration. To me, I'm just living my life. The fact that I am in a wheelchair makes my story no more or less significant than someone else who went to law school and opened their own law practice. I am just Silas, living his life doing his thing. I am not an inspiration to any person or anything. I've done nothing to warrant the title of inspiration. Do I think it's cool? Sometimes when I'm at Costco or something, there'll be a little kid in a wheelchair and you'll kind of be okay. He'll be like, "Oh, an adult in a wheelchair," like that kind of thing.

I mean, that's exactly the same thing that I thought when I went to that CLA with that judge in a wheelchair. When I met him, I was like, "Whoa, so like, that can be a possibility." And he, not to be, ableist or anything, but he was far more disabled than I thought he was going to be. So that just kind of opened my eyes to the possibility. I'm not saying that it's kind of the wow factor, or "oh, there's somebody I can look up to and identify with." It's just back to the same thing of "Oh, my gosh, I can't believe you do what you do. Because you're in a wheelchair, it's just so hard." There are thousands of lawyers out there doing the same thing, and they just happen to be on their feet all the time. So that's kind of what I want people to know. And other than that, I'm not shy. If you ask a question, you will you will get an answer. You may not like that answer, or you may get a very sarcastic answer.

*How is my view of myself is different from other people's view or society's view of what it means to be disabled?* Yeah. I mean, this is all that I've known and all that I've experienced in this society thinks that it's some grand thing that I've done. Yeah, I accomplished a lot, but no more than any other able-bodied person that's going to law school and done the same things. Am I proud of the fact that I went to law school and graduated and passed two bar exams? Absolutely. But is it any more meritorious than me? My able-bodied colleagues? Absolutely not. It just the other thing is, I don't think that enough society views people with disabilities as people with a lot of confidence. Their and societal views that they're very unsure of themselves. They are very dependent on others. If you said confidence or competence: It's both. Because I have had a couple of people get like, really close to me, like, I'm hard of hearing and talk to me. I'm like, you don't have to be that close. You can back up, it's fine. But no, they don't think that we can do things. They don't think that we can go to the grocery store. They don't think that we can we can have a relationship with a person who is not disabled. Well, that's the other big societal caveat, just like any other. Yeah, I'm thinking the correct term for .....I think it's inter-abled or something relationship like. It's just like the commingling of like, multi-racial or multi ethnic or multi religious. Society just hasn't caught up to what's actually happening in the world. And the other thing that society seems to think is that if someone is married to someone that is able-bodied, it's like, "Oh, well, you either have to do a lot of taking care of them," or "Oh, you obviously met after the injury at the hospital when you were his

therapist?” And it's like, no. And while that is a common thread that is not a one does not equal the other. Correlation does not mean causation. I do think that society thinks in tropes a lot of times. Especially the South goes, Lord blesses.....Yeah. It is not as welcoming or inclusive as it could be, and as it should be. I don't think we'll ever get there. This kind of goes back to your societal perceptions of disability. My answer was kind of more on a national stage. But even if you want to break it down into just a regional stage, it just like in the Bible, the way they used to think of like people with disabilities was like, well, what did this person do? What sin was so great that this person, they did it this way? It's not to that level (in the South), but it's like, “Oh, my goodness, this is such a poor pitiful person.” They're like, “Oh, I'm so sorry.” People are just trying to overly apologize. “Bless your heart.” Yeah, people just try and be overly apologetic or they try in a nice way, but also a very insulting way, they try and relate to you. If like, “I know what it was like to be in a wheelchair, I broke my leg one time.” And it's just like, you have absolutely no idea what it's like to replace this ability.

### **Tech & Perceptions**

*The technology or assistive technology in my daily life.* Okay, assistive technology, I don't use that much. I probably should, but I don't. I basically drive with hand controls and a spinner knob. And how that hand control works for someone that doesn't know is I push down for the break and then kind of pull up in an angle for the gas. And that goes and it stops when it should. And then I just use the knob to be able to turn freely with one hand. I've tried different things as far as the dictation software Dragon Naturally Speaking. In an ideal world, that works great and does what it should. But for me, with people coming in and out of the office, or the phone going on and off and with all that coming and going, it's kind of hard to sit there and dictate, “plaintiff objects to the interrogatory on the grounds that it's not relevant.” I have to go back and scratch this, scratch that. It's just easier for me to type it out. I definitely, probably would benefit from assistive technology in my law practice, that's kind of it's a situation of-- I don't want to look at something and then go out and buy it and then hate it. Then, I basically just ate all that money. But that is the extent of my assistive technology. Does the grabber counter as assistive tech? Yeah, it's rather archaic, but yeah, the grabber is always important got-to-have one of those and a

manual chair. I do use that. And that gets me where I need to go. And people always asked me why don't you have an electric one or this and that. I don't want to call it a burden, but a consideration of all assistive technologies. It's so expensive. I mean, it is just so expensive. I mean, there's this wheelchair that I'm sitting in doesn't look like much, but it was \$5,000. And insurance companies. You think insurance companies stick it to you when you're able-bodied, you should try it when you have a disability. They are not friendly in the slightest. And that was one of the bigger battles when I was a child because I needed a new wheelchair, because as children do, they grow. But insurance only allowed me one every three years. And as we all know, with children, they grow a little faster. You can't really put them on a chart and the timetable. Yes, in a way, because when I was growing up, I primarily used a walker or crutches or this and that, and I only used a wheelchair for sports. That worked to a certain extent, but I always had to rely on someone else to like, help me carry my books, or help me get this from place to place or carry my lunch or do certain things. Then once I got to college, mainly because the college was so massive. I said, I'm not going to be able to walk because my walk was very labored. I'd have to swing one leg through and then drag the other one through, and it was just a lot of maintenance. Once I began to use a manual wheelchair, or everyday chair, as they call it, it just freed up my life immensely because, I was able to get around a lot faster. I can move in, grab things way up here, way down there. I don't have to ask for help as much like picking up and carrying things. Obviously, I'm not going to be able to move furniture or anything like that, but it definitely has benefited my life immensely, because it gave me so much freedom.

And there's this, I guess it's a meme. It's hard to keep track of what things are on the internet, they change from day to day, right? It says, "a wheelchair shouldn't be like a symbol of confinement, but more of a sense a tool of liberation and freedom, because it allows the person so much mobility." And then when the hand controls..... driving is just a massive part of life in general. And without that, I'd have to go to the expense of taking Ubers everywhere, which I would have to constantly print money to be able to do that. Or constantly have to rely on friends to take me somewhere or my parents to take me somewhere, which is not ideal. Then you start talking inconvenience other people's lives. "Hey, can you give me a

ride to work? Hey, can you get me to where I live?" It's not like a major metropolitan New York area, or even Atlanta where you can take the Marta. You're pretty isolated. Sad to say, if you can't drive, you're basically at the mercy of strangers, or close friends or family members, and even then that gets a little worn, sometimes. That's the thing to me, independence is such an important thing. I broke my femur in February. I had to learn to redo everything again. It was just so awful to be, I can't even turn over in bed, or I can't even push myself up in bed. Having to go from being able to transfer and do everything that I normally do. Then all of a sudden, I break my leg. And then I use all this effort and all this strength, and I move about a quarter of an inch on the shower seat, and I'm exhausted. I'm done. So that was an eye-opening experience. To me, my independence is, in a way, the thing that makes me *me*, because without that independence, I wouldn't be able to do half the things that I do.

***First time with a particular piece of equipment.*** Okay, Dragon Naturally Speaking, stuff, I used it and I immediately hated it. Just because of, and I don't know if it was just me, because I'm from the south, and the automated computer systems don't really know how to handle Southern-English as opposed to English-English. It just got really frustrating. It would take me a couple of minutes to go through a sentence, and then I would have to go back through that sentence and be like, No, that's not what I meant here. It was just really frustrating to have to constantly deal with that. The point of that thing is to make it faster and easier for people to type. Well if I've got a 30-page document, I'm going to be there for the next month and a half trying to figure it out. Whereas I could just type it out with my slow typing just as fast and as easy. The other thing is, I would have to be in a room like we're in now completely closed off, completely silent, nobody coming in and here to bother me, and have to say, "Oh, wait, hang on, let me put this down." I'm the kind of a person that talks to myself. So in the middle of thinking a thought, I might say, "Oh, I gotta pick up eggs." And I don't need that to go in my Legal Brief of whether or not someone's sixth Amendment rights have been violated. It was just really, I don't want to say pressure, but they were like, "We understand you have trouble typing. We will get you this program. We think you might need it here. And it works." It's not like somebody said, you have to use this. Here's the thing that we can probably address your problem. It might work out for you, might not. but no, nobody ever said,

“Well, you've got this trouble typing. So, you have to use dictation software.” It's offensive, in a way. Say you have two people, Greg and Bob with the same problem. Well, this thing worked really well for Greg. I'm just going to assume, yeah, that it works well for Bob. And then Bobby ends up hating to use it. Then it just makes you look like a jerk. Because you're like, you're not listening to what that person says. But I can also tell somebody 1000 times, I don't like to use this, or I don't need your help, or I don't want this and that person will always be “But here you go. I think you should. I think you should. You probably should.”

*Do people view me differently with technology?* This is just going back to the assistive technology of a manual wheelchair, very basic function. Maybe not so much in college. But definitely when I got into law school, a lot of people's exposure to somebody in a wheelchair, unless they knew someone with a disability was, “Oh, my grandma's in a wheelchair.” “Oh, my uncle's in a wheelchair.” So, they see someone going out and doing the same things with people with the same age group. It's just an explosive “I didn't know people could do that! I didn't know that you went to a bar, just like everybody else after class or after a big test!” I don't want to say I just exposed people to a whole new world, but in a way I did. I did remember the first week of law school, everybody was like, “Oh, my gosh, have you met Kurt? Have you met Kurt? He is like, so awesome. Oh, my gosh, oh my God.” Then eventually, the new-penny kind of wore off a little bit. I went to hang out with more of my friends that I grew to know on a personal level, as opposed to everybody. But for that first week or so I was the talk about town, because everybody was like, “Oh, my gosh, if you met him, he's so awesome.” Pump up the shiny unicorn. Yeah, that's right. \*sarcastically\*

Also people have no filter, either. Like the other Sunday in church, this old guy that sits behind me, it was before the service, was just coming up behind me. And just right off the cuff he said, “You mind if I ask you a question? What do you got?” And I was just like, “Oh, boy.” That's not the exact way to approach that. But I've been asked that question 1000 times. So, I tell the same story over and over again. And as far as the assistive technology, law school ...the law school did a great job. Maybe



not, because I didn't need that much. They gave me a note-taker. They just had somebody typing notes for me and things like that.

**Tool or integrated part of who you are?** Oh boy, tough question. Oh, I don't know. I'll answer it this way. Maybe it's a little bit of both. It's a tool that helps me do the things that I need to do. But it's also very much a part of my identity. This is just my personal experience, but a generalization is that a lot of kids are that are born with disabilities constantly think, "Well, what would my life had been had I been able bodied? What would I have done? What would I have seen? Would I be married? How would my life take off from that? And try as I might, I just can't imagine my life anywhere else, or any other way, because this is all I've known. A friend of mine that got hurt when he was very young. You know the question, if science had its way, would you walk again? The answer to that question is, "I don't know", because he was like, "Listen, I've been in a wheelchair longer than I was able to walk. So, to me, I've kind of gotten used to this thing." Whereas me the...same thing. I don't know if I would go through that either. Because all the times you see, I hate to kind of shift subjects, but sometimes what's been termed by the disability rights community as inspiration porn, and these people that are paralyzed, get up with these robotic legs and just walk and do this. And everybody's like, "Oh, gosh, that's so magical." And to me that's not walking. That's not walking in a meaningful sense. Something is walking for you, you are not walking. So that is kind of my stance on the thing. Being in a wheelchair is, just part of who I am.

### **Social Justice, Advocacy, and Politics**

**Politics** I never had to use a personal care attendant. I never had to rely on anyone to get me to places other than my first year of college because I didn't ever call one. I never had to have any assistance with dressing myself or getting myself from place to place. Even if I did, the University, I'm sure would have gladly helped with that, because their disability program was rather robust there. Fortunately, I'm lucky enough to where I didn't have to have any of those things, because I'd seen the pitfalls of that system as well. A lot of people that use those are at the mercy of Medicaid, and as we all know, that changes like the wind. It may not be around depending on what Washington does. We're all at the mercy of Washington, or sadly, a lot of individuals with disabilities are at the mercy Washington. I remember

being in law school and in college, and anytime there was talk of a government shutdown, I started shoving money under the mattress, because I didn't know if I was going to get any more money. So, I had to make it last.

It's so hard to have that meaningful of a discussion on a big enough stage to where everyone can see it. You're not having that discussion on a national stage. And not to get political, but the President certainly doesn't do the disabled community, any justice or any favors by doing what he has done or saying what he has said. It is a civil rights movement, and not even that, but it's basic human rights, in a way. That's the thing if you don't pay attention to it, or if you sleep on your rights, one day they can be gone. Then all of a sudden, it's like, "Well, where are the things I used to have? Or where's this? Where's that? How am I going to be able to live on my own because my funding for a personal care-giver has been cut?" So, it's just a discussion that permeates so many different levels of thought thinking on policy.

And it really needs to be had on a more national scale, and we're getting there. But with all of the other groups that are fighting for their own rights, disability rights, once again, is kind of in the shadows. While you have civil rights between African Americans, and then the civil rights of lesbian and gays, and then other immigrant rights being very hot in discussion and in politics now. And I think, unfortunately, the public's attention span for focus on things that should be changed is so short, that it is about competing for attention. And that's terrible. It shouldn't be. Everybody's human rights should be fought for, regardless of marginalized title. But, and it's like when we, which I view it as particularly abhorrent, but when we started to detain children in the camps on the border, that was all you saw on the news, all useful for like a solid, three weeks. You're like, boy, they are just inundating this thing. Then all of a sudden, the next thing happens. Next thing moves along. Then all of a sudden, because it's starting to be a presidential race again, and people vying, they bring this ugliness back to the forefront. All the while, these things have still kept going on. But now we're all deciding to suddenly talk about it again, because it's the hot topic of the day. It's the 24-hour soundbite that will get us through the next thing until something else happens.

You certainly don't have to answer it if you don't want to, I don't want to say a pointed question. But do you find yourself shifting political ideology? And the reason why I asked that question is, I grew up, the county that we live in, is terribly conservative. It is Crimson conservative, as I like to call it. And eventually through college and getting to know other individuals with disability, and then certainly, looking at it through the legal realm, I've certainly started to shift, more purple, a little more purple. Because I started to realize, well, I'll just go ahead and say it, the Conservative Party doesn't pay attention to me as a person. They pay attention to me is a poor pitiful thing, but needs to be taken care of. Whereas the other party, at least acknowledges my existence on a national stage. Doesn't necessarily allocate the focus they need to, but they at least acknowledge that I exist as a person. I have always felt that our two party system is so fractured right now that that it's difficult. Other countries have a coalition government.

We also need to change the stigma of people with disabilities from an economic standpoint, because as it stands right now, people with disabilities often don't have a lot of purchasing power, right? They're either of two paradigms. You're either extremely wealthy, and your parents buy you everything under the sun, and all this wonderful assistive technology. They'll buy you a Mars moon-rover, if you want. And then there are these other families that have to barely get by on what the government can provide. And we just need to shift and say, there's a quarter of the population of America that has some sort of a disability. And until we have a congress and kind of get together and say "We're here. We have needs. We have a voice. We can use it, and We can stop, God forbid we ever do this, but stop using Netflix, or stop buying on Amazon ostensible purpose. I mean, I'm sure people would eventually pay attention, but it's getting everybody on the same page. It's just tough to do. It's hard to get people to fight the fight, because they don't want to rock the boat they want to be, "I just want people to leave me alone." And in some sense, people fear retaliation, just like anything else. If I rock the boat, about my assistance through Medicaid that I'm getting and complain and groan, is there going to be some sort of reprisal against me? Are they going to cut my PCA hours? Are they deny me the new walker, I'm trying to get? That kind of a thing.

And we also need to make people aware. I hate to call it the welfare state, it's a very negative term. But we also need to make people aware that getting an SSI check is not glamorous living, right? If that is your only way of subsistence, you can't live in very many places, because it's only a check for \$700. And I mean, where on earth, are you going to live and be able to buy groceries for \$700? And then it creates a cycle of poverty. Because, yes, you are not allowed if you get SSI to make over \$2,000. And I learned that because for some asinine reason, the government finds that me having some of my student loan money given to me, was counted as being overpaid. So I am paying back the federal government for that oversight on my part. They take it very, very seriously. So it's not something to be taken lightly. But that dissuades people from trying to move forward in their life a lot of times. I always viewed it, but because I knew that I had goals. The government program certainly served their purpose, and got me to where I am now. But if you are just somebody who doesn't know any better, because you haven't had the exposure as a person, let's say that you are the one person with a disability at 17 years old, in Brooklet, Georgia. Yeah, and you don't have much exposure to athletics or anything like that. And you have and your parents, Lord bless, and tried to help you, but they also haven't really pushed you. So the only thing that is there are those checks that comes in the mail. And then, that's all your life is ever going to be. And that is a sad way to make it through life. But then it's somehow just what people know.

But another thing is just my personal opinion, and I hope, where society is going, I want everybody to be inclusive, nobody treated different. One of the things that I see on a national stage all the time, and they talked about how great it is, and Lord bless him, he does a great amount of work. But Tim Tebow's Night to Shine, I feel like does the disabled community a disservice to service. Not so much on the parents' side. Because those parents need to break from caring for their child, if their child happens, and you need a lot of care. But it also paints a picture of these kids are not accepted by society and they don't have any friends outside of the disabled community. So we need to give them something special to where they can make friends in their own community. And if we unpack that a little more, and it spins off into kids are not very kind to, well, kids in general, but especially kids with disabilities. So it's kind of natural at first growing up for them not to have that many able-bodied friends. But as you get older, you

start to realize, well I'm no different than anybody else. You and I know that those are cognitively impaired individuals. But does society know that? Probably not because they see a wheelchair, they automatically assume a physical disability as to both a physical and cognitive disability.

Although it's fair to say, I'm speaking at that continuing law education engagement, I basically got profiled. I mean, it was a great program, because it talked all about kids in special education and kids with disabilities going through a divorce and what you need to look for. But the lady came up to me and just assumed, well, you're in a wheelchair, you're divorce lawyer, or you're you've met, you've dealt with kids, or families with kids with special needs that have been in divorces ----not the case.



**McKenzie (29)**

McKenzie is the third of my three interview participants that I worked with in my early tenure as a special educator. McKenzie actually worked with another teacher, the “OI” teacher, teacher of Orthopedically impaired. At that time one model was to have someone separate from interrelated resource teachers work with students with orthopedic impairments. McKenzie has a twin brother Corwin that has some of the same physical impairments but more intellectual impairments than McKenzie and more dependant on help from others to be independent. Both of these young men started 9th grade with service dogs. I do not know the whole story, but I know their freshmen year the service dogs were in the building to assist with fetching fallen items and other tasks. I honestly cannot remember if the dogs were there the whole time the twins were.

I worked with McKenzie and remember him through his work in a Biology class. His brother was taking classes with more of a functional academic course load. We would talk and problem solve, and I would assist but I had less of a direct impact on McKenzie’s schedule of classes. McKenzie needed to do something different to reach his educational goals, due to some frustrations I was unaware of. He withdrew at 16 and took the GED (general equivalency diploma) and started on his post-secondary career. His brother continued to work through the functional curriculum for several years after that before

graduating. McKenzie then attended a college in North Carolina with a BA and Masters of Arts in Spanish and certificate in translation. He has worked with the Latin American Coalition as volunteer assistant to community engagement director and currently is a post graduate fellow teaching several courses of Spanish at the college he attended after getting his CELTA certification (Certificate in Teaching English to Speakers of Other Languages). He has traveled to several other countries and had an extended stay as a semester abroad in Spain during his educational journey.

### **Disability & Identity**

*When thinking about the word disability* The first thing that comes to mind without doing much, much thinking is problem solving, and figuring out how to do things and be at the same level as everyone else.

*How would I describe myself?* People say that I'm a go getter. I try really hard. I'm earnest. I'm passionate, and have a zeal and zest for life, I guess, is what I'd say. And I'm a bit crazy, because sometimes I do things that....I think I told you about this on a message via messenger one time. I said, as I get older, sometimes I do think I do things that are, I realized that I've done things that other disabled folks haven't had the privilege or gumption to do. I go to a lot of places, and mainly I'm referring to my trips abroad. That, many people in wheelchairs don't have the chance to go. And so, I often arrive and find that there's no infrastructure there and type really have to adapt. And so that's why I say too, I'm a bit crazy, because I just if there's something I want to do I just do it. It's there's not a second thought.

(So, one example of that might be when you went to go live in Spain? Yeah. And did you have to arrange like, like the places you're going to stay?)The second time (I went to Spain). There were only a few residences in Malaga student residences that do short stays, because they want you to rent a place for the entire year. Then when you say, "Okay, I need one place, I need a place that's handicap accessible." It's like when my mom sent me to go buy a TV at Costco, she's like, "just put it on the credit card." And I'm like, "Mom, I've never spent this amount of money, I want to make sure you do it right. Or I do it right. Please give me more guidelines." And she said, "Well, when you give them the dimensions, you're only going to have one TV. So just come home with that one." And she was right. So, it's about like that..

And then when you get there, and you look at the resources, and you're like, "Ooh, wow!" Places are small anyway, in Europe, and wheelchairs are even more, you feel even more space constrained. I had a friend walk into my apartment here (in the States), which isn't adapted or anything. And he walked in, he was from Spain, he was like, "wow, this is huge." And I'm like, "But this is small for over here."

*What would I like others to know about me?* That I'm just like everybody else. And that one thing that really, I've had to work on these past couple of years is people. People say, "oh, you're such an inspiration or I don't know how you do it, yada, yada." And I just want to tell people that this is my normal. I do this every day. It's nothing special to me. I was born this way. I think that a lot of people that turns heads because they don't expect it. I will tell you that in Spanish culture, it's a lot more stigmatized than it is now. And I have a friend of mine, David, who also went to Barcelona, but his family's from Mexico. And he's like, "dude, I realized that it's a lot different and a lot more stigmatized. And it's like, some sort of burden, you have to overcome on an everyday basis." Just for people to look and see me as normal, not because I want to be normal or something that I project. It's just, this is me. I think that my mom always says to me "You may see yourself that way, but others may not see you that way. And the fact is that the reason you might be called an inspiration. I just see you as McKenzie, that's a normal guy. But other people see people with disabilities, and they're like, "Oh, my God, if he can do it, then why am I not do you know...." It makes them feel, makes them take an inventory of themselves. My mom would say, "sometimes it's not all about me as the person, it's surely what the other person is projecting onto me." Back to my friend, David, he was really surprised. And I said, "I realized I was disabled Barcelona, and when I went to Spain, because I was so well adapted here that nobody outwardly mentioned that I had a disability. I mean, in my family, we did everything else everything like just every other normal person. We've been parasailing. We've been on trips abroad. But never for an extended period of time. And, and he was like, "Wow, you just now realize that at like 24." He's like, "I realized that when I'm 12."

*How is my view of myself is different from other people's view or society's view of what it means to be disabled?* I think a lot of people see disability as an impediment, something to get over. I hear that a lot. In my daily life, and people stop me on the street. They're like, "How do you do xy and

z?” Like, I love Zach Anner and his YouTube channel about going to get the bagels in New York. People need to do that. I feel like that is a that is a very worthwhile cause. Because people are naturally curious. And they ask a lot of questions. It I think it's hard for people to put themselves in our shoes. And so they literally look at it and say, “I don't know how you do it. I don't know how you get on the bed and put your shorts on in the morning.” At some point, I just want to scream. “Well, how do you do that? Honestly? I don't know how you shower?” Why is that? Why does that matter?

I had a friend in Spain. He was a retired philosophy professor, so I go get coffee with him a lot. I took a took a half load (of classes). Because I didn't, I wanted time to do other things. And I sort of had to advocate for myself there. Because I was like, “Hey, I'm going to waste time moving” It's going to take normally allow an hour, I probably allowed two or three hours to get to where I was going when I was in Spain. So that's how I made that case. He said to me, “ McKenzie, when I first met you, I thought you were this fragile person. And but then when I started getting to know you, and we went on think we took trips together with other people in the residence, I just realized you were just normal, and I didn't even see the chair.” So, I think I think you're absolutely right, that people need to have that time to cultivate that relationship. And on the surface, it seems like oh, “well, how do you?” And then once you get to know someone, you get beyond it. You just know, you move past it.

### **Tech & Perceptions**

*The technology or assistive technology in my daily life.* So I use Dragon Naturally Speaking, whenever I need to do any sort of writing emails. Any sort of word processing is Dragon Naturally Speaking. When I was in graduate school, I had to use a program called ReadWrite, I'm sure you know it. I didn't really have to request alternative textbooks for undergrad. Because once I got to my major, you didn't really.... I won't say you didn't need to read the book. I mean, you need to have a copy of the book. But I was also, because I'm so linguistically-minded I was picking up a lot just from sitting and listening. And I didn't need to take notes. And then I got the graduate school. And I'm like, and they're like, okay, read 80 pages a night, and that was like on a on a light night, and you had to go in and be prepared to talk at length on these 80 pages. And then I was like, well, I it's still read the same line twice. And when I...



reading traditionally, is not a pleasurable activity for me, because I have to concentrate on getting my eyes to move and track correctly. So I called my mom and I said, “Look, we need to buy this program, I’m going to find it.” And she said, “Get whatever you need.” I looked at one because I need the one to be able to read PDFs because I knew that was how disability services was going to give me the files. And unfortunately, it was like 700 bucks, but I used it, and I still have it. I’m in a manual wheelchair. Dragon Naturally Speaking is becoming universal design. I know a lot of people use it. I even have professors that write with it now. And the thing that I think I was at Riverside (Middle school), and when I was your student when I started using it. And we all know how terrible it was. (And when you got to high school, yeah, it was not much better.) But now, it’s really improved. And those are really the two main pieces that I use, beyond hand controls (for driving).

*Is my perception of myself the same or different with technology?* I won’t say that my perception of myself is different. whenever I have a problem, I immediately turned to assistive technology. So, it is part of my identity in the sense that it is a tool that I exploit to its fullest extent, I remember my first semester teaching and the fall grading papers, and they had us grade like we were..... So, I saw students once a week, for an hour and 15 minutes. And I taught six different sub sections. So, there were three,if you put them together, there were three full classes. But they were six different subjects. And so, when you had somebody, you’d have a class testing, but also a class that needed to turn in, like their pre-essay, writing assignment to help them do the written part of the test, that was the input for that test. And so, I was really grading all the time, and I got really frustrated, because I was like, “Man, I’m losing time turning, moving papers and manipulate papers, right?” And I was talking to my colleagues, and they’re like, “Yeah, well, it’s all about getting the paper in the right position, and whatever.” And I’m like, “Listen, I literally feel like I sometimes I’m working with mittens on my hands. I was like, how can I computerize this stuff?” I approached my department for the spring. I said, “Okay, I’ve really like given my life to this job. And, I spend six to eight hours grading.” And that’s not an exaggeration. And that’s per class. And I said, “So what I propose is that I want everything on the computer and everything through Canvas, so that I can when I make corrections to the parts of the test

that they need feedback on, I can do it with Dragon Naturally Speaking.” And they said to me, “Well, no, you can't do that. Because if you do that for your class, then everybody's got to do it.” There are three reasons that you can appeal a grade at UNC Charlotte, and it's either there's an error in grading, unequal treatment, or....It's actually those two reasons. So the reason that they didn't want me to do it all on computer was, they didn't want to give somebody else legal grounds to say, “Well, why is this class doing it on the computer?” And so, their, their solution was to hire two graders. They were going to pay two graders like \$700 and said, Wait, no, it was a course reduction. So, they were going to take one of the classes away, and say, you're going to co-teach this class with mine, but you're not going to step into the classroom ever. You're just going to grade all this stuff. Now, what happened to that they chose one grader, that was not an experienced grader, was having trouble getting her shit graded on time. She never took work home ever. And she had a two-year-old. So, I was going nuts. Yeah, I actually ended up taking some of the work back from her and said, Well, I'm just going to do it. And I'll just stay up for however long it takes to do it. And so really, it was quite frustrating. Because I even said to myself, there's a way that I can do this. And if you're worried about people cheating, people are going to cheat anyway. If they want to cheat, they'll find a way to cheat. And I don't mind being like, “Hey, don't cheat. If you if I see your computer on some site, you're out, ‘cuz this really, it really helps me.” With as much (many) online classes as they have now, there's ways around worrying about cheating concerns for online class. And I said that there is software law schools use it that you can buy, that locks down your whole entire computer, so that you can.... you're working within the self-contained program. Try this on for size. The bureaucracy .... if the Communication Department tests that way. It's just the communications department that has this test, that bought that license, so there's no sharing resources, and people are so concerned about, oh, well, that costs money.

***First time with a particular piece of equipment.*** I remember thinking when I, cuz we went to we went to Washington, state for a while. Mom, Michelle, calls it our sabbatical. And so, we were away. And one of the cool things about Washington State (school system) was they had a lot of money. They had all these resources and things that (Columbia County) did not have at the time. And I remember thinking,

they had us, we were using WYNN reader. And I just thought, "How cool is this, that my brother," and I'll use my twin brother here, because he's unable to read. Traditionally, he has to read by audio books, but he's literate. So, but I remember him whenever he had to read something to the class, the aide that was helping both of us turned on this Wynn Reader and it just started speaking, and I thought how cool it was, for his text to speech software, by early 90s. Early 2000s. Yeah. And I just remember how cool it was that he could be able to share what he had written without having to physically read it. And so that's the first time that I remember that I remember getting or having experience with technology. I also remember when they unpacked like the AlphaSmart when I was .....it was a little portable keyboard. It wasn't really robust. And, but I just thought it was so cool. It was like Christmas, that there was this AlphaSmart, and then later a laptop that was sitting there that was just for me.

I was excited. I can't say that I remember how it made me feel that one, like back when I was using it. But now looking back and reflecting on it. It really opened things up for me and put me on the same level playing field. It's like Why? Why would I write something, if I can use my voice to dictate it? A lot of my friends text. I text a lot. But beyond three or four texts, and I tell them all, you're getting the call because I can't keep up with the rapid-fire texting or, and I use Siri a lot. And Siri sort of. She understands my English well enough, but it's not. Siri is modeled after, I read an article one time that everything is modeled after Dragon Naturally Speaking like all of the engines and stuff. but it's just that Siri and in particular is not as a robust of a program. And so, it's not really, it's not really as good as Dragon. And so that's why I always tell people, Hey, you, you're getting the call, when if, if it extends like a 10- or 15-minute thing, texting. I feel when I don't use technology, I get to that point where I have to get things out, because my mind moves very, very quickly. And I really can't. No matter how hard I try, I can't get my hands to move any faster. So, the thoughts are there. If I don't use something like Dragon, I'll lose the thought or if I'm typing, let's say I'm typing a paper, back when I was in undergrad, I'll use a different word because it's quicker to type. And with Dragon, I really don't have to worry about that. So, it just puts me on the same level playing field as other people.

*Do people view me differently with technology?* I don't really think there's a difference. I will say when I told people that I owned and use the Spanish version of Dragon, and I was in elementary Spanish (in college) and in a lot of elementary language classes, you do all of the grammar and written grammar exercises online. You have to type everything in. And because it's a computer, you have to get it right. If you leave out a period, a capital letter ... it's a computer. And so there again, my sister said, "Why don't you see" This was in 2010 my first Spanish class, "why don't you see if they make Dragon in Spanish." And I remember people noting because I knew what it was. And I told one of my Spanish professors and she said, I think it's so cool that you can use that like you're a beginning speaker, but yet you have an accent that is that the program recognizes and, I've noticed in class that you're a natural mimic. And then I actually took part, when I was in undergrad, I took part in some seminar where they needed people to test speech recognition software for use in language classes, because they've done studies and it helps a lot with immediate feedback of pronunciation and things. So, I was one of the people that asked to test it. And then when they they were talking to me about Dragon I said, "Oh yeah, I've been using Dragon for years." And so, I guess it's made me sort of a resource and I am expert. I used Dragon Naturally speaking before it was cool. Like before there were ads on TV. Before it was really, when Dragon actually speaking first started the first thing that comes to mind about Dragon Naturally speaking it was assistive technology. It was a very specialized piece of technology. That's now gone mainstream. Right. So I guess yeah, I used Dragon before it was cool to use.

*Tool or integrated part of who you are?* I would say that it's an integral part of who I am in the sense if there is a problem that needs to be solved, my first go to is how can I put this on the computer? I'll give you an example. I was training I did CELTA last summer. And CELTA is the Cambridge certificate for teaching English. And it's world renowned. I remember commenting to my mom, , everybody's using this doc-cam. And they're using all this board stuff. And but I can't really reach the board, because boards aren't made for people to be from a seated position. And I have colleagues that say, Well, if you're short, it doesn't work, too. But you're really not supposed to use the whiteboard sitting down because you really only have the last third of a whiteboard. And I remember telling my mom all this

that was going on, and I'm like, Yeah, they're using the doc-cam. And CELTA is really big. They're like, "don't get too hung up on technology." And my mom said, well, "McKenzie, you're gonna go teach someplace with technology you like telling them not to use? Having them tell you not to use PowerPoint, you're not going to go to some third world country and teach adults English, you will need to go to a to a first or second World country, just by sheer necessity."

***What about Corwin and technology?*** Because of technology, Corwin, he lives a very full life. Corwin when he got hooked up for Voc rehab, from this for the state. I don't know if you know this story, but he wrote the governor, because there was no funding. He wrote the governor, and Peggy was like, the governor is not going to respond back. You know Corwin, that just kind of egged him on. So he hunted and pecked and he wrote a letter to the governor. And sure enough, the governor calls and taking into account your words. And so, with that, and having people that come in from an agency, he has his own life. I mean we're sitting down at dinner and what's Corwin doing tonight? We don't know. He goes to dinner and it's awesome. And I remember buying, because Dragon Naturally speaking got better. And so I bought it, or mom bought it for him. I showed him how to use it. And he was like, "I'm not gonna use it because I always type." "Corwin, it could make your life easier." And he was like, "I don't know."

### **Social Justice, Advocacy, and Politics**

I think that's very valuable, because I talk in reference to LGBTQ. I think about those minority groups, that they have their own culture. We, as part of the disabled community, we don't. I don't know if it's that we don't get together, we don't talk or we just kind of go and trudge our own path. And there's a lot of people in life, Ellen that I was surprised because, what I didn't do, I left the house when Corwin was just when mom and Corwin were just starting to discover Voc rehab, and all this kind of stuff. And I left high school at 16 and took the GED. And so I missed all that. So, I was surprised when I was employed, and I called to request reasonable accommodations for employment. I went in thinking of this person as an advocate, right? She herself is moderately disabled. But what I discovered was something entirely different. And that is when they have these 504, hearings for employment, it's just a legal hoop, you have to jump through to make sure that you get your forum for discussing, whatever it is that you need to help

you do your job. The office themselves, they don't help you problem solve, or anything. There's none of that. And so, and I was in a room with people, Ellen, that, clearly had not any experience with people with disabilities. They kept telling me, "this is our first time, you're going to have to give us a little bit, a little bit of grace and yada, yada" and I would say, "Well, I've been through undergrad in this department and you guys have PhDs and stuff like, can't you think outside the box?" And so I was really surprised at how many people still don't know, and they don't. And you're closer to it, because you work with it. I would put you on the same line as people who have kids with disabilities are part of a family. You are closer than anyone else. But there are a lot of people who I thought were like, "Okay, you guys have seen me like for every day for what, six years? And you're just now having this conversation. And you mean to tell me you don't know what to do?" We had to talk for 20 minutes about a solution. The Disability Services is so quick to say, "Oh, we're for students. Like we were first students only and that student money and so we can't really help and yada yada."

*Do I feel like I'm teaching disability 24/ seven?* I feel like that sometimes. And I was especially kind of frustrated when the person, like the coordinator who I was working for, she had arthritis. And she was fighting me on putting stuff on the computer and using speech recognition software. You of all people, and the department head was ready to do it. Reflecting on it now that it was we had a short turnaround time between fall begin to fall on the start of spring, and she just wasn't ready to deal with that. And I took a lot from that meeting

*Sharing these stories.* I think this will help a lot of people. And I hope that people read the thesis. I think it'd be great if you, for the dissertation, that maybe you could just put it in a book that's available to the public. I think it would be great because we do we do need things (like this) and you're in a unique position to show people. This is what disability looks like, from the inside. So and you wouldn't have to do much, I don't think, because I think a lot of us speak for *ourselves*.

In this chapter, I have shared stories of disability as an identity, technology and perceptions of society and social justice, advocacy and politics from the perspective of three men that entered my life when they were 14-18. These professionals aged 29-33 have a unique perspective to share with me that is

much different than my relationship with them as young adults. They opened the door for me to start looking beyond my profession and the medical model of disability. The same dominant ideology most of society still holds when it views disability as an identity.

In the next chapter I will share the experiences of two people that entered my life when I started being interested and working with assistive technology. I will also share the counternarratives of two people that entered my life when I started changing my view of disability and embracing more advocacy and social justice oriented world view.

## CHAPTER 5

### COUNTERNARRATIVES: REGIONAL & NATIONAL

In the previous chapter, I shared stories of disability as an identity, technology and social justice, advocacy and politics from the perspective of three men that entered my life when they were 14-18. I contextualized it discussing their influence on my life when they entered it as students and ongoing friendships we now hold as they navigate adulthood and professional lives.

In this chapter, I highlight the stories of four individuals who entered my life as I began my interest in assistive technology and advocacy and social justice. I share the stories of individuals that are part of my journey into advocacy, policy change and learning about technologies that might be solutions to make the lives of people with a disability easier to navigate and break down societal barriers.

Using my ever expanding concentric circles of influence. My second group of participants expands that geographic circle. To remind my readers, two of my storytellers live in Atlanta and are heavily involved in the assistive technology community as both product users and as product creators or facilitators to help others choose the right technology to help in their daily life. Finally, my circle widens to include the nation with a friend, advocate, disability studies doctoral student/screenwriter in California and a military veteran that splits his time between here in Augusta and Washington, D. C. He travels around the nation for both surgeries but also in his mission of adapted sports and outdoor adventure activities for veterans and people with disabilities. The expanding concentric circles of influence in my life is similar to a rock dropped in a still pond with widening circles of energy expanding outwards. I hope these stories disrupt the stillness that is a dominant negative stereotyping of disability and create waves of change individually and nationally.

Again, as was in the previous chapter, each of these interviews and counterstories falls into three general categories that fit my three major themes of (1) disability identity, (2) technology and AT, and (3) ableism, advocacy, and social justice. The stories will be arranged in that similar order for each



participant to give some consistency for the reader as they learn about the lives of these individuals through these vignettes.

## **Regional Stories of AT and Disability**

### **Context of Georgia and My Involvement with AT**

According to the Georgia Disability Status report of 2015 (Erickson, W, Lee, C, & vonSchrader, S, 2016, [http://www.disabilitystatistics.org/StatusReports/2015-PDF/2015-StatusReport\\_GA.pdf](http://www.disabilitystatistics.org/StatusReports/2015-PDF/2015-StatusReport_GA.pdf)), the prevalence of disabilities in Georgia for all ages was 12.1% which meant in 2015 1,221,400 people in Georgia were identified with a disability. Statistics from the federal department of education showed in 2010, Georgia had 162,884 students (10.8%) identified with a disability. (Data Display Georgia, 2013, <https://www2.ed.gov/fund/data/report/idea/partbspap/2013/GA-acc-stateprofile-11-12.pdf>).

Georgia, like all other states, is required to comply with federal laws involving people with disabilities such as Section 504 of the Vocational Rehabilitation Act, or IDEA (2004) and amended through Every student succeeds Act (2015) or the Assistive Technology Act (2004). As a state, Georgia is asked to create procedures and agencies to implement those guidelines. Often those agencies, should work together on overlapping parts of the law to improve the education and lives of people with disabilities. As school systems work to implement these laws, that could be considered incremental civil rights laws for people with disabilities, the teachers and administrators of school systems get more involved in HOW to help with these questions of access to technology.

My interest in technology as been strong throughout my teaching career starting in the Fall of 1997. Somewhere around 2009 a few years after I had taught the interview participants highlighted in the previous chapter, I was asked by the special education director of the county to be part of our county's assistive technology team. At the time the team consisted of a speech language pathologist, an OT (occupational therapist), PT (physical therapist) and a special services coordinator who worked with teachers of students with severe disabilities. I was the only teacher on the team as the rest of the team was based at the county office in support roles or related service providers. We would meet at Fort Discovery

downtown Augusta and use fairly new internet meeting software to video conference call across the state and discuss assistive technology in the schools. GPAT or Georgia Project for Assistive technology was a department under GA department of education and special services tasked with technical support of professional development and AT evaluations for school systems that requested it. It was also charged with building capacity within each school system to have their own AT evaluation team. In addition to the one day meetings several times a year, they hosted a Summer learning conference at Epworth by the Sea near St. Simons Georgia. Assistive technology became an important included component in the 1997 and 2004 reauthorization of the Individuals with Disabilities Act.

Those summer consortium meetings hosted teachers, service providers and teachers of hearing impaired, blind and deaf. They hosted sessions for teachers of multiple disabilities or severe impairments, and for school system administrators interested in building processes to improve the use of AT in school systems. Eventually GPAT was reorganized in the GADOE and the GPAT summer conference was expanded to include other topics that special educators were interested in such as vocational rehabilitation transition, behavior, learning strategies, technology in more inclusive settings.



#### **Liz (40)**

It was in this setting I was introduced to Liz and several years later George. Liz has been doing presentations at various AT and education conferences for years regarding her role as a program coordinator with Tools for Life, Georgia's Assistive Technology Act program. I was exposed to TFL when I was an undergrad at Georgia Southern when it was housed in what was an older theater near campus converted to Georgia Southern Offices. Soon after 1996, it was relocated to Georgia Tech to coordinate with work already being done in other areas of disability access, tools, and technology, such as the Alternative Media Access Center (2006) and additional programs. When I began attending GPAT's summer meetings and later IDEAS conference in the 2010s, I attended many sessions hosted by Liz or Carolyn Phillips, the director for

Georgia Tools for life throughout the years. I am not sure when I got to know Liz at first but it probably has been approximately ten years ago. We got to discuss her thoughts about disability, technology and advocacy on the last day of the 2019 IDEAS conference where she had presented several times on various topics that week.

### **Disability & Identity**

*When thinking about the word disability.* Okay, for me, disabled and disability mean two very, two very different things. Personally, I feel like disabled is oppressing, I feel like it's a, "You're disabled." That's it, period. When I describe myself, I don't say, "Oh, I'm disabled." I say I am someone who just so happens to be living with a disability because I truly don't think about it. This is the way I was born. This is the way I drive my chair. This is the way I navigate my worldview from where I'm sitting. Technology is awesome. I can elevate my chair. So I get a different worldview now. I wouldn't even call it ---my co-workers that have disabilities or friends, like those people are disabled it's something that's never just resonated with me. To me, it's what people label you as, and it's something that they see you as a whole person as just a disabled. A disabled person. But if I say, "I'm Liz. I work full time at Georgia Tech. I'm married to the love of my life. I've got awesome friends. We're going to the movies. And Oh, yeah, by the way, I have a disability. I just so happen to be living with a disability." To me. That's two very, very different, different definitions,

*How would I describe myself?* I mean, if I, if I'm talking phone, so...the nature of my work, even at TFL, like I oversee the training team, and Tory answers, 800 lines, the incoming email for years, I did that. And it would be so interesting when people would be on the phone with me, they would say "Really, you don't know what it's like to have a disability. I can't work or I can't get out of the house. I can't do this." And we would talk and I'm in my head, I'm thinking, you're basically on the other end. And so I disclose, actually, I do know. Let me tell you a little bit about myself and what it is I do when you know when I try not to get into, we're on the phone right there customers. So I'm not trying to get in the nitty-gritty of it. But I think just two minutes of, listen to me talk, like I'm not dwelling on the fact that I have a

disability, I'm not dwelling on the fact that like, You called me, it took me 20 minutes to pick up the phone, where I'm not dwelling on those things like that.

I'm being honest about it. And I think that's something that has just worked. For me, my whole life is just being honest about the way I feel, the way I see the way people are talking to me, the way their words affect me. It's very much when I'm describing myself, or introducing myself to someone, it's very much what I said. I'm Liz, and these are, because those are the things that are forefront in my mind. This is all just second nature.

*How is my view of myself is different from other people's view or society's view of what it means to be disabled?* I think that it 's not constant. I absolutely have my moments. Prime recent example, yesterday, then went into the women's restroom with me over to Strickland (auditorium at the conference site), and there's a metal shelf in there. It's weird. And I actually I'm going to talk to them about taking it out. And the way I had to angle my chair and Ben was helping with my catheter. So I angled my chair. And he stood up. He thought he was clear and it gashed on his back. So he's got like this massive cut. He was bleeding. So, I'm his wife, and I'm his partner, and I couldn't reach out to help. That was one of the first things that came to my mind. So I'm using my words, right? That's what I do. Well, I use my words to comfort to give advice, this is what you should do next. okay, we're gonna do this, we're going to do that. And so then I said, Okay, we're going to go to Gina. She's the first person that came to my mind. I'm going to ask it. We're gonna get Gina to help you out. And Gina did. So Gina helps him by getting him patched up, whatever came out, he's all fine. And she rolled over here, "My sister, thank you so much, I really appreciate it." She just put her hand on my shoulder. And she got it. She was "I'm happy to help. Hi. I understand." And I think she just saw the look on my face. I wanted to be the one to say, "Let's go, let me put where's the gash, get a bandage," Cleaning up that I couldn't. I had to rally the world around me to help him. So that's a tactic that I use in my life for a number of different things. I still think about it, I'm in my own head. So to answer your question, I do feel like I've had a lot of confidence when it comes to just rolling up to people talking about myself to just being in this world. But that's not to say

that I never have, those moments when you think that that that does change like people see you as confident. And then they're like, I'll talk to her. I'll interact that way.

*I want you to know that* I am Liz like I just want people to see me for me. Talk to me. I think the majority of the time, like 90% of the time, that's how my life is. That's awesome. And I said this in the self-advocacy presentation, I meant it when Danny asked that question about who's your biggest advocacy influencer. He's badass. He is awesome. Sometimes I'm just like, "Woah, it is like we need you." You know he keeps me very grounded. But this is something that I've actually been talking to Dan about this a lot lately. And he's actually brought this to my attention within the past three or four years. He's like "You, you definitely are an individual living---- an individual with a disability living in the world. You do know you have a lot of friends that have disabilities. You're very strong in the disability community. And it's kind of like, they talk about integration and not being separate. But there are a bunch of people with disabilities hanging out with each other.

And what does that mean? (Society, high school, the normate), their experiences aren't vast is mine. So what are they seeing? Are they going to make fun of me? Or I'm different? Or I'm already struggling to make friends and not have this be the forefront of conversation on my life. And if I throw like a big AAC device, or if I have this talking whatever, or if I'm having to have a printer on my lap all day, right? Or something like that, how does that make me look? Am I going to be approachable by that cute guy over there. But I just want to ask you to homecoming, and whatnot. But why was he when, beautiful Brook is over there?

I mean, I love hanging out with my friends with disabilities. But growing up, I didn't have a lot of friends with disabilities. And I do now. But if I think about the people I hang out with, like, the majority of the time, it really isn't one type people. Every single person, every single person in my life without a disability, at some point in my life, has said to me, you've taught me so much about the way I view people. They have said, I'm the first person they've ever met with a disability, and they still have questions. I mean, they still say things. I'm just like, "No, don't say that. Like, this is what it means, you

know.” So really, and truly, that's what Dan was saying. He said “You are a person with disability living in the world, but you're changing the way people without disabilities are interacting.”

### **Tech & Perceptions**

*Technology or assistive technology in my daily life.* So I often say to people I use upwards of 27 to 32 pieces of assistive technology. That's like a good range for me. Technology it's everything, everything to me. If I count my durable medical equipment as assistive technology. That's one thing that just as a professional that we talked about that the DMV category falls under assistive technology because you've got the proper definition of what AT is and how it helps people. When I'm bringing it down, I say it's anything that can help somebody with a disability to be more independent, and you've got the categories of low level, middle high tech. So with that being said, technology helps me get out of bed every day. Technology helps me pee, helps me take a shower, brush my teeth. My electric toothbrush, that actually was bought for me. It's one of those Philip Sonic, that you put it in the glass cup to charge. It's the conduction charging, so I don't have to plug it in. I don't have to find an extra board. When I'm done, plop it in the glass top. It looks nice on the looks attractive. Like it's really nice. So those are all things that their mainstream that typical people, if they were gifted that toothbrush, they wouldn't be thinking about that, right?

My roll-in shower, the way my handheld shower set up in the shower. We have an elevator in our home. It gets me from one level to the next. My office at home is set up for me. Smart Home technologies, adjustable desk adjustable monitor. My wheelchair, that's one piece of assistive technology. But within my wheelchair, I've got elevate, I've got power legs, I've got tilt, recline, I've got multiple switches. I can click this button, do wheelchair functions on it, I can click it a number of different times and it goes to mouse functions from my computer. And I can use the joystick as a mouse controller, which is really cool on my adaptive van just all the modifications. And that van is when I get to work on again, more switches, my iPhone, my voices, my voice for ----everything. So at the office it's lights, it's an email. I've been sending you all the forms I filled out, just all me using my voice. So technology is just always been there. I just never knew it. You don't know. I didn't know what that was. My parents just sat

me in a different chair to support me or we just were using things right. Just, it was just stuff then I come into this world. I'm like, wow, this is assistive technology. That's what that means.

*Is my perception of myself the same or different with technology?* I'm more in tune with it. So even our team like their in tune with me to like, I'm now the manager, and so actually got a text from Sierra back at the office. She's like, "Hey, we got the Ubi feeder." I've been looking at just eating and feeding and what that means for me and how that's really changed because the progression, and my life. There are some ugly feeders out there, but the Ubi looks sexy. And I'm just, I can't wait to try it. So, our team pays attention to just technology in general, because that's what we do for a living. But I'm very grateful that there are a lot of people in my life that are like, "Hey, I thought about you, when I saw this." Or Martha, it's often like we just put the order in she says "I think you're going to love this. Or what do you think of this?" Even as I'm just researching, and finding things on? I think for me, my experience now is I'm incredibly grateful. And I'm just if I try new technology, I'm like, "Whoa, I mean faster than I was before." And for me, like, it's all about speed. My body slowing down, but my brain is just going a million miles a minute, it's I want whatever it is that's out there, and they're going to help me.

Okay, yes, I do feel different if I am sitting in bed, and I don't have my mouse my props and put my arms up, let's say, the electricity went out. My lights are down. I can't use my voice to do anything. Yes, I am. I am helpless. I mean, I hate it because I am completely dependent. I am absolutely helpless. But then I get in my chair. And then I'm mobile, I've got my cup with my 36-inch straw. I can get to where I need to maneuver in my home and the community at work. If I am completely without technology, it's a nightmare. There are times that sometimes your tech just doesn't want to work right? and that is extremely stressful. Like, knock wood, there have been just a handful of times where I rely on Dragon Naturally Speaking so much, and it's just crapped out. My stress levels are through the roof. Because emails are just pinging in, my team sending me messages, all these things have to get done. But I can't do it. And I'm maybe using the on-screen keyboard, which is great technology as part of my goody bag if you will, but I'm pecking on like a chicken, I'm still not as effective. So absolutely if there is there's no technology around me, or I'm using, I absolutely feel helpless.

*The first time with a particular piece of equipment.* This is actually really funny. I was four years old, my very first power chair. That's a big deal. And I was so excited. So when you get fitted for your chair, and it comes in, it's pretty basic. Then they're going to fit you to it. So everybody gets me in my chair. I remember my dad had like, standing beside me and he has his hand behind my head. Just because there's no headrest yet, right. And the mom was just standing there watching and somebody I remember was on my right, it might have been like a PT or something. And they had set my hand on the joystick and I was so excited. And I push as hard as I could and I went flying down the hallway \*laughs\* and I hit the wall on the other end. My dad had to keep up, my head flew back. Everybody came. And they were like, "Are you okay?" And I was like, "Let's do it again!" I was moving on my own when I was four years old. I just knew this was going to be a game-changer for me, which is happiness. Another big thing again, I absolutely remember using Dragon Naturally Speaking, for the first time. Now, granted, it was like in seventh or eighth grade and training took three hours and it didn't recognize my voice well. And but I remember the first time that picked up my words, I mean, just saying a sentence. And I was like this is something that I'm going to be able to do. And even then being seventh grade, eighth grade. So what 12 or somewhere in there, I just knew that my body is going to be changing. And this is going to help me for the better. It was exciting. It's really exciting. It's awesome.

*Do people view me differently with technology?* Yeah, I think so I think that. so Ben and I have been talking about taking a couple of trips, and we drive everywhere. It's been a very long time since I've flown. And great example, Amy was just flying by herself. They turned her chair on the side. They took it apart. And I just she's by herself. Great. She's very independent, but you take away her chair, she's a quadruple amputee. What is she going to do? and she literally was on the other side of the country. Nobody was with her. So I need to have people with me, I'm not that physically able. But so we talked about these trips, we drive everywhere, getting on a plane, what that would be like, and maybe not taking a power chair and making maybe taking a manual chair. And the first thought I have in my head is I'm not going to be independent, and I'm gonna just be sitting there. And it makes me think about interacting with people. I'm an extroverted person, Ben's very introverted. So I'm just like buh buh buh buh buh (imitating



talking a lot) when we meet people. Everywhere we get He's like, "People know you everywhere." He was, "You can literally just swim 50 miles out in the ocean, you'll just make it fun." This is me, I talk to everyone. So I do feel like I personally wouldn't have that confidence to reach out to people-- strangers because I don't think I feel like I was 100% me (in a manual chair), you know what I mean? If I was sitting in a wheelchair chair, I also feel like, I wouldn't be as approachable because I feel like when I'm in this (power)chair. Like I'm moving. Constantly. I'm sitting up, right? My demeanor is different. So that could just be more of me and my attitude, maybe not feeling the way I feel not being approachable, or making myself more approachable. If I feel like if I had to be in nature. Yeah, I know, that's just kind of a far off example. But just thinking about some of the recent conversations I've had with Ben about traveling and he's pushing me, it just feels very disabled. It doesn't feel like I'm me, but just a person with disabilities just feels like somebody brought me in this chair. Here we are, you know.

***I don't know if you've had this experience or not do people like address then Ben and not you?***

They still do it now. I mean, even when I am sitting up, right, zooming around and everything. I mean, people still do that often. But I guess I do feel like if I didn't have the support sent me from community every day, and I was kind of, more dependent situation. Absolutely. Absolutely. People would talk to Ben. Oh And it drives me nuts. \*Laughs\*

***Tool or an integrated part of who you are?*** Definitely an integral part of who I am. I mean, there are some pieces of it that I use at work that are specifically, like just for being at work, I wouldn't necessarily dive too deep into Saturday, Sunday. I was on vacation and just was being personal, but even then. Yeah, it's an extension of my body. Like really and truly, that's how I feel about this. Everybody's always you take really good care of your chairs. I've always been that way just because and I've always liked taking pride in how I look and dress like I love fashion hair, and just, all that gets me. So I think with my wheelchair, that's definitely what it is like, it's an extension of my body. I care for it. I want to look nice. I mean, wheelchairs can be just gross in general. It happens. Right? But yeah, absolutely. It's definitely an integral part of who I am. But even so you kind of got me thinking about AT, about tools,

even those tools that I consider. This is just a tool. Thinking on it, like it's going to be an integral part of my life at some point. Yeah. Just thinking about the future.

*Do you think that changes with familiarity and the use or how much you use it during the day?*

Yes, it absolutely does. Practice makes perfect, right? And then it's like, wow, this is really saving me from x y&z that I was doing, and not really thinking about that repetitive motion over and over in the switches, solving it? And then for me just having spinal muscular atrophy, and it being a neurodegenerative disease process, like it's the nature of the beast, where it's progressive, it doesn't get better, I'm getting weaker over time. And so that's what I'm also thinking is that, yeah, I may not be clicking the switch to much function so much at home. But I probably will. But at least that they are, and I'm used to it. And I give you I was using that 10 years ago. And 'm familiar with that. So I'm just going to use a little bit more often.

### **Social Justice, Advocacy, and Politics**

*Do you think the invasiveness of technology has narrowed the divide on how people think about technology being good or bad?* Yes, I do, because so again, our self-advocacy presentation, you heard people talk about students, kids, younger kids, specifically. But this happens with adults, I actually had a conversation with a professional here, who was just disclosing the way they were diagnosed with LD at a later age. And something happened here at the IDEAS conference. And they said that they reverted to being 10 years old. They felt so insecure. They left. They said that they did exactly what their students do. And they said, I'm going to go to the bathroom, I'll be right back. And she went to and that is when she lost it and she said the only person she could think about was me. And she came to the exhibit hall to talk to me. We stopped, five minutes talking about it and she felt better. And she was like, I'm going to go back. We were talking about using technology and just changing our mindset and all that. So yes, I do think that with the mainstream technologies that are out there, that can be leveraged by people with disabilities, and it's powerful for them. So again, all those Smart Home speakers, right? Everybody's all about Alexa, everybody's all about Google Home. Apple Pie. I mean, Facebook portals even, there's all these like, funky things coming out. And everybody's all about it. Everybody's like, what's the weather?

What's my commute into work, but when you literally you're able to say unlock the door or call Ellen or order medical supplies off Amazon, order my frequent medical supplies, and then is there the next day. I just use my voice, I don't have to say, "Hey, Mom. Hey, personal care attendant. Hey, Ben. Hey, whoever, can you help me do this?" It's all on my own. So yes, with all that being said, and also going back to when I was starting to say about younger students, younger individuals, just being a little embarrassed, shy, not wanting to work different. But if you're sitting there with your iPad, your apps might be helping you but people will see you as an individual. I've never had a problem with that. I think for me, I just I talk to people my life. What is it about me that I'm just like, "Hey, yo, this is me, I'm coming at you. And there's nothing you can do about it." Even in school, I never was terribly embarrassed. I remember when my very first word prediction software. And even remember, Ellen what the program was. It was on the clunkiest laptops were there. \*laughs\* And then they actually put a portable printer. So I literally was like a rolling mobile office in middle school. In high school, that's the time where nobody wants to be different, right? Hormones are raging. All the cute boys are there. I'm just like, "Oh my God, oh, my god." I just was like, "If you guys want to see something cool,." People were like, "That's awesome." So I had lots of friends in school. I've always been very different. I've never really felt shy about those things. But I love that technology that's available for everyone is just a complete game-changer for people with disabilities.

***Educating the public.*** I love being with my friends with disabilities. It's like I'm recharged. I'm energized and they keep me grounded. But interacting with the world, I want people to see me for me, and I welcome questions. I would rather people ask me questions, than to just assume. There is always a great time and place for it. There are definitely times Ben and I are just out and I just want to be Liz. With my husband, Ben. We're just gonna go get a drink, we're going to go see a movie. I think that (educating people 24/7) happens a lot with people disabilities like I feel like I'm an educator 24 seven, I'm a trainer 24 seven. It's hard to have work life balance, especially when you are a person with disability working in the disability field. It's your life but I know that I very much accept that. So for me, it's like work-life integration. It's still trying to balance everything is definitely integration.



### **George (19)-**

Two years ago at the opening session of IDEAS conference, a bright young man in a power wheelchair using his AAC (Alternative augmentative communication) device got to present an award in his mother's name to an advocate in the AT community called the "Squeaky wheel award." His mother who had passed away was described as a strong advocate for her son, for AT and children with disabilities. George was a wonderfully humorous and interesting speaker and very well composed for a rising senior in high school. I touched base with him and talked to him several times and our friendship started there. He is also friends and has worked in conjunction with TFL and Liz, even making YouTube videos regarding SmartHome technology for people with disabilities. Their entrance into my life helped me to think inside and outside the classroom of ways to help others improve the quality of their education and lives. They are just two of the many individuals that helped my journey as a teacher to an AT advocate and enthusiast. I was especially excited to hear his story. He is a computer science major at Georgia Tech, while his sister just graduated from vet school at University of Georgia. He uses several personal care attendants during his school week and weekend. Alan, his weekend PCA, drove him to the interview and helped clarify his conversation. Georgia chose not to use his iPad as AAC but spoke slowly and carefully so I could understand him. Occasionally, I would repeat what I thought he had said and he would nod or assent that I had heard him correctly. It was more laborious a conversation and therefore much shorter in length, but not in time or importance.

### **Disability & Identities**

*When thinking about the word disability,* I think of someone that is extremely creative. That they can tackle problems from a whole different angle.

*How would I describe myself?* I like technology. I am just like any other college student who likes to go out and have fun.

*What would I like others to know about me?* I think outside of this disability, I am just a typical college student. I am at the point in life where I am trying to decide about grad school, how I'm going to

do that work, just figuring out how to do work, and what the barriers are out there and how I'm gonna knock them down. Also, on a more personal note it's interesting being a student that is so disabled at a school like GA Tech. People at Tech still have some misconceptions. But none of them have to do with intelligence. Because, if you can get into Tech... It automatically breaks down that barrier and misconception "Oh, he's not mentally able." Everyone in my high school knew me. So at a certain point, it wasn't an issue. But if someone wasn't in my AP class with me or didn't see me and know me from academics, then automatically there was an assumption I was in special ed for academic reasons. It didn't help that Fulton (County schools) didn't have inclusive school buses. And most public schools don't. So I'd have to ride the buses with wheelchair lifts where most of the other students were in more self-contained settings. The kids saw me coming in on those buses made assumptions about me, but once kids started seeing me type in and talk in class and use my technology that that was that key that started changing it. And I also had some help from my paraprofessional. For example my conversations at the lunch table. So between my paraprofessional, myself and my best friend, it would change a lot of minds through conversations at the lunch table.

*How is my view of myself is different from other people's view or society's view of what it means to be disabled?* So, I think it's very ableist (society's view). It's hard for able-bodied people truly understand. Social stigma is one thing. I think everyone knows that feeling one point or another. But what I am talking about is not necessarily social stigma but how much energy it takes for me to just go to class everyday and manage my life. People take that for granted. I feel my assistants have a better understanding because they get to see all of the behind the scenes more and work. For example his best friend (Alan's) is one of the assistants during the week. Alan, he still sees some of it. She sees more of an extent during the week.

(Alan) So yeah, one of my best friend's works with him during the week. And so she's really the one that sees going to class and the early mornings. I kind of have a different view because I'm on the weekends when George is relaxing. (George) And she would be watching and the moment I get back from class and so exhausted. I just have to take a nap \*laughs\*. And then it is a difficult balance into

making sure I have the energy to function as a human being but also enough time to get all of my homework done. Because at GA Tech I am taking all of this extra difficult Math. And there's not enough assistive technology to let me do it by myself. And I am past calculus. (Alan) None of us knows how to do that math either. So we're not taught so the systems and kind of the format and comes down to it? We don't know it.

(George) But like a single homework assignment it takes me 20-30 hours to verbally dictate symbol by symbol. And I think it also takes us back to the social aspect. On school days I may get so physically drained, I might not want to go out and be social. Yeah, it's a difficult balancing act.

*Do I feel like you are "on" 24/Seven to teach others?* Yes. Absolutely. And God gave me this mind and body for a reason. (EH) So you and you don't at this point, at least, resent being that ambassador. (George) I'm not gonna lie. Sometimes it's incredibly difficult but I don't resent it.

### **Tech & perceptions stories**

*Technology or assistive technology in my daily life.* I probably use around 30 pieces of technology to live on an everyday basis. The most important is my iPad. It is everything. It is my most important technology. Because it is my pencil, my way of controlling other tech, my way of communicating. To help me use and live life to the fullest. I use that to control like smart home technology in my dorm. And the communication software on my iPad. In the past, I have used an app called SpeakIt. However, I have not used it. They have not updated it, so now I use the accessibility features on the iPad that basically lets you select certain text that is already programmed in. Like word prediction. I type it out and select it, hit speak.

*My perception of self the same after using technology.* This is an interesting questions. I have been using some sort of devices ever since I can remember. I use technology almost every moment of every day, so I guess the best way to understand the question. Like I said before, I feel much more independent when using technology. (EH) So you view yourself as as the same with and without it's just this helps you show your independence and you have been doing it for so long. (George) I can't

remember a time where I haven't been typing on a device. So my parents got me going early. I remember typing on my parents' computer. That is how I learned the alphabet, by typing on the computer.

*First time with a particular piece of equipment.* So definitely my iPad. I remember my sister had one, the old iPod touch. I wanted one, but my mom said "No, it cost too much money and you do not have finger coordination." She was also, "You would tap too hard and you would break it." And then this (pointing to iPad) came out. I was like "Oh my Gosh--it's big." I was "Let's get one." So, I remember I was ten, I think I got a first generation iPad. It started out as just like a big iPod type. I was just doing games, music and stuff, like any other kid. Mom and I discovered "Wait a minute-- I can type on an iPad five times faster than on a computer." So then, I started integrating more and school work and different aspects of my life. And then it's become like my partner in crime. (EH) That brings up an interesting question that I haven't run into with other participants. So did you and your mom approach your teacher and your school about using it? (George) Yeah. (EH) It's always interesting to hear whether the parents have brought something that works at home or the kid or if the teacher has something that they want them to try. So that's interesting that you guys brought it to your to the school to show what you could already do. How did it make you feel once? You could use that in other other than it being a game. (George) I was very happy because I would type on an onscreen keyboard and used a joystick before, on a laptop. I discovered I had enough control to do the onscreen keyboard it was faster. And it decreased a lot of fatigue. It kind of changed that relationship between technology and me.

I think it is incredibly important to recognize that assistive technology has to evolve throughout the lifespan of a person. For example, if written on this (the iPad) there is no way to use disability as an excuse (not to understand me or not to achieve). I do not like to use my disability as an excuse for anything. That having been said, getting AT, for my condition has been work. Getting to the point, I asked my vocational rehabilitation counselor to see if I could get funding for an eye-gaze so that I could give my arm a rest. It gets tired out. I am probably spending 90 hours per week doing homework when I am in school at Tech. And eye gaze would speed that up and make it less fatiguing.

(EH) I know, there might be huge issues a lot of times with the idea of evolution of needs. I'm sure it's difficult. Anytime the government's involved in helping things out, It's not an easy answer. But that is that is interesting. I personally think it's important that as a person evolves, their needs evolve and things that they need now. To me, that makes absolute sense. But it's interesting that I think outside society sees disability as a static and I see it as dynamic because it changes. (George agrees with Yeah and nods)

***Do people view me differently with technology?*** I have a perfect story in mind. So at Tech, I'm involved with an organization on campus with Christian campus fellowship. It's a cross between ministry and a frat. It is basically combined kind of in one. They have been super nice and welcoming from the beginning, but one night. Open mic night. I got there with my iPad to speak. Stand up comedy. And I end up speaking. I think they-- listening to that routine, that I had. Made quite an impression. and some people were like "Wow, he's more than just disabled." (EH) So the fact that you got up there and you did your comedy routine, with your iPad it really shocked some people because they probably had a one dimensional view of you with your disability and view disability is your only identity not? Hey, this is a funny guy. (George) Yeah. After that show we started having more in-depth conversations with the folks in the fellowship group.

***Tool or an integrated part of who you are?*** Integral. Yeah \*Laugh\* not only do I use it every minute of every day, but I'm an engineer and I am a computer science major. (Alan: Personal attendant) , not to jump in here. But also, like, whenever there's in his free time, he likes to like, "I'm going to come up with an idea how to put x y&z on my chair" and you're always thinking about ways to fix and modify your technology and make it better, literally all the time. (George) \*HUGE LAUGH\*

### **SJ/Advocacy/politics**

***On campus advocacy and sharing knowledge about AT*** Captioning...Let me tell you, it is not just useful for the deaf. So, I had trouble getting notetakers through Disability services. So (Liz) at Tools for Life said let's get captioning for you for your lectures. And that is how I do all of my notes. Through captioning with AMAC (<https://www.amacusg.gatech.edu/>) [AMAC was an accessible material program



incubated on the UGA campus and now is part of the Center for Inclusive design and innovation on GA Tech's campus]. So they Skype into my classes and it pops up with an overlay of the lecture. Then they send me an email copy of the transcript. Thankfully, we have new staff at the Office of Disability services. I'm not gonna lie, I've gotten some people fired. Honestly, they're not doing their job. They wouldn't set up Proctors for exams. (Alan) Lost tests, lost paperwork. It's a mess.

(George) But I am hopeful for the new staff and new Dean. We are working to get it all better. I am trying to push our registrar's office to amend the Dean's list policies, so that if you are a student approved by Disability Services to take less than a full course load, that you'd be eligible for the Dean's list. Anyay, I am looking now that I was able to walk into Disability office yesterday and counter this idea, and work on this together. A few months ago, I would not have been comfortable doing that (with the previous staff). Now they are being a strong advocate for me since they started with the new staff. Now we have a Dean who has a PhD and is on national committees. It is just wonderful. They should have new stakeholders coordinators. They are all ex-special ed teachers or special needs parents. They were just hiring anybody off the street and downtown at Tech. .... I am not joking. But this past spring. I could tell you my professors have been amazing. They know how terrible that office has been. They got messages to administration. For example. one of the people they had scribing for me didn't know the difference between a comma and a colon. And she was scribing for me.

George and Liz had a state and regional influence on my life. I think outside of my classroom and community to what is happening across Georgia with people with disabilities. They opened my eyes many times to small aspects of disability all the way to large aspects of state agencies and laws that govern programs and funding and what is "out there" and available. I now turn to national influences that seem to lean into more community action and advocacy to influence what I think my future pathway might include as a result of this research and study.

## **Nationwide Influence: Advocacy and Community Action toward Social Justice for All**

### ***Context of National Connections and My Involvement with Advocacy and Disability Studies***

According to 2017 disability statistics annual report (Kraus, L., Lauer, E., Coleman, R., and Houtenville, A. (2018). 2017 Disability Statistics Annual Report. Durham, NH: University of New Hampshire. [https://disabilitycompendium.org/sites/default/files/user-uploads/2017\\_AnnualReport\\_2017\\_FINAL.pdf](https://disabilitycompendium.org/sites/default/files/user-uploads/2017_AnnualReport_2017_FINAL.pdf) ), the percentage of people with disabilities in the United States is 12.8% according to data from the American Community Survey. The work and lives of the two people I am highlighting last in this section show a much more national outlook than the rest of the participants. One interviewee, Leila lives in California, the other Paul, lives in Georgia but travels across the country and is in Washington, D. C. at Walter Reed hospital often for weeks or months at a time. These two participants also can show how similar and different an outlook based on their own life experiences and possibly their wider geographic net. The concentric circles analogy mentioned in the previous chapter comes to their widest point here with expanding influence on my work and outlook, and hopefully my path for future work in this area of research that this study entails.



#### **Leila (31)**

Leila is my only interview participant that I met through technology itself. She and I became friends through shared interests in

Disability studies through Instagram. For approximately two or so years we have shared messages, and kept up with each other through that social medium. Our interview was actually the first time we had Skyped together and I had heard her voice. She is a fierce advocate for herself and others and with a steady rate of progress, barring hospitalizations, she is working on her Ph.D. in Disability studies at a university in California while she continues to write stories, novellas and screenplays. She has an MFA in creative writing and is pursuing a career as a screenwriter in addition to her doctoral studies. She

understands the intersectionality of identities as she claims disabled, female and LGBTQ as identities that intersect in her life and her writing.

### **Disability & Identity**

*When thinking about the word disability*, I think a lot of people associated with something negative. I think when I was growing up, maybe I had associated it with “Oh, there's something wrong with me.” I think I grew up with that. I think if you grow up with a disability, if you're born with a disability, and you grew up with it, I think the disability culture that you grew up in, enculturated in that to see it as a negative. I don't see it as a negative now. But I think when I was younger, I see it as something. I didn't really see it as a part of me.

I think that when I was younger, maybe I associated with something negative and people are always telling me like, “oh, like it is negative because the word -dis I'm like, if you break down the word, it has all these negative connotations, but really, that's not true. I refer to myself as disabled. I do prefer identity-first language but, I'm not offended by person-first language. Not me. I know some autistic people would be, but I prefer it's much easier to say like a disabled person, less words than a person with a disability. I think disabled comes with this identity marker of having pride, but I think that's something you learn. I don't think that it's just there, because there's so much Ableism, internalized and externalized that it's not like a disability identity. I don't think it's something that someone just grows up accepting me. It was hard, because when you're the only disabled kid, or one of the only disabled kids who doesn't have, a cognitive disability or impairment to a great degree, there is a kind of exclusionary-- then you kind of feel excluded. You're like, “Where do I fit in? Do I fit in with disabled people? Do I fit in with abled people, non-disabled people? Where do I fit in?” So I think, it can be an identity, an identity marker, depending on the person. So yeah, I identify as disabled, but I could see how it could be used as something negative.

You have to pay attention to language and to what people prefer because a disabled person could say “I prefer being referred to as a person with a disability.” When I give my lectures and when I talk to other people, I always say “Ask what someone prefers because you don't know. Someone might not care,

someone might care. But you don't know.” If you talk to someone who's autistic, some will say they prefer identity-first. Person first has been so weaponized by able-bodied, abled people, non-disabled people. Put the person first, not the disability, that erases the disability and the stigma. I think we have to use the words both disability and disabled to reclaim as a disabled person. To claim parts of our identity. To use them in a way that's, I don't want to say positive, because I think that's wrong, I want to say empowering and affirmative way.

***How would I describe myself?*** To somebody who doesn't know me, I would say, I identify as a disabled person. I'm a queer, disabled person, and a writer, and someone who's creative and wants to challenge ableism and ableist ideas. I'm someone who wants to mentor and give back and help people, both disabled and non disabled to have some influence in the world around me and in my community. I want to sort of approach my own practice of what I want to do from like an intersectionality perspective. Because I'm a screenwriter, and I want to I write short stories, novellas, and I'm trying to write a novel, I want to approach my characters as a way of telling parts of myself and parts of my story, but also challenging the ideas of things that I can't say, but I can through a character. So like challenging the liberalism and the ideas that are there through creativity and through fiction and through Art. I would say that's the kind of person that I am. I say I'm a writer before, I'm a scholar, which is weird. But I would also say that disability studies has influenced everything that I've done. But I also would say how to describe myself, I would say that I don't feel like they say when you're in a doctorate program, or you're in a higher-ed program that the imposter syndrome---- I don't feel the way some of my peers do in terms of like academia. I feel I have one foot in the arts world and one foot in academia. So, I would describe myself to someone who's like trying to figure out how to balance my life as a doctoral student in studying in academia with this creative side, and then merging the two and balancing the two, and it's a struggle. That's how I would describe it.

***How is my view of myself is different from other people's view or society's view of what it means to be disabled?*** I view disability as a circle in a way. I think our society views disability as not an identity, not as a source of pride, but something to be overcome and something to be ashamed and hide it

away and put us in institutions. That's why we hear so many inspiration-porn stories of this person, walked across the stage at their graduation. They could just not do a story on it, just let them get on with their life. If I want to share a story about me walking across the room on crutches, I literally have to say on my Instagram video, "No inspiration porn comments, please." They're also going to get shit from people that say "Oh, you're so inspiring." I know what they're saying. But the message is so inherently negative, because I'm still disabled. Just because I will walk in with crutches or even if I will walk a little, it's not going to make my cerebral palsy go away. So I think that society's view of disability is either negative or is ignorant. Society is extremely, extremely ignorant. And I also have an issue with like, other abled-minorities, who aren't disabled are able, but they're part of like another minority group, will not see disability as part of the fabric of diversity.

### **Tech & Perceptions**

*Technology or assistive technology in my daily life.* I don't use as much as like, a friend of mine uses. When I was in high school, I wasn't able to type yet. And so I used one finger typing for middle school. So I used in high school, when I got a laptop, I used a Dragon Naturally speaking. I don't use it anymore. But I'm saying that because it reflects aspects of my life. And when I went to the computer class, a required computer class in high school, it was the only class I ever got modified, but ever was it modified. For me, it wasn't like special ed or anything, but they gave me a modified grade because I didn't think I could type. I would sit with my fingers on the keyboard, and they would like hurt. And I would try to try it. But I learned from that class. I learned how to type. And eventually going through high school, I learned how to type so that I didn't need Dragon Naturally Speaking anymore. But that was some of the early technology in terms of computers and adaptive stuff that I used.

I used when I was younger a stander.(A stander is a device that holds a person up in a standing position with straps and Velcro to strengthen the use of legs as a therapeutic/physical therapy tool). I use like a stander to stand in choir sometimes and my parents thought "Oh, you shouldn't stand up until I stretch your legs." I can walk with a walker. But I know they wanted me to do that. So I'm just thinking of when I was younger. Now, I have a few different wheelchairs. That's the interesting thing. I have a

power chair that I use primarily. And then I have a folding power chair that I've used, like on trips and stuff. And I have a manual chair, but it doesn't fit me right anymore. So I'm hoping to try and get like another manual chair. And then I use a walker, not regularly, but I use it to get do transfers and stuff and in physical therapy. Then in physical therapy, I've been starting crutches, which is exciting. Yeah, I haven't used my iPhone, I don't really have assistive technology on the phone. But I do use it as , and a way to communicate. Then my computer, it's how, because of technology, because of Google Docs and all these things. That's how I work. That's how I have a job, because of technology. The job that I do (transcription of research). My friend lives in Arizona. I live in California. Right now we're Skyping and you're in a different state. This is wonderful. I love this. But when I do my own interviews for my doctoral stuff, I use Skype or Zoom or whatever. I definitely have seen in terms of technology and assistive technology, the way things have changed since when I was younger, and how technology has improved. But also how it was so beneficial to people with disabilities who need it. But also how, like how it can like hinder us too. So, it's a double-edged sword kind of thing.

*Is my perception of myself the same or different with technology?* I don't know if I should tell this story. But I don't know this isn't coming from me because this is a story that my dad told me cuz I didn't know how to feel about it until later. It was a story that my dad told me about my mom, which was when like she wanted me to walk and be independent, so badly that like when she found out that I needed to have a wheelchair. When I was little, it made her really upset. And having a wheelchair for me gave me freedom for what I needed to do.

Yeah, I do have an example. This when I was in high school, I had an aide who would push me around the campus and stuff. I didn't have a power chair until college. So I did see how technology helped me because I didn't have a powerchair in college. I had my manual chair. And an aide that helped me and then I went to Berkeley. And they actually required when I went there, I don't know if they still do this. When I entered there, they said, "because our campus is so hilly, you have to have a power chair to get around. We want you to have one because you're not going to be able to get around on these hills and unfortunately on campus without a power chair." So that was my first time getting the power chair was

when I was 18. I didn't have a powerchair until then. And people were like, "Oh my gosh, Your arms are so strong." I don't know if I've lost any strength because I haven't used a manual chair in a while. But I will say that having the power chair has made me a lot more independent. And I didn't realize how independent it would make me because I had it under the perception of from my mom and from ableism being in a power chair will somehow make me more disabled and all. In some ways, I'll need more help. And that is just not true. It's made me more independent because I can get places myself and not have to ask. I still need help with certain things. But well, I'm kind of in my power chair, and I have my shoes on. I can pretty much go places. So I think that my perception of that change because I saw before I had the power chair, I thought, "Oh, it's gonna make me more dependent" or "it's gonna it's gonna make me look more disabled or something." Make me look like something is wrong with me. I was so nervous when I got it. I was so nervous. I didn't want to go faster. And then a few weeks later, I was like, whooshing down campus not afraid.

*First time with a particular piece of equipment.* It definitely made me feel more independent. I'm from Southern California and I learned very recently on a trip to the east coast that in other states they're much smaller. There you drive an hour and you're in another state. In California, you drive an hour and you're still in California. So it takes eight hours to drive to get to Northern California. So that was me going away to college for the first time, that was me living on my own for the first time eight hours away from home. An hour plane ride, eight hours away from home, from Orange County. If you look up Orange County I live right near Disneyland and where I went to school to Berkeley is like eight hours. So this was my first time using a power chair and being away from home, besides like sleepaway camp. Really being away from home, being 18 years old. I was adjusting to something totally new. I was scared out of my mind. I haven't told you this yet. I don't mind this being in the dissertation because it's part of my story. So school has always been--- even though I'm in a Ph.D. program, "What are people like, oh, you're doing so well with school"--school has been difficult for me when I was 18. And I moved away. I was there for three months. November '05 was my freshman year of college and I was hit by a car and I almost died in the wheelchair. A car didn't see me and the car hit me and flipped my chair over. I'm very

lucky that I wasn't hurt worse. My chair kind of basically saved my life. So, I owe my life to that chair at the time. I have a different chair now. But I think that that experience really changed me. And it's not that I never resented the wheelchair, but I think that it really made me see things a lot differently and made me realize "Do I still keep going to school here like I really had wanted? I wanted my independence. And my wheelchair was part of what gave me that being away for a while. But I also didn't know if that was right for me anymore. So I went to community college. For a year and a half. I had surgery, I had my very first back surgery. I was 19. I know, you saw when I was hospitalized 11 years later, I was not expecting to go back in for the scoliosis surgery. But my first one, I was 19. And, I went through the surgery, and my parents said after " just go to a community college for a while then see what you want to do." And I would get around the community college with my powerchair. They gave me a new powerchair. The insurance paid for it. And when I went to community college there were all kinds of new technology.

I did not want to go to community college, I wanted to go to UCLA. I wanted to get out of Orange County. I have grown up here. I wanted to get away. I wanted to be independent. I do think the power chair in some ways was a part of that. I just wanted to get away. And when I had my accident, I realized that, hey, I need to take a step back, I need this for a while. Going into community college was actually the best thing I've ever done because it made me more confident. So, when I went back to Berkeley when I decided, "Okay, this is where I want to go, I want to go back." It made me more confident in it. my grades were better. I didn't have, good grades that first year at Berkley and I didn't do well because I was suffering with post-traumatic stress disorder, PTSD. So, I think that having a piece of technology and having that option of having that share in the different educational spaces that I was in, whether it's community college, or Berkeley or wherever, I think it gave me an independence that I didn't even know that I had. I feel when I went back to Berkeley, I felt like, "Oh, yeah, like, I felt more equipped to handle it, academically." But I also knew that I'd be okay, on my own, because I had done it before. I would just add hopefully, it'll be better this time. You know I knew the campus. I knew the area. I knew how to get around. I knew my way. I knew how to navigate in my chair. There were other people in power chairs and stuff that I had plenty of issues with that I won't get into that. I was very badly treated



by the disability community there. I do think having the powerchair, gave me a sort of empowerment. It's interesting, I've never written about this that I didn't know was possible. And from being on Twitter and being on social media, now especially I've gotten to learn and hear from other people that it's okay to rely on your chair and take it easy on your body. Do what you need to do. But I didn't have a sense of that when I was in high school or growing up. I didn't really have that because I didn't know and I was young. I feel like people now are growing up with the internet who are teenagers or early 20s are very lucky (to have that community of support).

Yeah, but we didn't have. And I feel like, I wish I would have known that. That being in a chair is okay. And it's not the end of the world or a death sentence. It's not like, I wish I would have learned that earlier. And I didn't and I wish I did.

*Do people view me differently with technology?* People come up to me, they've never met me. I'd rather talk to you and talk to you for hours then have these random? People are scary. No, they're not. It's the *randos* on the street that come up to me and want to touch me. Like something I feel called to me and grab me and touch me and be like, "Oh!" Because they see me in the chair and see metal attached to my butt. They see this contraption around me. They see me as something that's glass or something that needs pity or sympathy. They view me through this ableist gaze of pity or sympathy. So they think that somehow praying for me will fix me or whatever. I don't mind people praying for me. If I know them, I don't mind, but if it's some *rando* on the street wants to grab me or touch me or lean on my chair, like "No back off." I have a lot of stories like that. I had random people cat-call me. I had people talk to me and baby talk. I've had people pat me on the head. I'll just be in places in my life, just they pat me on the head. You've probably seen this on my timeline on Instagram. I like going to ComicCon every year. This wasn't a big ComicCon. But it was a specific convention for a specific show. And one of the actors and I went up to him was, "Hey." I wanted to shake his hand. I'm a fan, but I'm going to be appropriate, you know. And he just looked at me. And he was like, "Oh," and he pat me on the head. I was.... I didn't know what to do. In the moment was like, "What do I do? What the fuck do I do?" I don't know "Thank you" (said quietly and trailing off). Like what do you do? Is funny and it's horrifying? "Why would you? I'm not

going to go up to anyone else and pat them on the head? Why would you do it to someone who is visibly disabled.” So I had that. People at the train station say that I’m like, sexy, and catcall me. I’ve had that. So I’ve had plenty of things like that happen from random strangers that don’t know me. And it makes me really uncomfortable. But it also makes me, because of the industry that wanna go into-- the entertainment industry and because I’m friends with actors and writers-- it makes me appreciate more and have more respect for other people. Because I’ve been treated this way, I don’t want to treat other people that way.

To help me without permission, you could hurt somebody. If you do it the wrong way. You can hurt somebody. I’ve never been hurt that way. But I had people fall on me and fall on me and my chair and land in my lap. I’ve had people just trip over me. I don’t view my chair as an inherently negative thing. I view it as something that helps me every day. But because other people view it as an inherently negative thing or makes people feel awkward.

*Tool or an integrated part of who you are?* Do you know the show “Black Mirror.” Okay, so I think about that show. And I think because I’m a writer, how cool would it be? I’ve always wanted to write a speculative episode. But I think it’s too late. But a speculative, a sample episode about disability and tech. Usually, those episodes are about how the technology can like, correct you or screw you up. But for technology for disabled people, it’s usually designed to help them. But what I think we need with in terms of technology in general, is we need a society that is accessible to the disabled. Yes, we need the technology. We need society to be accessible to disabled people. We need acceptance from society and from both abled and disabled people in order to have the technology work for us. It’s like a shitload of ableism.

If you put universal design principles incorporated into a home or into an apartment, you can make it accessible to anybody, not just disabled people. And think there’s some disconnect, where people are just not getting that. I also thought of another piece of technology that I use, this just came to me. So my apartment has, I push a button and I push like a clicker, my door, my front door I can’t open it’s too heavy. So it’s operated by battery, so the door is too heavy for me to open, and I use a button to get out of

my apartment. And then I have a clicker and I push it to get back in. Or also be too heavy for me to open. My counter spaces are low. And this is the nicest apartment I've lived of all of them.

I think the disconnect between abled people and even some disabled people and the rest of the disability community who are passionate and more engaged in these issues is that accessible environment is for everybody, but they're not. I put this in my lectures I have done before even on media accessibility. So you're not excluding somebody by creating an accessible environment, whatever that environment is, that's an apartment, house, a workplace, you're including everybody, by making that accessible, whether it's universal design, from a design perspective, or in the education, Universal Design for Learning those structures are in place. It's not going to be perfect, because everyone's needs are different. But it will be better, It will be better and across the board with 20% of the population who are disabled. I think that there's this disconnect between people who don't know about it or don't care. And people who are saying, hey, it might cost a little extra, but that means these spaces are comfortable to us because so many spaces are not accessible to people with a variety of disabilities. I have sound sensitivities badly, I wish there were more not soundproof but like quiet rooms at conferences. I live right by Disneyland, the fireworks. I hate it. I wish people were more cognizant of that kind of stuff. And they're not. And I don't know things like fragrance-free and just these things to adapt to the environment. And it's not necessarily all technology, but it all incorporates technology I want we can do it or life and make it better.

### **Social Justice, Advocacy, and Politics**

**Disability/Diversity Umbrella & Disability Pride** No matter who you're talking to, no matter what disability and Disability Studies you're talking about, disability is not included, as part of diversity. The diversity umbrella- it is not included and just accepted as it is. That's where the problem is, that's like the root of the problem. And that's where the liberalism is. And that's why abled people are so afraid of becoming disabled because they see it the messages they see in the media. The messages that they see technology can be used as a cure. Then you won't be disabled anymore. And a lot of people who are disabled myself included, view disability as an identity. It doesn't mean that there are certain disability

identities, or there are certain people with certain disabilities, who might want to care for particular types of their disability as if they have a chronic illness. Or if they have something else they might want to cure for that. But they still might want to have that pride. But we're not taught from a young age because we're probably being raised by abled-people. And we're surrounded in this society that doesn't know how to deal with disability. It comes from the special education model. The medical model. We're not taught from a young age, to view disability as something to be proud of. There's something to be as something to identity and to fix the society around us, or else you're going to deal with a bunch of internalized ableism and end up hating yourself. That's why so many people commit suicide. I hate to get really, really dark. That's why-- it's because society is telling disabled people to hate themselves, to kill themselves, that they're not worthy of love, that they can't have sex, that the images in the media aren't positive or productive or affirmative. They're negative, or they're just neutral. There's no empowering message. To see a girl in a wheelchair or crutches or using some type of technology in a way that is empowering in a sci-fi world where someone can use it, and it can use it and be a part of them. That'll teach a little boy or person, that whatever they have their braces, their prosthetics: their prosthetic arms, legs, prosthetics, that that's a part of them. They shouldn't be ashamed of it, and they shouldn't hate it. But they have to get the messages young, or else you're gonna go with this, like, ableism and you're not going to know what to do. I've heard so many stories from disabled friends online that have said when they were younger, that they wanted to kill themselves. Because these messages are so toxic. I think that if we had more positive images of disabled people using technology in an affirmative positive way and having messages from society that just because you're disabled you still live a full life and be disabled, then there would be more room for acceptance.

*ADA and Ableism.* Yeah ADA It's 30 years old practically. That's not very old, and there's still so much still this huge gap, Right? So I hope that as dissertations are supposed to do, I hope that yours does fill a needed gap, where it should. I just want to add that it just bothers me that ableism isn't recognized as a problem. Like racism because if you don't acknowledge that Ableism is a problem, then you're ignoring it. I'm not trying to play oppression Olympics. I'm really not. The reason why I get so mad that Ableism

is ignored is because, if you're ignoring ableism and you'll ignoring that it intersects with racism, sexism, antisemitism, misogyny, trans-misogyny, fat-phobia. All of those things all intersect with disability. If you're ignoring disability and ableism, you're ignoring the intersection of racism and sexism, and all of those things.

*Closing thoughts.* I want to say that it's really nice being on the other side. I never have been interviewed yet. I think for someone's class assignment, but not for like someone's dissertation. So it's definitely really nice. As a Ph.D. student myself, being interviewed, like being on the other side of being able to contribute to someone's research in a way. I want to say that I value you for asking me. Technology does influence my life. You don't realize that the technology that you have you take advantage of until it's gone, or you can't use it. I appreciate adding my voice to the conversation, because I have a lot of things to say I feel like. I'll go to different things, and especially when it comes to disability-related things. The more that I realized that we need to start looking at things in a different way and I appreciate you taking on disability a technology like from this angle. [Disability] needs to be explored more and explored more narratively. Whether it's in a book form, or a screenplay or a poem or whatever. I think that we need to see disabled people in these worlds that you wouldn't normally like that are, "unconventional." Part of being disabled is learning how to adapt to your environment. So they are going to be doing that anyway. How can this kind of tech that we have and the tech that we're dealing with the future benefit disabled people more? People are already disabled. They already know how to use their technology. It's about just having them accepted in our world, you know?



**Paul (50)**

Paul's entry into my life was atypical compared to everyone else, but so is Paul. Paul entered my sphere through his wife. In 2014, she was moving from being an elementary teacher to an adapted PE teacher working with students with intellectual disabilities and she was to share an office with me at the high school I worked at previously. So at the beginning of the school year cookout during preplanning, I met Paul for the first time. At that time he did not bring his dog, but was sporting his everyday wheelchair.

Over the years through my friendship with Paul's wife, I got to hear bits and pieces of his story and some of the adventures he has had since becoming an amputee and becoming interested in adapted sports such as hand cycling in interesting places such as Colorado, Alaska and even the Texas ranch of George W. Bush as part of Team 43 biking event for wounded warriors the w100k. Paul's story I knew would be different as he acquired his disability in Afghanistan. I suspected he would have a very different and unique perspective on disability. His interests and what types of technology he is now using and adapting to on a daily basis might be different than my other participants. His story and influence in my life makes me look outward past the educational arena to additional places that advocacy. This social justice work could be an important future direction for myself. His influence is national through his work with adapted sports. He has been interviewed by the Today show with his work with VetDogs and I am proud to be friends with him and his family now.

### **Disability & Identity**

*When thinking about the word disability*, I don't like it. At the same time, I don't like your alternatives. I hate differently abled, and all that just sounds canned and made up and politically correct to me. So when I hear it's just one of those words, it makes me cringe. You're either a disabled vet or a disabled athlete. No, not really. I have better in so many ways, I have better legs than you now. I have said it's a superpower, not a disability. But I just think the word, I don't know how you replace it, but it just, it's a very negative word. Challenge ...there's the challenged athletes Foundation, the CAF and I think their name is even better than Disabled Sports USA. They have a great reputation. But it still says Disabled Sports. They have Warfighter Sports within that, which is the military side. And that sounds neutral. You don't think there's a bunch of guys missing limbs and things like that. It's just Warfighter Sports. Ones that are challenged athletes I think those types of terms are much better. Challenged individual or just anything that isn't, *dis-* anything. It becomes a negative term.

*How would I describe myself?* I'm pretty easy. A guy missing a leg. I am an amputee who enjoys challenges and for the most part, enjoys adapting to everything I have to adapt to. Because I think I enjoy the challenge of it. I am a guy who likes adventure and likes to do things, no matter what. And that's probably the part that gets me in trouble. No matter what. That's the good and the bad I push. My body doesn't give off any signals until it's too late. No minuses? Yeah, go for it. Then I'm in the air and things are falling off. And everything's in slow motion. That moment, my body is going yeah, that was a mistake because we're gonna hit hard now. So I do some things that gets me in trouble. Trouble with my surgeon, trouble with my physical therapist, trouble with my prosthetist. Trouble with everybody.

*What would I like others to know about me?* When I'm out there, I'm not somebody to feel sorry, that's for sure. I might feel sorry for myself. But that's me. I don't need you to do these things that are different. That are just part of who I am and part of my life now. And you know what, I want to take my life back sure, but I can use what I've gotten and do things better. I don't need pity. That's probably my biggest one that I can't stand is, even if I fall in my wheelchair, roll my chair over trip and fall, don't feel sorry for me. People trip all the time.

That's the one thing I don't really don't appreciate is pity. I don't know a lot of people with with disabilities who pity themselves. The ones who do, don't really want to promote people. It's really irritating. You know it's fine to ask me. If I'm struggling, ask if he can help. And if I say no, move on. The worst thing is when somebody just can't let it go. Can't understand that. Okay, maybe me struggling with getting up the steps, or maybe me struggling with getting these boxes moved is part of me getting better. So I'm not just being nice. And no, I don't want your help.

*How is my view of myself is different from other people's view or society's view of what it means to be disabled?* The general view is almost pity. We get special parking. You go in the store, and we get special carts. Just so many things that are accommodations, which is great. But I just feel like the view should be more one of looking at people and of “what a strong person that can get through and figure out a way to adapt.” The way kids, kids especially, but the way, adults, kids that adapt to these different disabilities blows my mind. People learning to draw with their feet. There's one guy driving with his feet. He's got no arms, and he drives with his feet. I couldn't do that in my wildest dreams I don't think.

Whenever I see somebody in a wheelchair, I'm looking at them and then I'm looking from the other perspective, not, what's wrong? And what are they looking at? What's wrong? We do that. But I'm not looking from a standpoint of feeling sorry for them. I'm looking at what are they doing right now to manage the situation? What is it that they're doing? We we pick on each other. it's the above knee amputees pick on the below knee, because they got it easy. And the paralyzed guys pick on the above the knee guys. We got an easy and so on and so forth.

One of the biggest compliments, you have to know me a little bit, you can't be a stranger— one of the biggest compliments I get is when someone, even if it's five minutes, when someone gets to know me just enough that they'll make fun of this (leg) in some capacity. Once that happens that is like, yes, you accept exactly who I am, as an individual, you would have picked on somebody else for something similar but had a leg to get picked on even if it's about the disability. Trip and somebody laughs and



makes fun of it. Because they know me. Again, not a total stranger. Right? If you can joke about it, you've gone beyond feeling sorry for me for sure. That's huge.

### **Tech & Perceptions**

*Technology or assistive technology in my daily life.* Well, I use everything from ancient crutches, and a wheelchair. It's about as old school non-technology as it gets. And I use those a lot. I've been fortunate because I'm a veteran. The military provides me with, really, the best of the best with prosthetics. And so my day-to-day walk around leg is a waterproof shockproof, computer-controlled. The amazing leg that is now attaching to my body through osseo-integration. And so I'm really getting the latest and the greatest as far as prosthetic stuff. So I get to use that set of technology. It's pretty incredible when you compare it to some of the mechanical legs that have, the older style legs, what the newest things are.

The legs don't do neurofeedback, yet, at least not really well. So it uses instead, it uses motion sensors and a gyrometer. Works in the same technology that Fitbit smartphones and all those things work. In addition to just pressure sensors. So it knows what I'm attempting to do, whether it's the walk or run, or whether I'm trying to go sideways or backwards or forwards. And it adapts the leg swaying, and it can tell if I stumbled and it will lock down in order to tip to avoid a fall. When I would wear a mechanical leg that if you miss the lockout, when you swing the leg, you're going down. Unless you save yourself, you're going down. That kind of technology is huge. So I was lucky that way the neuro technologies coming for legs. I have friends who already have the neuro arms and it is if you could cover in skin, you'd never know. It's out of Star Wars, almost everyone like Luke lost his hand, right? It really is that good. , I had a buddy who just, it's amazing, what happens and how it works. And the legs are coming, and I'll get one of those someday. So that's exciting.

I use the direct physical stuff. Like when I do PT, and the latest thing to with alterG or zeroG equipment, so I can put on the harness. That's not just hanging from the ceiling. They can actually take my body weight, lets just say 195 pounds. But "We want him to walk with with 50 pounds less weight 30 for safety and to let his body adapt." So they can do that so I can get on a track. And I can walk as 125

pound person which changes the entire rehab process. That stuff you can get it a top notch rehab facility, but I've had these things available because of the military.

I'm currently driving without any adaptations. My previous truck I had hand controls. So that was that was great and a breaking-gas combination for my right hand. And then I had a not just a spinner knob on the steering wheel, but it a spinner knob that had all my basic controls, turn signals, lights wipers, so I didn't have to take my hands off the control to drive. I'm going to put some stuff in the new truck. We just haven't. We're in that process right now. And that kind of technologies, those adaptive technologies to get out of the house are huge. The difference in independence and relying on others for a while when I couldn't drive at all from knee surgery.

I couldn't drive at all for various reasons. I had to have every day -- it was a headache--- to be picked up and taken to the VA for my appointments. I know some people don't mind. For me, it was pretty humiliating. Humiliating is a pretty strong word. But it was very humbling to have to be loaded into a transport van and strapped in and driven to an appointment. That loss of independence is so bad.

There's a kid that I have followed for a long time. He was born with Spina Bifida. And he's been in a wheelchair his entire life. And his wheelchair is such a part of his body, where he can use his wheelchair. I've used legs when I had both legs. And I love watching him because he'll tell you he just doesn't know any different is into the things he does seem crazy. But for him because "the chair is a part of my body, I just do it because I can?"

I use specialized hand cycles, the two of them, because they function very differently. And they can get different places and do different things. And those actually can replace wheelchairs for getting out. Literally some people wanting to realize if they know about hand cycling, and there's actually off road hand cycling in that couple of them were built up to be. The friend of mine took his, it's identical mind, he took it to Mount Rushmore for one of the holidays. He wanted to explore and he went with this thing up and down the stairs. He took it on the walking trails. You can't do that with a wheelchair. He went in independently with his girlfriend. They went everywhere they wanted to and that's because he had this super pedal power hand cycle. He didn't even take his chair. I was actually asking him about it.

“Hey, how'd that work out?” Right? “I didn't even take my chair to the park because I didn't want there to be a difference for them to differentiate.” You can go in the building where everything he needed, he was able to do. Which is an amazing independence level. And a lot of the guys hand cycle with it, they don't think twice about going 15-20 miles into the woods alone. They know they can get in. They know they can fix the machine if something goes wrong, and they can get out. So, that really brings some serious independence. And there's so much sporting equipment like that. Any sport there's an adaptation for. That's the cool thing. There's literally nothing you couldn't have the equipment to do.

This war has produced so many amputees. There's a lot of missing limbs from Iraq and Afghanistan and Syria. But it's the population that's lost the limbs that has the money that goes into that. If you go overseas and fight, you lose a leg, the government's going to take care of things and part of that is getting you back to the maximum full life you can have. That has generated a lot of this stuff getting made. There's a market for it over where there wasn't because, insurance companies suck frankly. When it comes to there's so many flaws (in insurance), it should just be illegal. Well, New York State has a lifetime limit.... So, you can get a very cheap crappy Third World prosthetic because it's going to last because there's nothing can really go wrong with it. You're not even afforded the chance to get the best things. But all these things have improved because there's been such a push from the military VA side there's a lot of money has been put into the development technology, equipment and instruction to do because the equipment is great. You got to have somebody qualified to teach? So that's also disrupted that side of it. Well physical therapists and occupational therapists, rec therapists are learning a lot. The sports PT folks now and huge realm where they are there. They're learning to do these things and to integrate them and come up with a whole new thing. So, sometimes the new sports that come out, amaze me. This, somebody comes up with an idea and “hey, we could do this.” Wheelchair sports are through the roof. Almost anything that can be played now they're playing with, power chair soccer and wheelchair lacrosse.

They're doing the colleges. My buddy, Ron played wheelchair basketball from Missouri. It's incredible that the colleges are taken and creating NCAA athletes with the adaptive side. That's

something so overdue. Now we have Title IX for women's sports, but there's never been a real, equality factoring there (for adapted sports). What are you going to do for adaptive athletes, wheelchair tennis or whatever? The track, the AU coach is so wonderful in trying to start up this athletic program, adaptive stuff. He's like, "You got somebody wants to run? we'll just put them into the track practices." That's incredible and he's willing to work with somebody like that.

*Is my perception of myself the same or different with technology?* My perception is --it is pretty good. But you look at everybody at a lower level. You can't get through things. You get unwanted attention, sometimes good and bad. All someone who has the best intentions "I'm Okay. Leave me alone. I don't need help. I'm independent." If I have my leg on, and long pants, and I can walk around, nobody gives me the time of day. It brings a lot of confidence to have adequate adaptation for things like let you get back to a normal life in my confidence. Using the athletic equipment goes beyond because I'll do things that other people won't even do. That part puts you up here, (hand motion high) because you just think, I just ripped this mountain man and I don't have a leg.

*First time with a particular piece of equipment.* The first one, I got my last leg and I had gone a relatively short time. I only got about six months without the ability to use my leg. And without the ability to walk being in a wheelchair. We cut it all off, I had to recover from that. And then they took me into the VA for they just want to do a fitting, so they were going to make a socket, and they were going to attach -- I was actually somebody else's leg that had been returned for some reason. They were going to attach that leg and they wanted me to stand up to see if the socket fit was good, and how it felt to put weight on it. And then they were gonna take it back and then order me a leg and build everything for me. And I stood up and walked in that parallel bars, about five or six steps and walk back and, and then they were fiddling with the computer to change the settings in the leg. This is a computer leg. The PT and my prosthetist were looking the other way. I just start walking and that feeling of getting that back being up on my feet. Again, independence looking at people in the eye was just CLOUD NINE. I ended up leaving with the thing and dared them to try to take it. I was literally not giving it back. And if you want to take it from me, "Come on." Just because that feeling was was better than anything. I'm about to get that again.

I'm standing again, but I haven't been allowed to do any walking yet. With the new leg, with this \*pointing to osseointegration metal from his stump\*, I'm not up to the point of walking yet. It's just that you have to do time. This is one of those things where harder work doesn't get you there faster. There's just you "do this for a week," and then you add 20 pounds. And you "do this for a week." And there's no in between. Well, I did 40 pounds instead. Can we jump ahead? Right? "No, sorry, It doesn't work that way." And so it's been very painstakingly slow. And I'm the kind of guy that if I had the pieces here, I would have already cobbled myself a leg together. But I don't have the right pieces. Because of this \*pointing osseointegration metal connector again\*. It's a very different connection. I don't have what I need to build my own leg right now. I've done that kind of thing before. I'm having to be patient till next week. Yeah, after I'll go back up there after Labor Day, and I should get a leg after that.

This is much harder because all my reactions have been based on how quickly you can accomplish. It's not like this slow time. This is about a 16-week time-thing that you just do what they tell you to do. They're trying to build something up and they're trying to give it the maximum density. I get it. The good thing is that guys ahead of me, some of whom have done the things that I think about doing and they tell me "Don't do it. Because, it's a mistake, and you'll pay for that setback may not be a week or two may be a year." He said, " it just changes it." So just do what they're telling you. And that's been this guy's voice in my head every time I think about those things. I literally hear him and see him and him telling me that it's okay.

*Do people view me differently with technology?* I think there's an advantage in the whole disabled veteran. There's that word again. But I think the view is less pity and more admiration. There's just a different attitude. Sometimes I feel like I'm cheating because of that, because people don't see it as a... it's always "Oh, my God, thank you for your service, and sacrifice. I look at you, look at what you're doing. Now, look at that, you're amazing. Look at that, you're better than ever." And I was going to say, "You think so? Because I'd take your leg right now." I'm not better than ever, but I the I feel like the perception is especially using the technology is --it's very hot. People really see it as someone who is overcoming challenges and thriving in it. Without it, again, it's more pity. When I'm in the wheelchair, it's

a lot more pity. It's a lot more of "Oh, you poor thing, How can I help you? Bless your heart." Versus, if I'm just standing up nothing changes, except I've got a leg on sometimes I have a leg on, in the wheelchair. I just can't walk all the way across the airport, right? I roll. And then I get to the plane, I get up and I walk on the plane. There's a different perception there. So, when things like stand-up wheelchairs, and I have a couple of friends from Walter Reed, who have used the exoskeletons, talking about a life changer for somebody who's paralyzed-- to stand up and walk around the room. It's amazing. That kind of stuff changes, everything. It'd be nice if those kinds of technologies can start filtering through to those insurance companies and people that aren't veterans too. We don't need healthcare change. We have the best health care and we need insurance reform. We need to fix the insurance system, because that's the root of it. All this stuff is available for a reason. We built it. It's here. It's available. It's not that our healthcare system doesn't have all this awesome stuff. It's not that any doctor, any one of these doctors or PTs wouldn't question who they're putting this equipment on. It comes down to who's going to pay for it? Yeah. And the insurance companies don't want to pay for the stuff that's out there on the leading edge, because the justification is always it doesn't do enough, beyond other things. And so they give you the lesser of the two and that's not fair. That's not right. I would not disagree with that at all. And it's not somebody's fault, they were born with spina bifida, born with a defective, deformed arm or leg. It's not their fault. It's no different than it's not somebody's fault they got blown up in Afghanistan. But it's two different systems.

*Tool or an integrated part of who you are?* It's changed, really. I think initially, they were tools, and now they've become robotic leg. It is part of who I am. It's weird because doing this, that you go through psych meetings, But my biggest misgiving going into it had nothing to do with having this metal rod sticking through my skin and infection risks. And will it work? My biggest misconception was, I'm going to get rid of my socket, which my socket has been the whole problem with everything. And yet, the socket is part of who I am, that carbon fiber that's slick looking. They're slick. You can decorate them. I had the first few I had made, I had all my military stuff inlaid into it. It was a little walking trophy store. And so, and that's gone. I'm still going to have the legs that I had, but it was a psychological thing that I'm

losing a piece of. That was really weird, because it felt like you're losing a piece of you. I'm not just changing the technology, I'm losing part of me. It is going away if I get rid of the socket. It was really weird to work myself through that, because I kept going back to "But sockets are what I do," even though like the end sockets and I don't get along.

After four years, a lot of these things are just part of me. They're ingrained into me. This (osseointegration) will be this is literally part of me now. My prosthetic now that I'm through this point, it's crazy bad ass that my prosthetic is going to literally be part of my skeleton now. It is part of my skeleton, and that is huge. Yeah. It's amazing.

### **Social Justice, Advocacy, and Politics**

*Outreach, Advocacy and social justice.* Well, I hope, as much as anything with technology that there's so much going on. And I think there's a lack of exposure to people who have the needs to get connected to the stuff that's available, especially through research. the research that's coming up and out there, if you're just willing to step up and and look for it and be part of it is incredible. (EH) And that's kind of your passion now isn't it is kind of trying to connect with other people. (Paul) Yeah, whether sporting technologies, or whether it is research studies. I'm in every time, like "Mr. Research" at Walter Reed. I've got so many facts, I gotta do an online survey tonight or tomorrow that I forgot to do. There's so much going on, there's so much. And I always look at it as just, they are like, "Hey, we're doing this, would you be in it?" Yes! Because it's not going to benefit me but it's going to help somebody else or maybe it is. There's some of these things where you actually get the equipment. And that's cool, too. I'm promoting a lot more with adaptive sports and kind of getting the word out.

Yeah, there's more agencies that I'd like to join agencies that don't just focus on veterans. Because, again, I feel a little humbled, and how much is thrown at me. I literally can ask for anything, and somebody's going to give it to me. And it's easy to run away with that. Early on, I was just grab anything. Home equipment, things to manage your life. I can get anything I need, it's going to be given to me, and that's a blessing. And there's people out there who can't. So finding the means to put that kind of stuff to everybody, so that it's not limited. All this stuff shouldn't be limited too.

**Research programs.** It's really cool, like your handcycle and University of George Mason. That's another program. I'm signed up for this program that's research-based, sort of research-based. And they just take vets and military. You have adaptive needs, and you tell them, "Hey, here's what I did. Here's what I need. You're either what I need to accommodate, or here's the equipment I need, it doesn't exist." They send the work out to engineering programs. These guys take on, they sign up to take your take your challenge and do it. And I've gotten, I think three of mine now are accepted. I've got one going for a better way to connect the leg that I can't even wear yet to this because I already knew of the problems. I've got one out to build a better hand cycle, because the one I have is designed for somebody who's paralyzed, so you have to redesign and rebuild. And then I have another one they're looking at right now that is a better means of getting wheelchair into smaller car pickup. Because the typical thing, somebody who can't afford a big car truck or a van is: you roll up to the driver's door, and you load yourself in, and then you reach down, you take your wheels off, and you throw them in the front seat and you pull your wheelchair frame across you and lay it on the passenger seat. It damages the car, it's a lot of twisting and lifting. It's just a better way to get a wheelchair into a smaller vehicle. There's not one. So these engineering students are the ones who can write about, they'll figure out something. There's a way to do it, even if it's different vehicle modification.

More of these partnerships, like San Antonio, with the military, Walter Reed, they that do very similar things. There's departments for all these things within the realm. And I know, the research the military puts money into is massive, on these universities, they may, (Georgia) Tech could be tapping, they hopefully are tapping into some of that money. Because even though the military is funding and the outcome has to, you have to show an effect on military veterans, but they give preference to fund anything that can be universally used. So if you can generalize it to a population.

So it seems like there's a lot of funding for really cool stuff. But the day to day living is where you can really foster someone's independence and really make a difference. Gary Sinise Foundation, and again military, but they are building these state of the art adaptive homes for guys who are going to be wheelchair-bound or amputees. They're going to use wheelchairs a lot. It's amazing what they do. The



kitchen especially is just off the top with all the things that lower down. Yeah, so it's doable. The spouse is working down here with everything that things move. I've seen bits and pieces of what is out there and it's so cool.

*Making lives better & politics of insurance.* I like what you guys do with the athletic stuff. (Special ed teachers and adaptive PE teachers. His wife teaches Adapted PE in public schools and helps coordinate local Special Olympics) because I think that that imparts confidence to stand up out of your chair if you have that ability. To reach something new, little things, but I think that's Special Olympics. Confidence. Yeah. The military side, you're pumped full of confidence from day one. And then after you get injured, it's sort of the same system, they just take you like basic training. The differences, you're broken down to some degree. Now, they don't have to do it for you. They rebuild you. They built you into a soldier or Marine, the first place.

I've got a buddy who has done a lot of things with me, and he's a civilian. He got to play through Missouri, play basketball. And the only reason he gets the opportunities he does is he works for Per4max chairs, part-time. They sponsor stuff for athletics and other things. I'll talk about doing something and then "you should do these" like, "dude, I'm civilian, my insurance company won't pay for that. Yeah, so I can't have that or do that." He wanted a handcycle, the VA bought me a \$10,000 handcycle, he wanted the same one. And, we're two years later, and he still hasn't bought one because he doesn't have the money saved. It's a different world. He's got insurance, it should pay for something like that as an adaptive tool. You should be able to get anything you need to go back to the life you had or go to the maximum life you could have. For those born with what they got, You should be able to live a maximum life. Especially here in this country, you shouldn't be limited by a lack of access to things. That's what blows me away is that we can do a GoFundMe for a dog who needs a leg surgery and raise \$200,000. And yet we can't seem to or will fundraise for a politician who has to go to court. and they'll raise money to pay their legal bills because people like their stance. Put that money to really use right? All the good that we could do, if we just did it.

Sometimes makes me feel guilty, because I can get and have anything I want. And I try to share the things given to me. People get on to me about keeping equipment and why do you keep this? Why do you keep this? Somebody else will use it and I'm not going to just get rid of it. When I gave the handcycle away, I knew it was the right person at the right time to do that. There's things that I won't give away. But I'll share here, here, here, here. And yeah, it's a little lending library over here, right?

*Future goals/closing thoughts.* Ultimately, that's where I am headed, my nonprofit is, once I get home and can build things and have space. My ultimate goal is that we can get money. I know we can get money into the veteran side of the house. And then we can use it for anybody. That's one of these dirty little secrets that you can do. That's all on paper. And my plan is to really have all this stuff and expand it. If you guys have a kid who's got the ability, enough high enough functioning and ability and wants to go out. Get them on a recumbent bike or hand cycling then we'll go to the canal. And we'll do some practice and see where they are. And you know if you're into it and good at it, eventually we'll be out here at FATS Trail running. No, it's with liability and parents. Nightmare when you get into that. I get my biggest holdback is legal. Every time I go to implement something, I run up against a legal challenge. "You can't do that." So we get this clear to make sure that we have insurance. but I just want to take people out and show them the things that they can be doing. I don't care. It's driving me crazy, because I've been so held back on something that's so simple. It's fundamentally simple to put kids and adults on bikes and let them have fun. Yeah, as a route and the other one other activities along with it, Cycling is what I enjoy. So I'll focus on it.

In these two chapters, I have highlighted the counternarratives of seven individuals with an identity label of disability among other intersections of their identities. I have shared their thoughts and stories of the disability as an identity and stories of technology and/or assistive technology. Their lives have impacted my growth as a teacher, educator, and now as an advocate, an ally in the area of disability studies and assistive technology. In the next chapter, I will reflect on this study and its impact on me. I hope that my study will enkindle in others who read this work. The stories of the participants' experiences, their ideas and lives counter dominant hegemonic views of disability. Their stories of

independence through technology prove how wrong society's views of disability are, which highlight several findings and considerations I will discuss in the next chapter.

## CHAPTER 6

## REFLECTIONS ON INQUIRY

In this chapter, I will reflect on my inquiry. Eight findings have emerged from my dissertation research: **(1)** People with disabilities experience disability as a social reconstruction rather than medical deficits and physical impairments which fails to capture the multiple abilities and complex aspects of their identities. **(2)** Technology is a path to independence and connection. **(3)** Technology is both a tool and an integral part of these participants' lives, not an OR but a BOTH/AND. **(4)** Disability has informed and shaped parts of these adults' lives, livelihoods, communities, and even their leisures. **(5)** All of the participants want to be viewed as who they are in their many dimensions and intersections but not as a person with a disability as the main or only aspect of identity. **(6)** Living a life as a person with a disability engenders advocacy for other people with disabilities. **(7)** Working with people with disabilities through my teaching, research, and life helps develop critical empathy and engenders strong advocacy for people with disabilities. **(8)** Listening to and learning from the counternarratives of people with disabilities fosters urgency to develop a curriculum for social justice that helps create equal opportunities for all to reach their highest potential (Siddle-Walker, 1996) in an unjust and contested world.

These findings help answer my key research questions:

1. How does the intersection of identity and life experience with assistive technology and technology shape the lives of people with disabilities?
2. How does technology, either as a tool or integrated part of their lives, change the perception of being a person with a disability?

To explore these ideas and stories theoretically, I build on critical disability studies and disability studies relating to oppression, and exploration of disability against the dominant view of ability as the "norm" using a variety of scholarship (Goodley, 2017; Davis, 2013, 2017; Erevelles, 2011). I also build on posthumanism (Haraway, 1985/2016; Snaza & Weaver, 2015; Weaver, 2010) to explore the use of

technology and assistive technology as a tool or an integrated aspect of our everyday lives, our everyday selves. This foundational work is explored in depth by a wide array of scholars in both critical disability studies and posthumanism in Chapter 2. In addition, I explore the applications of this work through the lens of social justice through curriculum and assistive technology (Abbott, 2007; Edyburn, 2000; Freire, 1970/2000; Hackman, 2005; Harro, 2018; hooks, 2000; Jaeger, 2015; Johnson, 2018; Kirk & Okazawa-Rey, 2013; Peterson & Murray, 2006; Pharr, 2018; Schubert, 2009; Swain & Edyburn, 2007; West, 2018). I challenge the deficit view of what it means to be disabled and society's lack of awareness and action regarding laws, policies, innovations, and simple problem solving. I strive to be an ally to those that face barriers of accessibility, diversity, inclusion, and belonging in this world. I support work being done through technology and assistive technology to open lines of access and communication to the stories and daily living experiences of those the majoritarian society considers having a "lack" through a *dis*. By studying the rich work being done in disability studies narratives, I build on the theoretical, historiographic, autobiographical methodologies and fictional work (Clare, 2015; Dick, 1968; Haraway, 1985/2016; Linton, 2007; McCaffrey, 1969; Mooney, 2007; Piepzna-Samarasinha, 2018; Sequenzia & Grace, 2015; Thousand, Diaz-Greenberg, et. al, 1999; Taylor, 2017).

Methodologically, I use counternarrative or counter-storying (Bamberg & Andrews, 2004; Carmona & Luschen, 2014; Delgado, 1989; Dyson and Genishi, 2005; Glenn, 2012; He & Phillion, 2008; He & Ross, 2012; He, Ross, & Seay, 2015; Sandoval & Davis, 2008; Sandoval, 2000; Solorzano & Yosso, 2002; Tuck, 2009) to hear the stories and thoughts directly from the participants' own experiences. Bamberg and Andrews (2004) in editing a collection of counternarratives explores the work of counternarratives from a "deep concern with power and hegemony" to the purpose of "mak[ing] headway in designing alternative strategies to public, institutionalized power relations, resulting in more egalitarian reciprocity and universal moral respect" (Bamberg and Andrews, 2004, p. 353). I hope my work echoes the intent of Tuck (2009) to not "fetishize damage, but rather celebrates our survivance" (p. 422). Counternarrative is well suited to the work of a social justice educator in efforts "narrative, craft, share, and explore critical stories" (Camon and Luschen, 2014, p. 7) and fit into the frameworks of social justice

models such as Harro's (2018) cycle of liberation where the first steps of waking up, getting ready, reaching out and building community can be based on the stories told and heard. Only then can coalescing, creating change and maintaining happen as essential next steps of liberation and social justice in our daily lives.

The findings I have discovered relate to some of the work being done in critical disability studies, posthumanism and social justice scholarship. Aspects of these findings touch on previous literature in these fields but points to a gap in these strands of literature. Exploring how technology or assistive technology modulates, or shapes the disability identity of people, is not extensively researched. Its implications for social justice and policy reform represent a new pathway to link research and theory to action (Freire, 1970/2000).

As I dive into the lives of these participants, I find that people with disabilities experience disability as a social reconstruction rather than medical deficits and physical impairments which fail to capture the multiple abilities and complex aspects of their identities (**Finding 1**). This highlights the important distinction between the medical or deficit model and a social or socio-political model of disability. Susan Gabel (2009) defines this distinction by pointing out "social interpretations of disability contrast with typical educational views wherein "disability" represents innate individual deficits. In disability studies, the disability-as-deficit notion is referred to as a clinical or medical model and is rejected as the basis for understanding the lived experiences of disabled people because it tends to pathologize difference and rely upon expert knowledge" (p.2). In a deficit model doctors, therapists and teachers are the experts on disability which is viewed as something to fix because it deviates from the norm of what humanity "should be." This has been a majority view from a "normate" or normative standpoint. Davis (2013) points out that "disability studies has promoted the idea that it is not the individual who has the disability, but society at large that creates disabling barriers and a lack of accommodation (p. 62). This social construction of disability reconstructs the identity of disability something that does not need to be compared to an average or a norm, puts people with disabilities as an

expert and emphasizes that it is society that needs to be “fixed” to accommodate bodies, minds, voices that disrupt and counter the image of who is the “average” human. Critical disability studies also extend those views through exploration of dismodernism, or through the lenses of globalism, cultural relativism, relationalism, critical inquiry or political activism.

Some of my participants also point this out and have moved beyond the medical model to view disability in creative ways that push against the homogeneous view of disability as “a lack of.” By viewing disability as problem-solving, creative, empathetic, or challenged the participants are flipping the script on the word disability and its negative connotations. That is not to say these participants are homogeneous in their views between each other or even in the same conversation about different parts of their lives. The dynamic nature of intersectionality makes homogeneous statements and generalization among individuals impossible to a certain extent. Silas, the lawyer, was quick to point out the differences of thinking about the word disability by saying “I believe in a way it's outdated. And still, stigmatizes. I don't know if you're familiar with the medical model and the social model? I feel like it deals more with that medical model still of like, there's something wrong with this person, we need to fix them instead of the social construct of this is just the person, how the person is how they live their life, they just live their life a little different than you and I. I think that, it doesn't have necessarily a negative connotation, but it just shows a difference that I really don't think needs to be noted” (this study, p. 101). Eli echoed this same sentiment, but his view pointed that he felt we were starting to move beyond this medical-infused model telling us “I'm very glad that we're getting we're getting away from so much of the medical-infused model of looking at the condition, as opposed to the person behind the condition. And I prefer, I like to say we're living in a post-ADA world. To be even more specific, post-ADAA, world. The Amendment Act of 2008, that kind of amped everything up a little bit. I think that, as far as even from a political socio-political standpoint, that galvanized a lot of things and really promoted inclusion and getting away from the label. But there's still some pockets of prejudice. There's still some \*sigh\* discrimination. And I'm even seeing it across different settings” (This study, p. 93).

This illuminates the experiences Silas and Eli have encountered and problematized in day to day experiences that reiterate what theoretical work points out. The definition of disability studies according to Society for Disability studies put as its first point “(1) challenging the dominance of medical, individual, deficit-based models of disability (while not dismissing their contributions)” (This study, p. 24, Cushing and Smith, 2009, Disability Studies Quarterly, Vol. 29, No 3, <http://dx.doi.org/10.18061/dsq.v29i3.940>). The definition continues to include the move to a social construct or socio-political model by saying disability studies “(2) considers disability part of the continuum of human experience; (3) examines the environmental and social barriers” (This study, p.24).

The binary that the majoritarian view sets up is a false dichotomy. The medical model that compares each individual to a “everyday man” a “norm” and pathologizes people according to a “lack” a “-dis.” This majoritarian view of disability is seated in those who can and cannot. The binary supports who should be in power, and who should be pitied, scapegoated, fixed, cured, changed or celebrated as inspiration porn when people with disabilities “achieve” what others in society do as a matter of course, such as a graduation, or becoming a lawyer.

These counternarratives are along a continuum of experiences. Depending on the individual and how comfortable they are in their experiences and views of self, there is a variety of expectations and expressions of what “disability” looks like as seen throughout the stories of my seven participants.

Technology is a path to independence and connection (**Finding 2**). Whether it was a power chair or manual, a smartphone or iPad, high-tech prosthetics, hand controls in a car, or software such as Dragon Naturally Speaking, the technologies that these participants use in their daily life create paths to independence and connection. Stories of first time zooming in a powerchair (see p. 140), or using one to scale the hills of a California college campus (see p. 146). Stories of using smartphones and SmartHome technology to aid independence in communication and seemingly simple tasks like controlling lights or temperatures yourself in your own. Stories of communication through typing on an iPad or writing quickly and efficiently using speech-to-text software inherent in any smartphone now or software such as



Dragon. All based on speech engines. Or even text-to-speech engines to read books to those who cannot read with alacrity such as WYNN by Ray Kurzweil (p.119 of this study). All of these stories and technologies, some assistive tech, some not all give that path of independence craved by the ideals set forth by Western philosophies. This isn't to say that relational parts of human to human interactions is not essential. Some of the participants rely on roommates, spouses, parents, friends, and even support animals to complete many activities in daily life. The relational aspect is still important, but pride in self-sufficiency that technology fosters is just as important.

The stories of these participants in often similar wording illustrated the independence felt from being able to use technology and not having to rely on family and friends to complete tasks in their lives. According to Eli (This study, pp. 96-97), "I was going somewhere if I was standing and walking by walker holding. It held a very special place in my life, because that was also the time that I felt a little bit of independence. Because my mom didn't have to hold me up. I didn't have to hold her hand. I didn't have to rely on somebody else to pick me up and move me." Silas shared that "To me, my independence is, in a way, the thing that makes me *me*, because without that independence, I wouldn't be able to do half the things that I do (This study, p. 106). He recounted breaking a bone this past year where everything became painfully slow, how he had to wait for a neighbor to come and help him get to the hospital. How moving in bed or showering became a trial again. The independence he had was stymied and highlighted how important that independence is to him.

George shared that he "probably use around 30 pieces of technology to live on an everyday basis. The most important is my iPad. It is everything. It is my most important technology. Because it is my pencil, my way of controlling other tech, my way of communicating. To help me use and live life to the fullest. I use that to control like smart home technology in my dorm. And the communication software on my iPad" (p. 137). Without that communication software, his voice is mediated through others. He cannot control his environment. He considers it his most important technology, beyond his walker or wheelchair for mobility the ability to express what he is thinking is the most important thing.

Leila said to me “I never resented the wheelchair, but I think that it really made me see things a lot differently and made me realize “Do I still keep going to school here like I really had wanted? I wanted my independence. And my wheelchair was part of what gave me that being away for a while” (p. 147). For her, a power wheelchair opened up the ability to attend college away from her family. Grow into her independence.

Paul having experienced disability as an adult shared several experiences of independence of both himself and of friends, such as the one that took a handcycle into a national park. “The friend of mine took his, it's identical to mine, he took it to Mount Rushmore for one of the holidays. He wanted to explore, and he went with this thing up and down the stairs. He took it on the walking trails. You can't do that with a wheelchair. He went in independently with his girlfriend. They went everywhere they wanted to and that's because he had this super pedal power hand cycle. He didn't even take his chair. I was actually asking him about it. “Hey, how'd that work out?” Right? “I didn't even take my chair to the park because I didn't want there to be a difference for them to differentiate.” You can go in the building where everything he needed; he was able to do. Which is an amazing independence level” (pp.156-157). He also talked about independence of modified hand controls for car and the loss of independence being loaded up into a transport van for his appointments at the VA. His felt keenly that lost of independence being loaded into the transport van and waiting on others for his appointments (This study, p. 157).

In talking about Paul's first prosthetic where he was able to stand up opposed to be being lower than eye level in a wheelchair he said “Again, independence looking at people in the eye was just CLOUD NINE. I ended up leaving with the thing and dared them to try to take it. I was literally not giving it back. And if you want to take it from me, “Come on” (This study, p. 159).

Technology is both a tool and an integral part of these participants' lives, not an OR but a BOTH/AND (**Finding 3**). Just as Haraway's (1985/2016) cyborg myth is about transgressed boundaries, potent fusions, and dangerous possibilities which progressive people might explore as one part of needed political work” (p. 14), just as Weaver's (2015) cyborgs and fyborgs explore permanent and nonpermanent “mechanical intersection” (p. 11), many participants throughout their lives feel that

technology isn't just a tool OR an integral part of their lives, but it is BOTH/AND. From moment to moment depending on function, amount of use, or view of self-identity some participants felt that their technology could both be a tool and an integral part of their life. Some moments or times of their growing up to adulthood would have shifting views of this questions. Sometimes that destination could change moment to moment even depending on the technology being examined.

McKenzie (p. 119 of this study) and Liz (p. 132 of this study) express how technology is BOTH a tool AND integral part of their lives. Liz points out “So I think with my wheelchair, that's definitely what it is like, it's an extension of my body. I care for it. I want to look nice. I mean, wheelchairs can be just gross in general. It happens. Right? But yeah, absolutely. It's definitely an integral part of who I am. But even so you kind of got me thinking about AT, about tools, even those tools that I consider. This is just a tool. Thinking on it, like it's going to be an integral part of my life at some point. ” McKenzie use of Dragon Naturally speaking in so many aspects of his communication and life be it personal or professional have become so much a part of his life he views it as integral. (p. 119).

George feels it is integral to his life (p. 139 of this study). Plant says it is both quoting Deleuze and Guattari's *A Thousand Plateaus*. She points out “man and his tools exist ‘only in relation to the intermingling that they make possible or that make them possible’” (This study, p. 49).

Eli's view has changed over the years. He has felt for himself it is mostly a tool, but in meeting with people in college and his work where the technology is a much more integrated part of their lives he could see the person was amazing behind the device and the device was just there. He even has the hope over time to have less use of devices. (This study p. 99).

Disability has informed and shaped parts of the participants' adult lives, livelihoods, communities and even their leisure (**Finding 4**). The participants' disabilities have shaped the types of work they do, the people they influence, and the communities and leisure. The participants are counselors to inmates with disabilities at a medical prison, lawyers, screenwriters with an interest in disability representation,

adapted sports and wounded warrior advocate, disability tools and AT program director, or research ways to engineer or “trick out” their technology. The participants advocate in their communities for access on college campuses for students and professors, and in foreign countries for accessible housing, or making sure disability services on their college campus is doing their job. These participants play wheelchair rugby, or hand-cycle rough terrain to hike. The participants advocate for appropriate work with personal attendants, Medicaid, disability services offices, and political activism relating to disability.

All of these participants want to be viewed as who they are with many dimensions and intersections but not as a person with a disability as the main or only aspect of identity (**Finding 5**). “The one thing I don’t really appreciate is put. Yeah, I don’t” Paul said and “one of the biggest compliments ... is to make fun of this (leg) in some capacity. Once that happens that is like, yes, you accept me exactly who I am, as an individual” (see p. 156). Another participant, Silas talked about “everybody was like, ‘Oh, my gosh, have you met him, he’s so awesome.’ Pump up the shiny unicorn.” He also talked about getting to know “more friends that I grew to know, on a personal level, as opposed to everybody” implying that relationship moved him from being the “new penny” or “shiny unicorn” to just Silas in college, or law school, just being himself (see p. 108). Liz pointed out “I am Liz. Like I just want people to see me for me. Talk to me. I think the majority of the time, like 90% of the time, that's how my life is. That's awesome” (p.128 of this study).

Living a life as a person with a disability engenders advocacy for other people with disabilities (**Finding 6**). Pity is not needed or wanted. There are many things THEY could help the temporarily abled-bodied with. Competence is presumed. The jobs they have, the outlook on society and their misconceptions about disability and their own lives shines out against the homogenic or majoritarian view that people with disabilities. One participant encapsulates this finding this way:

To me, it’s what people label you as, and it’s something that they see you as a whole person as just disabled, right. A disabled person. But if I say I’m Liz. I work full time at Georgia Tech. I’m

married to the love of my life. I've got awesome friends. We're going to the movies. And oh, yeah, by the way, I have a disability. (see p. 127)

Paul advocates for others through adapted sports and trying to enrich lives of veterans and others in leisure activities and adapted sports. Silas played wheelchair rugby in his undergraduate college experience as a political science major. Liz's work life is centered around helping people with disabilities find the right tools to make their lives easier and break down societal barriers of their disabilities. George is constantly tinkering with ways to make his wheelchair better or policies at his university better for others with disabilities, such as his fight to let people taking less than full courseload due to disability be allowed on the Dean's list. Eli counsels those in the medical prison that often are disabled. The identity of disability has shaped, in part, who these storytellers are in their jobs, their advocacy and their sports.

Working with people with disabilities through my teaching, research, and life helps develop critical empathy and engenders strong advocacy for people with disabilities (**Finding 7**). My life experiences and journey from a neophyte special education teacher to interest in assistive technology and integrating that into my classroom, to working with students with intellectual impairments that used alternative communication has forced me to grow as a person, educator and community advocate. The work I have done learning through the lens of critical disability studies and posthuman in my research has helped me to be critical of world, national and state/local events, laws, policies and programs. I am not the same person I was before teaching those three young men in the late 1990s. I am not the same person I was in the 2010s learning about assistive technology and advocacy for individual's needs. I am not the same person that began this doctoral program over four years ago learning it is okay to cast a critical, but not cynical gaze at what our society demands of people and teachers. I am not the same person after working in a classroom of students that depend on others for a majority of their daily life functions in the past two years. I am not the same person after experiencing the counternarratives of the participants during this experience. I am a stronger ally for my students and friends who have a disability, and people that could be disabled as they age in years to come because of this critical empathy.

Listening to and learning from the counternarratives of people with disabilities fosters urgency to develop a curriculum for social justice and create equal opportunities for all to reach their highest potential (Siddle-Walker, 1996) in an unjust and contest world (**Finding 8**). Just like Edyburn pointed out that most people's definition of fairness "argues from the perspective of a kindergarten child who believes fairness means that everyone gets the same thing" when "actually, fairness means everyone gets what they need" (p. 26).

The educational system I have worked in for the past twenty plus years is not too terribly different from the educational system I grew up in the 1980s and 1990s. The goals of education have largely remained unchanged. The marks of achievement and what is of value and worth knowing has largely been unchanged during the course of public education in the United States since the 1830s. Capitalist society expects good citizen workers that contribute to the economic growth of the country. Because of this people with disabilities are still viewed through the medical model of disability in public schools and not measuring up and in need of "fixing" or remediating. When will a curriculum be developed that creates equal opportunities for all to reach their highest potential? When just and courage teachers on an individual basis feel the urgency to create spaces and change within their own classrooms, and hallways infecting colleagues with the same sense of urgency. Social justice for education will never be a top-down bureaucratic process as its aims are often in conflict with many of the purposes of creating "docile bodies" (Foucault, 1977/1995, p. 135).

By its relational nature, social justice education or curriculum becomes a reality when each teacher sees the inherent value of all of their students and variation to the "the normal person (*l'homme moyen*)" (Davis, 2013, p. 1) and can pass along that fire in a teacher's collegial interactions and projects. My work daily is to open the eyes and minds of other teachers I work with, or whom might read this work and want to also reach for a different outcome of public education in today's contentious and often dehumanizing world. Through this work, I have come to realize, though, that my work in the classroom is not enough. I am called, as the word vocation means "to call" to build bridges of my work in the

classroom and research into the community. I plan on trying to work on an advisory board with AT programs or volunteer at my local service provider, Walton Options.

These findings have an interesting and sometimes unexpected answer on my key research questions. (1) Yes, the intersection of technology in the lives of the participants shapes their identity in different and shifting ways. Different identities and intersectionalities such as race, class, gender, profession, wealth and technology access shapes who these participants are as individuals in different and shifting ways. (2) The intersection of disability and technology changes not only the participants view of themselves (sometimes) in independence and communication but also shift other's views of them based on perceived competence in many of the daily tasks of life and professional work.

If I could expand on this work in the future, I would want to start collecting the stories of people with different disabilities rather than from the participants with primarily physical disabilities or cerebral palsy, a degenerative muscle disorder, and leg amputation. The stories of those who identify as having communication disorders, autism, intellectual disabilities, and those "invisible" disabilities such as learning disabilities or other health impairments related to chronic fatigue, or ADHD would be fascinating to see similarities and differences from the participants in this current inquiry. These participants were overwhelmingly white and male with one exception. The socioeconomic class shaped both the professional work they do and the higher economic class most of them grew up in, which leads to question of their privileges. Expanded research into this topic would benefit from a more diverse interview population in terms of race, gender, social class/economic status. I suspect the counternarrative could be markedly different if the intersectionality of different identity markers is explored in future research.

This research has raised some questions for me regarding access and ability to technology. These participants were overwhelmingly white and middle-class with professional careers. It is implied that many had parents with similar socio-economic backgrounds. The participants did have access to technologies. Some just went out and bought them, or had the information to work through various state

and federal agencies to get access to what they needed. Liz works with clients that often do not have ways to pay for the technologies needed, and has helped others through the red tape of Medicaid waivers or credit solutions to pay for expensive assistive technology. Paul mentioned how much technology was just available to him as a member of the military and a disabled veteran. What is the disparity between military and private insurance and state agency access for all people with disabilities? What would be the different stories of a more diverse participant pool, where race, or economic level creates additional barriers in their intersectionality to accessing needed technologies that create that pathway to independence. This would be a worthy question for further study and review.

These findings support my research inquiry that is based on critical disability studies, posthumanism and social justice research. It has revealed eight findings important to building community and advocacy in the disability community, as amorphous a community as that might be, and a greater circle of allies and societies in general. In addition, my study is important, not only for the benefit of the participants in sharing their story, but also how their stories and lives have created concentric circles of influence on my life. These circles of influence expand and widen to other aspects of my life such as my work as an educator, researcher, and advocate. These counternarratives will affect others who read them. These stories will affect change in my students, colleagues, friends, family, and community through the increased passion and willingness to advocate access, diversity, inclusion and belonging for those that are disabled with my role as an ally researcher. Those spreading circle of influence, I hope will reach national levels by coalescing around views of disability as an identity in more positive terms and the essential part technology plays in the lives of those with a disability. The important impact will be seen if I can kindle others to advocate, inform, and enlighten around topics of the ability to pay for that technology through federal and state agencies and policies. The counternarratives should inspire how we can implement assistive technology and technology better, and more appropriately, through the co-decisions of students and adults with disabilities.



## EPILOGUE

## “Translating the Crip”

Can I translate myself to you?

Do I need to?

Do I want to?

When I say *crip* I mean flesh-proof power, flash mob sticks and wheels in busy intersections, model mock.

When I say *disability* I mean all the brilliant ways we get through the planned fractures of the world.

When I say *living in America today* I mean thriving and unwelcome, the irony of the only possible time and place.

When I say *cure* I mean erase. I mean eradicate the miracle of error.

When I say *safe* I mean no pill, no certified agency, no danger to myself court order, no supervisory setting, no nurse, can protect or defend or save me, if you deny me power.

When I say *public transportation* I mean we all pay, we all ride, we all wait. As long as necessary.

When I say *basic rights* I mean difficult curries, a fancy-knotted scarf, a vegetable garden. I mean picking up a friend at the airport. I mean two blocks or a continent with switches or sensors or lightweight titanium, well-maintained and fully-funded. I mean shut up about charity, the GNP, pulling my own weight, and measuring my carbon footprint. I mean only embrace guaranteed can deliver real equality.

When I say *high-quality personal assistance services* I mean her sure hands earning honorably, and me eating and shitting without anyone's permission.

When I say *nondisabled* I mean all your precious tricks.

When I say *nondisabled privilege* I mean members-only thought processes, and the violence of stairs.

By *dancing* I mean of course dancing. We dance without coordination or hearing, because music wells through walls. You're invited, but don't do us any favors.

When I say *sexy* I mean our beautiful crip bodies, broken or bent, and whole. I mean drooling from habit and lust. I mean slow, slow.

When I say *family* I mean all the ways we need each other, beyond your hardening itch and paternal property rights, our encumbering love and ripping losses. I mean everything ripples.

When I say *normal* I don't really mean anything.

When I say *sunset, rich cheese, promise, breeze, or iambic pentameter*, I mean exactly the same things you mean.

Or, when I say *sunset* I mean swirling orange nightmare. When I say *rich cheese* I mean the best food I can still eat, or else I mean poverty and cholesterol. When I say *promise* I mean my survival depends on crossed digits. When I say *breeze* I mean finally requited desire. When I say *iambic pentameter*, I mean my heart's own nameless rhythm.

When I say *tell the truth* I mean complicate. Cry when it's no longer funny.

When I say *crip solidarity* I mean the grad school exam and the invisible man. I mean signed executive meetings, fighting for every SSI cent.

When I say *challenges to crip solidarity* I mean the colors missing from grant applications, the songs absent from laws. I mean that for all my complaints and victories, I am still sometimes more white than crip.

When I say anything I know the risk: You will accuse me of courage. I know your language all too well, steeped in its syntax of overcoming adversity and limited resources. When I say *courage* I mean you sitting next to me, talking, both of us refusing to compare or hate ourselves.

When I say *ally* I mean I'll get back to you. And you better be there.

(Hershey, 2010 in 2019 work edited by Day and Herd).

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