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Narrating Political Disability Identity

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Abstract

This dissertation documented the political disability identities of nine disabled adults. It also explored how these disabled adults enacted their political disability identities. I used narrative analysis to analyze the data, which included life history interviews and the authoring of memoirs. From these memoirs, the participants (Narrators) and I selected critical moments in the formation of the political disability identities. The findings show Narrators shifted or shaped their political identities when strangers pushed them beyond their personal limits by spouting ableist norms. Narrators also developed their political disability identities when they had access to political discourse and the relative freedom of postsecondary education. Other Narrators developed their political identities when they experienced significant changes in their lives, which included freedom from abuse and interacting with underserved disabled students. The Narrators enacted their political disability identities in various ways. Some Narrators were advocates for the elimination of ableism and during their struggles with it, showed that they also reinforced ableist norms. Some Narrators had been oppressed for so long that they first developed a new ethic of care for themselves and then worked to help other disabled people implement a similar way of life that was dignified, equitable, and without shame. Finally, Narrators selected careers where they could simultaneously sustain themselves and fight against ableism. This dissertation shows the political disability identity contextualized in the Narrators' lives, because isolating a component of identity both skews the findings and removes the necessary human aspects, which are unpredictable and complex. This research and additional research of the personal and cultural components of disability identity sheds a new light on our current understanding of the disability identity as a whole.

Narrating Political Disability Identity

By

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Dissertation

Submitted in partial fulfillment of the requirements for the degree of

Doctor of Philosophy in Cultural Foundations of Education

Syracuse University

August 2018

Dedicated to:

Katherine, my wife

Would you [Katherine] do me the boon of making the above statement nonfiction?

To you, I commit all my strength and all my weakness.

Katherine's response on May 24, 2013: "That's all? Of course."

Acknowledgements

A dissertation represents the work of both doctoral candidates and their committees. I would like to thank Dr. Alan Foley for chairing my committee and dedicating a great deal of time to this dissertation. Thank you, Dr. Julia White, for your attention to detail. I would like to thank Dr. Beth Ferri for taking a bearing and staying the course, which helped me finish this dissertation. I would also like to pay homage to the late Steve Taylor, a foundational figure in the disability studies discipline. Steve encouraged me to take up this project with statements like "I don't care what others say. If you are ready to do this work, it is exactly what disability studies needs." The last words he said to me, in his calm and relaxed way, were, "Steve, as you may know, I am not going to be here to advise on your dissertation. I am 'Not Dead Yet,' but it's coming. It's a shame, because it is an important work, but I know you can do it with or without me, so just go [looking out his office door, shrinking in embarrassment, and whispering] and kick ass."

I wrote the dedication of this dissertation to my girlfriend and now wife Katherine five years ago, before conducting any of the work. The dedication is a symbolic offering, but it does not speak of the work she, too, put into this dissertation. There was a great deal of emotional and scholarly labor involved being by my side as I struggled through the dissertation process. How many times did I ask her to read a chapter or help me change text from "Steve" language into standard language? How many tears has she shed for this and with me? Being married to your colleague can be blessing and a curse. While revising this dissertation my first child was born. Along with Katherine's support, my son Hugo Brace, unknowingly gave me the strength to persevere. "Bug," thank you! I will buy you an ice cream as soon as you know what that is. And while mentioning Brace, thank you Dean Neil Brace Vroman, my late father-in-law. Moving

forward, I hope I can embody your commitment to the academy, humor, love of students, and exceptional parenting skills.

I wish to also acknowledge the rest of my family. First, there is Bebe, my retired service dog. She attended every class with me from my bachelor's program until my very last doctoral course. Well done! Second, my parents. I have always been a difficult child and yet they have stood by me. Both have experienced substantial hardships in their lives and even in those times, they remained supportive. I hope that in some way, completing this work or more importantly, achieving a sense of personal fulfillment, demonstrates the fruit of their many labors over the years. Next, there is Eryk, my best friend of more than thirty years. He has always been the constant. When all sense of hope and reality slipped through my fingers or when celebration was due, he was there: sarcastic, stubborn, witty, and always irreverent. Finally, I want to thank Dr. Cheryl Jorgensen and Byll Reeve who have been an ongoing source of support and love.

Bethany Heaton Crawford from the university's Office of Disability Services served a critical role in my success both in coursework and this dissertation. She arranged my access accommodations. Her trust in my discretion, flexibility, and respect for me created a collegial relationship unlike any I have experienced with access service providers, creating a condition where I could focus on my task and not on access. These experiences are the standard by which all my future access services will be measured. Thank you.

Finally, I turn to the Narrators. Together we completed this work and I hope my appreciation resounds in the text. It is all of ours and none of ours. Thank you, my friends.

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Chapter 1

Disability Identities in Formation

It's like everyone tells a story about themselves inside their own head. Always. All the time. That story makes you what you are. We build ourselves out of that story (Rothfuss, 2008, p. 239).

We were the people who were not in the papers. We lived in the blank white spaces at the edges of print...We lived in the gaps between the stories (Atwood, 1998, p. 56).

Our stories begin long before we enter the scene, yet our stories are still our own. Embedded in the annals of human interaction are the forces of living as a social being. Just as the mountains wear away and the valleys grow deeper, scored and sculpted by the winds and waters that continually and imperceptibly shape them, so human experiences unfurl amid those obfuscated social momentums, invisible to human time. Sometimes, too, these forces are immense and imminent. In order to understand them, our role in their existence, and what we are as individuals, we must look to the stories and find the characters by which we might locate the relationship between Self and context. We look at, in, and between the narratives to discover meaning. The research herein samples both the slow process of becoming ourselves and the more cataclysmic events that result in significant changes, which leave indelible marks on our memories.

Studying the disability identity is an enormous task. In this dissertation, I begin by discussing the disability identity as a whole which includes three components: political, cultural, and personal (Fearon, 2000; Wren, 2002). While this research examines "What is the political disability identity?" it moves beyond this question to try to also answer "How do disabled people enact their political disability identities?" In this research, I describe the political disability

identity of nine study participants (Narrators). These questions tease out the experiences that

make people human rather than describe a product of disability identity.

The scope of this inquiry was large and I collected substantial amounts of data.

Consequently, I chose to focus on only the findings related to political disability identity for this

dissertation (see Chapter 2). I, do, however, discuss all three facets of identity in my literature

review. My research questions for this study included:

1. What are the political disability identities represented in the narratives of nine disabled

   people?

2. How did these disabled people enact their political disability identities?

Because I focused on political disability identity, it is no surprise that the primary contributor to

their political disability identities was ableism. The findings in Chapters 5 and 6 discuss various

manifestations of ableism that Narrators experienced and how they responded.

In crafting the study, I wondered "How do I study the disability political identities of my

Narrators?" My answer was that I must first look to myself, because looking outward

necessitates looking inward. By way of introduction, I begin to unearth some of the critical

questions I confronted in this research by exposing myself as a disabled person and exploring

what those critical questions should be.

I was summoned for a meeting at the county assistance office. $2.85 for the bus, $.70 for the first transfer, $.70 for the second transfer and then the trip home. I can't help but think that the amount is two days of eating. The letter arrived two days ago and stated, "If you do not attend this meeting, your benefits will be terminated." Fortunately, I feel able to leave my house. I stop at the corner store and fish out cigarette butts from that ashtray that have a drag left.

Clambering off the bus, I look at the digital clock in the front of the bus and take a mental note "The trip took three hours." Few houses or buildings have numbers on them in our neighborhoods, so I scout around trying to find the office. After some time, I locate the place by the large group of people standing around it. The door is made of gray industrial steel with no windows or decoration.

I sense this ooze of lethargy, friction, and dolor, like someone pouring motor oil over my head, as I enter the door. It is very dark in here and immediately I am overwhelmed with the pungent smell of urine, cigarettes, malt liquor, sweat, and desperation. Is that me?

It is dark, but that is good I think. I don't really want to see what those pooling liquids on the floor really are or the tired, beaten faces of the other people here. When I look at them, I see myself in reflection and that scares me.

The counter is encased in one-inch thick glass, there are four armed police officers around the room. Throngs of children scream while their mothers slap their faces and yank their arms so hard it seems they will disconnect. The police stand there lazy-eyed only moving at all when one of the young black men gets angry at another or screams something at a clerk.

It seems so calm on the other side of that bullet proof glass, where a clerk sits typing on an ancient computer. Holding my appointment paper straight out in front of me like a testament, I walk toward the window. Before arriving, I see a latex encased hand materialize across my chest, preventing any further progress.

A police officer booms "Number!" Staring back in confusion, I respond "Huh?" He replies, "Take a number and wait." I hold up the letter. He pushes the paper aside, "NUMBER!" I take the number – 83 and pushback purposeless tears. I look up at the crooked digital display "Now Serving: 59."

I sit down in a hard, plastic chair between two women. One woman gently rocks her baby while feeding her a bottle and the other screams at her two children for making too much noise. Waiting here, all of us sullen, is tortuous, but the numbers move quickly. Within an hour, 83 flashes on the screen. Jumping up with my paper, I dash toward the counter. "No running!" a dull but firm voice says from across the room. I slow to a walk.

Approaching the counter, I bend over and stick my face close to the vent that allows people to talk to the clerk. I say, "Hello ma'am, I am here for--" She interrupts: "Fill this out," thrusting out the stack of papers, which I fill out back at my seat. I turn to head back to the counter and I smell the distinctive scent of latex just before thump -- that huge, familiar hand bars my route. I look over and say "Lemme guess? Number!" He nods almost imperceptibly.

Number 108. Wait. My number arrives and I turn in the form.

Number 122. Wait some more. "There is an error on your form."

Number 145--and wait again. Turn in amended form.

Number 162. And... wait.

"Steven J. Singer? "A bedraggled woman props open a door that has no handle on the livestock side of the building. Relief. It took four hours. At her desk, she doesn't say anything so I begin, "Good afternoon." She mumbles "Social Security card." I respond, "I don't have it with me," I apologize. Without looking up from her computer screen, she mutters, "Gonna have to come back tomorra."

I skulk out of the darkness and back into the street. I count the change in my pocket and focus on reconfiguring my budget. When I get home, eleven hours after I departed, I pile all my clothes on top of me to stay warm and I take one of the cigarette butts I collected earlier and wipe off the pink lipstick on its tip. Sleep

Despite my dread of doing it all again, I arrive to the assistance office and head through the door. I feel like a veteran now and go through the motions without a single latexed hand or monitoring exclamation. Reaching out to grab the number I think of Wheel of Fortune and say to myself, "Come on...big money, big money!"

My number is 122. The digital sign says 43 and the time passes so slowly.

A police officer stands and bellows "5PM, the office is closing. Ya'll need to leave. Come back tomorrow." People are angry. I see it all around me and it hangs in the air. People say indiscernible things, but I only hear the venom, not the words. The officer stand, arms crossed. Additional officers emerge from behind the door to the offices. Everyone pauses, frozen in time, waiting for someone to do something. We all know that we waited, that we will always wait, and it really doesn't matter to anyone. Strollers, canes, wheelchairs, walkers, proud struts, dragging feet, and broken souls make their way to the exit.

I dig in my pocket and come up with $2.70 of stale cigarette smelling change and my remaining two butts. Standing at the bus stop, I hold that amount in my hand and ask the other people waiting "Anyone got fifteen cents? I have $2.70 and need fifteen for the bus. "I feel it's too much to ask for the full $1.65 I needed to get all of the way home.

A guy in a suit talking on a cell phone reaches in his pocket and hands me a quarter without looking at me. "Thank you" I say, but he just keeps talking on his phone. The bus arrives with a hiss of its air brakes. I exit the bus at its closest stop to my apartment I can get to without a transfer and walk the remaining three miles, arriving home at 10 PM.

When I wake the next morning, the world is in chaos. My skin boils. The feeling of anything touching my body rips me apart. I stand naked up on the tips of my toes in the thirty-degree apartment, unable to escape the pain that even the air causes me. "Please save me, please let me go" I plead. Panicked, I tear the place apart, gobbling up anything that might knock me out. I find a pill in the ratty couch and shove it in my mouth without any concern of what it is. I down what's left of a Nyquil bottle. The three and a half Xanax I had been carefully rationing are next. Slowly, the pain begins to numb and the flashing lights that pulsed during my search dim. I drift to sleep.

I lie in my makeshift bed, waiting to be well enough to face the outside again—1 maybe 2 days later. It is the need of a smoke that eventually rouses me and I make my way out into the street. I make my way down to the corner store where I collect the discarded butts.

When I return and enter the door to climb the stairs to the apartment, I stop at the mailbox. There is a letter from the county assistance office. There's really no need to open it. It states "Because you did not appear for your appointment, your benefits have been terminated. If you would like to dispute this decision, you can file an appeal at the county courthouse and a hearing will be scheduled within four weeks. If the appeal results in a reversal of the decision, you may choose to re-apply for benefits."

To be sure, this was not the first time in my life that I had politicized feelings. In fact, I had long been critical of the relationship between government, power, and money. In high school, I read and pretended to understand Marx while preaching the benefits of anarchy. I helped organize a school protest when the school board suspended a skilled teacher for receiving marijuana in the mail, because I felt that his value as a teacher was not diminished by what he did during his personal time. Still, when I did some soul searching for a moment that defined

who I am as a political disabled person, I chose the story I tell above because it represents who I am much more than anarchy does. I cannot separate poverty and disability in my mind. The experiences above changed me in a way that permanently affected my worldview. I understood my place as a crazy and broke man. While the story does not describe my political identity in its entirety, highlighting this critical moment in my invention of myself is a remarkably powerful tool of self-analysis. From this documented location or anchor, I can discuss the past, future, and various multilayer or nonlinear thoughts, actions, and reactions I have had over the years. It provides to me a framework to discuss how I used the lessons I learned, the feelings I had, and all the various truths and fallacies I held to enact my political identity.

Fifteen years have passed since those days at the county assistance office. Just like before the narrative and afterwards, I have experienced various glorious and not-so-glorious manifestations of "brain weather," which is what I call mental illness. I have had the good fortune of becoming Deaf, which I say because it reduced stimuli that affected my brain weather, gave me a sense of cultural belonging and made a substantial contribution to my financial health. Unanticipated and quite baffling, I sit now writing a dissertation. Chaos, rambling, a slew of social forces, and personal choice have led me to this moment. Specters of the past promenade through the halls of my mind, sometimes passing from the ethereal to the material. Much has changed or perhaps not. There cannot be a past me and a present me. It is all me. It is not comparative. However, as I write these words and this dissertation, I am enacting that political identity of that impoverished man in need of food and deliverance from pain. I selected this topic because I needed to feel empowered.

By presenting my own narrative and a discussion of additional relevant information and social context, I highlight and introduce the nature of this research. I also include them to be

transparent to the reader. I am, after all, a feeling, subjective, scarred, and hopeful disabled

being. Readers deserve to understand that my experiences shaped the data I now present to them.

Thus, within these pages, I document the political identifies of nine Narrators. The Narrators tell

their stories, which are personal, entertaining, sometimes painful, and sometimes triumphant.

They do so because they felt compelled to document and disseminate their disability memoirs,

which was a facet of this research I discuss in Chapter 3 as well as a political act. Like the

narrative included above about my trip to the welfare office, I explore critical moments in

Narrators' lives as a method to describe their political identities and then investigate how they

enact those identities. In the findings chapters, I quote large excerpts from the critical moments

the Narrators authored which are part of their larger memoirs. Additionally, the Narrators

selected writings that explained them as people, rather than as objectifications of disability.

These can be referenced in Appendix A. In the remaining sections of this chapter, I provide a

broad description of the study and the form it took. I conclude with a chapter outline for the

dissertation.

Developing a Needed Inquiry

When I began conceptualizing this research, the very first notion that came to mind was

serving the needs of the Narrators (participants) first and my needs as a researcher and doctoral

student second. I understood that these needs are not always the same. I committed myself to

conducting emancipatory research, which I discuss in Chapter 2 and review my level of success

in achieving this objective in Chapter 7. My task was to document disability identity from the

point of view of a group of disabled people. I did this by tracking facets of identity in Narrators'

life histories and memoirs, which I discuss in Chapter 2 (political, cultural, personal). As stated,

for this study, I focused primarily on the political aspects of disability identity formation. I also

understood that people actively participate in the process of identity development rather than developing identity in a passive way (Erikson, 1963; Sue, 2001). Therefore, rather than study only these three facets of identity, my analytical process included an examination of how Narrators thought, acted, and responded to conditions in their environments, which contributed to their identity formation.

To date, many disability identity studies focus on what disability identity does or its political power rather than what it is or who the people are as individuals. (see Barnes, 1999; Brown, 2002; Brown 1995; Cameron, 2013; Dunn, 2014; Evans, 2013; Gill, 1995, Hahn, 2002; Hahn & Belt, 2004; Mollow, 2004; Morris, 1993; Shakespeare, 1996; Siebers, 2011; Swain & French, 2000; Vernon & Swain, 2002; Zames & Zames, 2002). For example, discourse has proliferated around the idea of a positive disability identity. Shakespeare (1993) describes the positive disability identity as often taking "the form of replacing one analytical framework (the 'medical model') with another (the 'social model')," which then leads to a more positive identity (p. 7). This process has also been described as a kind of "coming out" as disabled (Shakespeare, 1993). Siebers (2011) takes this idea one step further by claiming that in a truly progressive democratic society, there is no justification for a negative disability identity. Thus, disability identities must be positive. The idea of a positive disability identity is reflective of a standpoint of disability identity politic and is a requisite for positive change in the social treatment of disability (Siebers, 2011). Gilson, Tusler, and Gil (1997) locate the flourishing of the positive disability identity in the growth of the disability community and the self-determination and self-advocacy movements.

To broaden this discussion of identity, I felt that I needed to examine disability identity beyond having or achieving a positive disability identity. Although the United States is far from

resolving many of the schisms that cause disablement, as a disabled person, I also know that the identities of disabled people include more than what is represented in the literature about disability identity (see above). Considering that people participate in their own identity development over time (Erikson, 1963; Sue, 2001), it was not only necessary to implement a theoretic framework that focused on individual agency, but one that centralized disabled people as authorities in their own lives.

Given the above rationale, it seems almost contradictory for me to then represent only my findings about the Narrators' disability political identities in this dissertation and not also the cultural and personal facets of their identities. Disabled people show the complexity of identity and how it cannot be only one component at a time because they are intertwined. For example, Kuusisto's *Planet of the Blind* (1998) represents a tension between aspects of Self. In this work, he upset about who he is supposed to become as a blind person, showing his strength and determination to create a counter story. At the same time, he was renegotiating his identity, vulnerable and curious. Mukhopadhyay (2011) discusses the trial he and his family experienced while searching for a reliable communication system. However, he shows a powerful counterpoint to this story of struggling. Half of his memoir is poetry, showing the beauty and frustration he feels and knows. It is a testament of him enacting his political identity through action with his family and his personal identity through creating art, affect one another. In these examples, one facet of disability identity cannot justifiably be extricated from the others. Instead, while examining one, it must be considered in relation to the others. Disability political identity scholarship does not do a particularly good job of that. In this dissertation I take up that task to represent the disability political identity in context of the other facets.

Developing an Emancipatory Methodology

To access and document Narrators' processes of identity development, I began by collecting life history interviews. I acknowledge that life histories provide one particular kind of data that tends to be linear in nature. The data from these interviews were simultaneously rich but also constraining. I say constraining because a tenet of emancipatory research is participants are positioned as knowledge makers and using only life history interviews prioritized me as the knowledge maker. With each transcript of each interview, I would have discretion over how much time I chose to mull over, organize, consider, write about, and revise information until I arrived at what I believed was knowledge. Meanwhile, Narrators' roles would be limited to immediate and unretractable accounts. This style of response and interaction is not only inequitable, but inappropriate for many disabled people. Many people with learning disabilities, intellectual disabilities, and those using people or technology to interpret or convey information, for instance, require time to process information and organize their thoughts to authentically represent their intended meaning (Lewis, 2002; Nind, 2014). Atkinson (2004) argues that to capture an authentic life history of people with disabilities, a qualitative researcher must provide time, space, support and practice. Goodley (1998) adds that when researchers develop a life history narrative, it is a process that must allow for continued reflection and refinement over time. Life writing or memoir seemed to offer a way to provide this space for my Narrators.

Once I had a general idea of the kinds of data I wanted to collect, the pieces of the puzzle of how to design an inquiry that simultaneously benefitted me and the Narrators began to fall into place. I hoped that by engaging in this inquiry, both the Narrators and I would benefit from producing a great amount of memoir. I have been writing memoir for twenty years, but until recently all those texts ended up as random sheets of loose leaf paper haphazardly stuffed in books. To this day, I discover them when I pick up a weathered edition from my shelf. I began

asking around and without exception, all my friends with disabilities authored memoir or were waiting for the right time to write [or otherwise document] their lives. None of these friends who had actually written memoirs knew what to do with their work. I felt this body of documented experiences was a tremendous resource to leave untapped. Perhaps this held true for many disabled people. Perhaps there were many disabled people that had stories they needed to tell, but had no audience or perhaps needed help expressing those stories. Therefore, this inquiry became a vehicle for promoting the documentation of memoir, however the Narrators chose to do that. Chapter 3 includes a more detailed discussion of how I sought to design an emancipatory study, while Chapter 7 reflects on how successful I was in this undertaking.

Participant Recruitment

I recruited only Narrators who actively sought to generate memoir (see Chapter 3 for recruitment procedures). I knew through anecdotal information, that there would be potential participants who might also have stories to tell, but might need assistance or a venue for their memoirs or life writing. Shortly after sending out my recruitment flyer (see Appendix B), however, 55 people responded! From this group, nine narrators were selected based on willingness to participate in a demanding research process, the variety of disabilities represented, and diversity in other human characteristics. The life history interviews served as entry points for Narrators to work through and organize their initial thoughts. In between these sessions, they further documented and elaborated on those thoughts and stories in memoir or alternative forms such as painting.

Data Collection

I felt it made methodological sense to pay attention to both the long processes involved in identity development as well as the critical moments when Narrators expressed their identities in

ways that forever shaped them. Thus, I designed the collection of data to capture both kinds of recollections. In the critical moments of identity development in which Narrators knowingly exerted control over Self-creation, it occurred to me that the way to create the most authentic accounts of these moments was to trust the Narrators to represent them rather than me interjecting or attempting to synthesize their experiences. While the Narrators continually authored their memoirs throughout the research, the memoir data collected was tethered to these critical moments. In narrating these instances, I believed that Narrators must be permitted to participate in similar reflective processes that I followed and that allowing such reflection would produce data they felt was more authentic. I thus designed the study to permit rumination, feedback, and consideration of their success at effectively representing themselves in this medium. Ultimately, there was a wide range of how Narrators participated in the process, but the crucial point is they decided what participation meant for themselves and my approach developed organically in relation to each participant.

Memoir often focuses on singular aspects of a person's life (Smith & Watson, 2010). In the case of this research, that singular aspect was disability identity. I hoped an inquiry that supported memoir-writing could become the research communion I sought—one that would simultaneously fill both my own needs as a researcher and the participants' needs. The Narrators all wished to author and share their memoirs. When asked "Why?" they reported, "Because people need to know about us [Stephanie]" and "Because if we don't tell people the right stuff, someone will tell them the wrong stuff. [Flora]." The final product provides readers portions of the Narrators' memoirs that best represent the critical moments in their disability identity development (see Appendix 1 & 2 for excerpts). The substantial body of memoir generated by the participants, but not included in this dissertation, provided a supportive context for Narrators

wishing to complete their memoirs. To date, three have completed a first draft.

Each Narrator participated in a collaborative process to help decide what pieces of memoirs should be included in this work and how those aspects of their memoir gelled with their larger life histories. I began data collection by conducting the life history interviews so I could gain a more thorough understanding of the Narrators' lives, but also so they could get to know me. I believed it was essential that we trust one another. We talked and typed for months. The summarized lives we often tell others soon began to expand and unfold. I encouraged Narrators to begin or continue writing their memoirs and as they did, they sought out feedback. My comments addressed both my experience reading their texts and stylistic comments. I also shared several sections from my own memoir. Over the course of this process, I became friends with many of the Narrators. I saw my own reflections in their accounts, which was not always comfortable, but enhanced the research, pointing me toward further questions I needed to ask or requiring me to critically interrogate my own subjectivity or analysis.

As stated, data collection began with exhaustive life history interviews while Narrators authored their memoirs, which were not necessarily going to be used as data. I maintained field notes and had all interviews transcribed. Using interview transcripts and field notes, I conducted a preliminary coding of what appeared to me to be significant moments in the Narrators' identity development in their life history accounts. These significant moments were ones that illuminated one of the facets of identity illustrated in the scholarly literature (reviewed in Chapter 2). I met with each Narrator and discussed the facets of identity I was exploring and asked them to start thinking about their lives and reviewing any memoir they had generated. When we next met, we compared notes and/or thoughts about identity and what that meant in terms of three specific aspects of identity (political, cultural, and personal). Narrators began thinking about their stories

not only as stories, but as data. Just as I did, they looked at my notes and portions of the transcripts or responded to my comments, they stared off into space thinking, and they uttered "hmm, interesting" many times. Together we interrogated and processed portions of the data. I began mentioning the various moments in Narrators' lives that my notes and transcripts suggested were important and Narrators further discussed the significance of those moments. I continued recording interviews and collecting data during these meetings. These discussions led to further exploration and fleshing out of Narrators' lives until we collaboratively pinpointed what the Narrator felt was the "right" critical moment of identity development to document. Sometimes the Narrators and I selected the same instance as a critical moment in their identity development, but other times not, which suggests the importance of including participants when conducting data analysis. Sometimes, these moments were included in memoir they already authored, but other times not. In all cases, the next step was for the Narrators to immerse themselves in those moments and show rather than tell the reader what they experienced. I asked Narrators to envision being in the space and in the moment where the event took place. I asked them to tell me what they saw, smelled, heard, felt, and thought. I then asked them to write or paint those words not as a person reflecting on the past but as themselves experiencing the moment presently.

After Narrators generated their first drafts of the four critical moments in their identity development, they conducted a varying number of revisions. This was their option. I also asked them to select one particular story from their memoir in process that best represented them or their personality to be included in Chapter 4, Meet the Narrators. I communicated that I was happy to read revisions of their work and respond to any questions. Most of my responses were iterations of "Can you tell me more about this" and "Can you show this rather than tell this?"

After completing the narratives (parts of the memoirs) to be included in the research as well as an introductory piece, some Narrators continued to expand their memoirs. As I have stated, three have finished a first draft of book-length memoirs and two others have a substantial amount of writing complete.

Data Analysis

Data analysis (detailed in Chapter 3) for this study included four main steps. First, I chunked data according to three facets of identity (political, cultural, personal). Second, I used inductive theme coding for the life history data. Third, I used inductive theme coding for the critical moments represented in the Narrators' writings and paintings. Finally, I looked at how the two sets of data aligned or diverged according to the themes I developed within them.

While the Narrators and I talked a great deal about disability, they are so much more than disabled people. There should be no reason to write these words, but often in disability research and memoir, we become so focused on the topic of disability that the other aspects of humanhood begin to pale. Narrators showed me the happiness, thrills, and adventures in their lives. They relayed the extensive traumas, uncertainties, struggles, and frustrations they have experienced. They communicated the complexity of the human experience that can never be captured, especially while I am chasing an elusive "truth" about disability identity formation. It was a mess. It was a joyous mess of lives lived, of living, and of bleak or promising futures.

Organization of This Text

In Chapter 2, I review relevant literature. Narrative inquiry is a well-established approach in qualitative inquiry and identity studies. I review this body of literature to guide this study and provide a foundation for how disabled people express their identities through narrative. Memoir, as a particular form of generating narrative, is central to this work. Memoir serves as the vehicle,

product, compensation, and most of all empowerment involved in this research. The narrative

that I included in the data chapters is but a small portion of the work the Narrators generated.

Paying due attention to the purpose of their writing and painting is critical to understanding these

Narrators' lives. Thus, in Chapter 2, I also provide a brief overview of disability memoir as a

particular form of narrative, discuss its purpose and effect, and contextualize it in relation to this

inquiry. Next, I review identity development, focusing on the identity of difference and the

influence of social forces on how individuals craft their identities. Finally, I focus the discussion

on narrative views of the Self, transitioning to how disability life writing and particularly memoir

can be productive ways to reveal disability identity.

In Chapter 3, I detail the research design of this dissertation, including the rationale for

the study, the research questions that guided its design and implementation, and participant

criteria and selection. I also outline the benefits and risks of participation. Next, I discuss data

generation, coding, and analysis, including the interpretive mechanisms that I employed in

analyzing the various kinds of texts, which included interview transcripts, field notes, and

Narrators' memoirs. I also provide a rationale for how I chose to represent and organize the

representations of participants' narratives.

Chapter 4 introduces the Narrators (the participants) by providing contextual biographic

descriptions of their lives, written by the Narrators themselves. Readers "meet" the Narrators and

become familiar with their families, work, education, disabilities, and various aspects of their

respective backgrounds. The reader begins to establish a more intimate relationship with the

people on the "other side of the text." The purpose of this chapter is to lay a foundational

understanding of and develop a non-objectified acquaintance with our protagonists, without

which the remainder of the research would lose much of its clarity and power.

Chapter 5 examines the critical moments in Narrators' lives that they selected to document in the form of memoir. These critical moments were times in the Narrators lives that significantly affected their disability political identities, which changed how they perceived their worlds. I used extended quotations from these accounts to show the Narrators' voices and present the narrative of these often emotional recollections in the Narrators' own voices. I organize my analysis thematically. These themes include: a breaking point: reactions to strangers or acquaintances, political activism in college, and changes in lives enabling new perspectives.

Chapter 6 examines how Narrators enacted the political disability identities. I present biographical information in Chapter 4 and the emergence or shaping of the political disability identity in Chapter 5. Together those chapters prepare readers to understand the influences in Narrators lives and identities that contributed to how they enacted their political disability identities. I arrange Chapter 6 thematically. Themes include: internalized ableism, Self-to-other ethic of care, and working for change.

Chapter 7 is a summative discussion of the preceding chapters. I begin by discussing the research findings as a whole. I return to my research questions and answer them by drawing on previous scholarship and reflection. Next, I reflect upon the methods used in this research and the successes, struggles, and limitations I encountered throughout the process. I review the emancipatory research objectives, and address the use of narrative methods for documenting lives. Next, I discuss the future of disability identity research and make suggestions for possible future research. Finally, I provide a conclusion to this dissertation.

Chapter 2

Literature Review

In the previous chapter, I provided a descriptive introduction about the nature of this research. I included a personal narrative about a critical moment that shaped my political disability identity and posed some critical questions about how disabled people develop their identities amid various social forces. Here, I turn my attention to reviewing scholarship that informs the study of disability identity and the theoretical lenses by which I chose to interpret the data in this dissertation. I begin this chapter by defining identity broadly and review how various scholars have approached the study of identity. Within this section, I also define terminology I used in my analysis. Next, I examine what it means to have an identity that is connected to difference, followed by the disability identity as one particular type of difference. I draw from disability studies to inform my review.

I dedicate the second half of this chapter to the review of disability life writing to represent and understand the disability identity. I begin by reviewing literature about narrative view of the Self and the significance of disability life writing. Next, I focus on disability memoir, a specific type of life writing. I focus on this form of writing because it aligns with the emancipatory research objectives of this inquiry by shifting the purpose of writing narrative from contributing to disability-focused research to benefitting the participants. This review establishes the context for this dissertation that uses the authoring of memoir for data collection.

Identity and the Disability Identity

It is a difficult task to define identity. It is a common word in discourse, but when pushed to describe the concept's concise meaning, it can be baffling. The literature on identity provides definitions, such as, "Identity describes the way individuals and groups define themselves and

are defined by others on the basis of race, ethnicity, religion, language, and culture" (Deng, 1995, p. 1). Jenkins (1996) defines identity as "the ways in which individuals and collectivities are distinguished in their social relations with other individuals and collectivities" (p. 4). Identities can also be said to "define us because they contain traits, personal characteristics, roles, and our ties to social groups, and they can be focused on our past (what was true once), the present (what still is true), and the future (our wishes, expectations, and fears)" (Oyserman, Elmore, & Smith, 2012). Berger and Luckman's (1966) definition of identity focuses on social positioning. They state, "Identity is objectively defined as location in a certain world and can be subjectively appropriated only along with that world....[A] coherent identity incorporates within itself all the various internalized roles and attitudes." (p. 132). Each of these examples highlights a liminal space where an individual is defined simultaneously by their individuality and their chosen or assumed group affiliations. These definitions suggest that this liminality can produce a point of conflict or ambiguity. For this reason, Hall's (1996) definition emerges as a better fit because it embraces this ambiguity. Hall states,

> Identity is a kind of unsettled space, or an unresolved question in that space, between a number of intersecting discourses. Identity is a process, identity is split. Identity is not a fixed point but an ambivalent point. Identity is also the relationship of the Other to oneself (p. 12).

The above definitions still do not bring us to a particularly practical definition of identity. Most simply stated, identity can be thought of as a self-understanding of how an individual defines him or herself (Fearon, 1999). Thus, in this understanding of identity, an individual can only be defined in relation to others, but chooses to focus on the meaning an individual makes from that interpretation. By taking this approach, identity becomes much more intimate. Identity

"is about belonging, about what you have in common with some other people and what differentiates you from others. At its most basic it gives you a sense of personal location, the stable core to your individuality" (Week, 1990, p. 88). Identity is not something that is inherent, given, or even claimed—in that even the act of claiming does not constitute a finished product. Identity grows, adapts, and matures. It is a way of "inhabiting, interpreting, and working through, both collective and individually, an objective social location and group history" (Alcoff, 2006, p. 42).

Defining Three Facets of Identity

Often minority groups are labeled as malcontent (Alcoff, 2006; Balsam and colleagues, 2015; Phenice & Griffore, 2000; Siebers, 2011) and politicism of minority groups may be interpreted as expressions of malcontentedness. I hope to represent the disabled people in this research as political people and yes, they may be dissident at times, but they are not defined by their politicism. Politicism is only one component of the disability identity and failing to recognize other components of identity risks perpetuating the view of disabled people as malcontents. My choice to examine only the political identity in this dissertation was one based largely on the scope and detail of this research. I walk a fine line between doing what I claim perpetuates negative views of disabled people regarding identity and conducting identity research that represents disabled people in an authentic way. I do this by showing the Narrators in multiple ways (e.g. narrative and quotation), but also providing space for their personalities to emerge in the text. I do this in Chapter 4, where I introduce the Narrators and in Appendix A where the Narrators each have a narrative that they authored for this dissertation without any prompt, aside from "Show me who you are." In this way, we see the people and not only the

politicism. The final mode of resisting the disabled as malcontent trope is to later conduct similar research on other facets of identity. I describe these three facets of identity below.

Political identity. Wren (2002) outlines what are now commonly recognized components in the study of identity (also see Almerico, 2014; Fearon, 2001). First, there is the political identity. One common expression of political identity for marginalized groups is when they "mobilize to regain control of their own action, they try to reclaim the right to define themselves against the criteria of identification determined by an anonymous power and systems of regulation that penetrate the area of 'internal nature'" (Melucci, 1989, p. 51). Disability political identity, for instance, often emerges in response to an ongoing struggle between disabled people and an ableist narrative that continually pushes people who cannot claim normate status into the margins of society (Siebers, 2011).

Cultural identity. The second component of identity is cultural identity. Cultural identity, in Wren's (2002) definition, involves understanding a person's subjective relationship with a group. A disability specific example is people who cannot hear may identify with Deaf culture, but not all individuals do. The ones who do, demonstrate behaviors that align with cultural norms of that group, such as use of American Sign Language, attending Deaf schools, and associating with and supporting the Deaf community. Definitions of culture have been hotly debated over the last few decades and the delineation between the anthropological and sociological ideas of culture have become blurred (van Meijl, 2008). Traditionally, culture described the behaviors of a homogenous group of people, who were seen as exotic or "far away" (Abu-Lughod, 1991). Such views of culture assumed a similarity between individual and group identities (La Fontaine, 1985) and a stability and permanence of the cultural group. In the modern world of transnational migration, technological reach, communication networks, and

general mobilization of people around the globe, this definition has been rendered obsolete (van Meijl, 2008). As a category of people, disability has always been heterogeneous, lacking a locale, covering varying personal and group identities, and maintaining little stability. People are continually entering and leaving the group identity as they gain or lose impairments or come into contact with others. Therefore, disability has traditionally resisted an anthropological classification as culture. Today, these definitions have been revised to include a diversity of individual constructions, representations, and interpretations of culture (Wright, 1998).

Personal identity. The third component of identity is the personal identity (Fearon, 2000; Wren, 2002). One's personal identity does not exist independent from political or cultural influence, but rather involves the relationship one has with him or herself within those influences. Personal identity describes how one group affiliation fits into an individual's general schema of all their affiliations and the particularities of those connections. The personal identity is just that, an individual interpretation of Self simultaneously looking inward and outward.

Identity of Difference

In order for there to be a "Self" there must also be an "Other"—something that is not the Self (Heidegger, 2002). As groups of selves gravitate toward one another, social orders develop and lines of demarcation begin to form between "us" and "them" (Hacking, 1986). Groups with access to resources and power enjoy the privilege of standardizing their own in-group ideologies, thus any other ideologies become deviant (Castells, 2011; Foucault, 1980). Intentionally and unintentionally, institutions develop policies that diminish the power of those who are different (Berger & Luckman, 1966; Garber, 1991; Wolfensburger & Thomas, 1983). From the perspective of the dominant identity group, the Other is shrouded in mystery, which breeds fear (Greer & Jewkes, 2005). Because of this fear of difference, Others live their lives stigmatized.

Goffman (1963) writes about this:

> The attitudes we normals have toward a person with a stigma, and the actions we take in
> regard to him, are well known, since these responses are what benevolent social action is
> designed to soften and ameliorate. By definition, of course, we believe the person with a
> stigma is not quite human. On this assumption we exercise varieties of discrimination,
> through which we effectively, if often unthinkingly, reduce his life chances (p. 5).

Despite being crafted 50 years ago, scholars continue to use Goffman's work as a foundational tenet of studies of identity and stigma (see Crawford & Ostrove, 2003; Fichten & Partington, 2012; Fine & Asch, 1988; Lewin & Reeves, 2011; Reissman, 1990; Robillard, Judd & Amsel, 1989; Smith, 2002; Taub, McLorg, & Fanflick, 2004). Williams (2010) and Riggins (1990) suggest the reason we continue to draw from Goffman is that little has changed about how we view stigmatized people, that the mechanisms of power that oppress people may look different, but function in similar ways.

The identity of the Other exists in its own right, developing for its own purposes. For many marginalized identities, oppression "provides the conditions with which the oppressed can begin to develop their own consciousness and identity" (Weeks, 1977, p. 33). Marginalized identities develop in conjunction with societal conditions (Salazaar, 2005). For example, members of any marginalized group must consider whether, when, how, or if it is possible or desirable to attempt to assimilate to dominant norms and values and there is a great amount of pressure to do so (Goffman, 1963; Kay 2009). For this reason, the processes by which marginalized identity groups develop their identities may be similar (Sue & Sue, 2003). However, this should not be interpreted as meaning all marginalized identities form in the same way (Sue & Sue, 1999). According to Helms and Cook (1999), the crux of minority identity

development is when a critical mass of its members recognizes a dissonance between the narratives told about them and their lived experience. At this juncture, resistance to dominant ideologies catalyzes group interaction and identity recognition (Anzaldua, 1990), thus crystalizing group identity.

All people have complex identities, but, according to Siebers (2011) and Alcoff (2006), the only people who talk about identity are "Others"—members of minority groups. If one is a part of a dominant group, one's identity can fall out of consciousness—one does not always identify with race if one's race is white, for instance. Alcoff (2006) posits that all "identity is linked ultimately to subjugation by others...[consequently] contemporary theorists banish identity when they associate it with lack, pathology, dependence, and intellectual weakness" (p. 66). Thus, identity studies become marginalized in research because these studies tend to reinforce stigmatized aspects of "otherness," despite the fact that the purpose of identity discourses is to inform the Self and society of all our inherent differences and manifold similarities. Precisely because identities are constructed within, not outside, discourse, we need to understand them as produced in specific historical and institutional sites within specific discursive formations and practices. This dissertation purposefully includes Narrators who hold (or have been given) multiple, often intersecting, "Othered" identities. These Narrators have experienced differential access to power and privilege and, whether they chose to name it as such, stigma. My approach, however, is to resist reinforcing "otherness" and instead to focus in on that liminal space of dissonance: between the stories that are told about the Narrators and the stories they choose to tell about themselves.

Disability Studies and Disability Identity

Following the precedent for social change set in motion by the American Civil Rights Movement and a national culture imbued with an increasing call for equality and justice, the

Disability Rights Movement formally emerged in the 1970s and 1980s, as individuals with disabilities began to question and challenge the systems of oppression in their own lives (Charlton, 1998; Fleischer & Zames, 2011.) Scaffolded by ideals of full participation and equitable citizenship and the U.K.-born "social model" of disability, people with disabilities in the U.S. began to situate disability in "the environment" rather than "the body," thus necessitating "not individual medical treatment [or other forms of "intervention"] but changes in society" (Siebers, 2008, p. 73).

As a theoretical and academic complement to this growing movement, disability studies evolved as a framework that coalesced the lived, shared experiences of people with disabilities and sought to both identify and combat their marginalization and oppression. The interdisciplinary efforts of scholars and activists established foundational theory and literature, interpreting the cultural experience of disability as not just medical malady or bodily impairment, but social construction (Ferguson & Nusbaum, 2012; Fleischer & Zames, 2011; Linton, 1998; Oliver, 1997). As policymakers, educators, and direct-service providers began to adopt disability studies frameworks or at least consider alternative explanations for what might be "going on," the understanding of their work started to veer away from the politics of care, cure and exclusion, and towards considering disability as another manifestation of difference (Linton, 1998; Shakespeare, 1997).

Disability studies is a counter-narrative to purely pathological understandings of bodily difference and is no longer "emerging" or "burgeoning" as it has been characterized in much of the literature in the late 1990s to early 2000s (David 1995; Garland-Thomson, 1997; Erevelles, 2000; Ware, 2001) but "flourishing" (Garland-Thomson, 2014). Scholars have acknowledged the ubiquitous internal diversity and divergence that accompanies this flourishing (Jarman & Kafer, 2014), noting the emergence of various "critical threads" of disability studies that each bring a

unique lens to their analyses (Garland-Thomson, 2014). Erevelles (2014) further complicates the character of this field, noting its tenuous and perhaps contradictory place "at the apprehensive boundaries between academia and activism" (Accountability/Disability Justice section, 3). However within this liminal philosophical space, Erevelles (2014) observes how disability studies is able to, "foreground the material conditions that can enable academia and activism to work symbiotically in the struggle for unexpected and evocative possibilities of living productive and celebrated lives" (Accountability/Disability Justice section, 5). It's perhaps not surprising that the voices included above that detail the "flourishing" of disability studies are all scholars that identify (in some way) as feminist disability studies scholars. These are the voices that, about ten years ago, began interrogating the gaps or silences within disability studies broadly, and thus produced scholarship that also adopted a feminist standpoint thereby centering new experiences and embodiments.

As noted above, Wren's (2002) identity framework delineates three facets that, when taken together, comprise an individual's identity. Identity also describes how we view and feel about ourselves, which includes how we believe others view us (Jenkins, 2004; Mead, 1934). Galvin (2006) found that inaccessible places of work promote negative disability identities because disabled people are evaluated against able-bodied norms, messaging to disabled people that they have little worth. However, when disabled people think about themselves or find themselves among disabled peers, they feel a sense of "coming home" (Gil, 1997). Dunn and Burcaw (2013) found that disabled people as a group identity was once primarily a counterculture, but has shifted to a sense of community. Dunn and Burcaw (2013) continue to suggest that the passion and activism of the disability rights movement have been internalized, contributing toward the formation of a group identity that reflects but is separate from activism.

Increasingly, disabled people have resisted cures and have viewed disability as a

significant part of their Self-concept (Hahn & Belt, 2004; Stefan 2001; Weinberg, 1978, 1988). They often don't wish to fit into the mainstream (Stefan, 2001). In a study of 165 participants, Hahn and Belt (2004) found that disabled people who had strong connections to the disability community did not feel that those links would be threatened if they no longer had disabilities. They also found that the clear majority of those individuals associated disability with concepts of connection with other people more than with concepts of loss. These findings indicate that the disability identity is much more than a utilitarian concept.

Nevertheless, the study of disability identity must still consider how disablement affects identity formation, because disabled people do not exist in a vacuum nor even in distinct geographical areas. For example, Cunnah (2015) found that students with disabilities, regardless of experiencing formative years riddled with bullying and other deficit-based messages about disability, often transformed themselves and adopted a positive disability identity in postsecondary educational spaces because of access to positive discourses about disability and additional insulation from deleterious societal discourses or treatment.

Throughout the field of disability studies, scholars have proposed and affirmed the idea of a positive disability identity. "This shift [toward positive disability identity] often takes the form of replacing one analytical framework (the 'medical model') with another (the 'social model') to lead to a more positive identity (Shakespeare, 1996, p. 7). But it takes work to affect change. We see evidence of the disability identity in historical civil rights organizations like the League for the Physically Handicapped (1935), The "Rolling Quads" (1968), Disabled in Action (1972), as well as in the occupation of the Office of Health, Education and Welfare (1977), the ADAPT formation and protests (beginning in 1983) and all the other protests, lobbying, and advocacy efforts that have transformed the nation and its policies around disabled peoples. These

claims "begin the radical task of transforming ourselves from passive and dependent beings into active and creative agents for social change" (Morrison & Finkelstein, 1992, p. 22). As Morris (1991) writes,

> Most of the people we have dealings with, including our most intimate relationships are not like us. It is therefore very difficult for us to recognize and challenge the values and judgments that are applied to us and our lives. Our ideas about disability and about ourselves are generally formed by those who are not disabled (pg. 37).

Due to its strong roots in the Disability Rights Movement, a disability studies definition of disability identity is inherently political. Disability moves beyond impairment and instead becomes a particular philosophical orientation towards the world and the people in it.

But isn't there more to disability identity than "pushing back" or existing only in contrast to the able-bodied? Disability identity must be considered beyond its political implications. Siebers (2011) explains that disability identity cannot be an individualistic construct, because it is inherently stationed within social parameters. True as this is, scholars must also account for how an individual makes identity their own and how they internalize it as personal, even if it is simultaneously not. Identity is Selfhood. Identity describes how an individual is affected by and contributes to the overall social context (Golubović, 2011). Identity is defined both by biological characteristics (e.g., having an impairment[s]) and by political position (e.g. "the positive disability identity"). Each component of these identifying markers together creates the entire identity, which itself is an ever-evolving construct. That is, a person's identity is determined not only by the group with which they identify or with which they are identified, but by all their identifications simultaneously ebbing and flowing depending on social and personal contexts. Identity represents the capacity to belong to a collective on the basis not merely of biological

tendencies but symbolic ones—the very capacity that distinguishes human beings from other animals (Siebers, 2011).

Nevertheless, a great deal of scholarship focuses on what disability identity *does* rather than what it *is*. For example, Bogart (2006) found a correlation between having an affirmation-focused disability identity and lower levels of anxiety or depression in people with multiple sclerosis. In a similar vein, Smedema Bakke-Gillen and Dalton (2009) found that having a positive disability identity eased acceptance of changes in their participants' disability status. Daulke and Mullaney (2014) discuss how disability identity could result in improved educational outcomes for disabled people. Nario-Redman and colleagues (2014) showed that claiming a disability identity led to increased knowledge about disability rights and increased interaction with disabled people. The list of studies both within the disability studies discipline and outside of it that focus on the benefits of claiming a disability identity is immense (see Barnes, 1999; Brown, 2002; Brown 1995; Cameron, 2013; Dunn, 2014; Evans, 2013; Gill, 1995, Hahn, 2002; Hahn & Belt, 2004; Mollow, 2004; Morris, 1993; Shakespeare, 1996; Siebers, 2011; Swain & French, 2000; Vernon & Swain, 2002; Zames & Zames, 2002) I feel these kinds of studies that focus on the effects of having a positive disability identity and correlations between identity and positive outcomes primarily reinforce ideas of politicism. After all, change is what disabled people need, and consequently the disability identity is tethered to activism (Davis, 2001). Disability studies, identity studies, and disabled people might benefit from a more comprehensive examination of the disability identity, which includes political, cultural, and personal realms of inquiry.

The gap that emerges in the literature about disability identity creates an opportunity for new scholarship that defines disability identity beyond identity politics. This opportunity is to

finally render disabled people as multi-faceted, complex people and not just a single thing (e.g. political or disabled). It is an opportunity to show personality and identity, which both informs scholars and resists the objectification of disabled people. This dissertation seeks to live within this gap, asking disabled people to narrate and represent their own identities, forging a collective path that leads us closer to a reimagining of what disability identity is or can be.

Disability Life Writing as a Means of Understanding Disability Identity

Narrative View of Self

The project of figuring out who we are and how we came to be this version of our Selves seems lofty, daunting and potentially indulgent—what a privilege to be able to undertake the ethereal pursuit of asking the question: Who am I? And yet, one of the assumptions upon which this dissertation builds is that the pursuit of self-knowledge and self-understanding is not only warranted but necessary, particularly for those whose Selves have been historically and persistently relegated to the margins.

In this dissertation, the conduit between the Self and its expression and representation is life histories rendered through narrative. It assumes an epistemological standpoint characterized by a narrative view of the Self that "allows the individual to continually locate and relocate his or her own voice within a social and cultural context" (Brody & Wallace, 1994, p. 74). Drawing on scholarship from Bruner (1987, 1990), Taylor (1989), and Vice (2003), our Selves (or, our identities) are forever intertwined with the stories we tell about those Selves. Moreover, Bruner (1987) notes that "life as led is inseparable from life as told—or more bluntly, a life is not 'how it was' but how it is interpreted and reinterpreted, told and retold." (p. 31.) Vice (2003) adds that not only are our Selves and the stories about them inseparable, but it's these narratives that have a generative role in Self-creation:

Selfhood or identity is constituted of the narratives that we tell about ourselves. More precisely, we are characters--usually the protagonists--of the stories we tell or could tell about ourselves. This claim about selfhood is usually conjoined with a transcendental claim, to the effect that we also necessarily impose a narrative structure upon the world, that narrative is the 'lens' through which our lives are experienced. Experience, in other words, is essentially narrative in form (p. 93).

In adopting a narrative way of knowing and viewing the Self, this dissertation resists the notion that people with disabilities exist in a constant state of dependence waiting for able-bodied researchers to call upon them. Instead, it builds on Vice (2003) who suggests that "The self, in other words, isn't something that's given to us, of what just happens 'despite ourselves.' We are responsible for its contours and so in a significance sense, are self-made persons" (p. 98). Thus, casting the participants in the role of Narrators and excavating their life histories lends credence to how Bruner (1990) values stories and their capacity to convey experience and shape identities:

We achieve our personal identities and self-concept through the use of the narrative configuration and make our existence into a whole by understanding it as an expression of a single unfolding and developing story. We are in the middle of our stories and cannot be sure how they will end; we are constantly having to revise the plot as new events are added to our lives (p. 115-16).

Vice (2003) concurs: "We grow up on stories; they shape our moral and intellectual development and show us the possibilities—heroic and ghastly—open to human luck and endeavor…They resonate with us because in some sense we are living them." (p. 98). Most salient for this work, MacIntyre (1982) credits individuals as active agents in the making and telling of our own

stories, however is careful to emphasize the role of social and cultural structures in what stories or roles in stories are available to us, noting:

> We enter human society... with one or more imputed characters—roles into which we have been drafted—and we have to learn what they are in order to be able to understand how other respond to us and how our responses to them are apt to be construed (p. 201).

As the Self continues to develop and we tell and retell the stories of which the Self is comprised, we lose touch with the story as it happens (Vice, 2003). We may be so immersed in living that our vision of our identity narrows. For self-analysis to occur, it generally requires some type of stimulus, typically an important person or major event to halt a person's story in-progress (Leary & Tangney, 2011). The individual pauses to consider their thoughts, pasts, and futures, rather than focus on the act of being (Hogg & Terry, 2000). It is in these paused moments, moments like participating in a life history interview, that an individual might think about how they have acted and the contexts in which they acted. They reflect upon the stories which developed their Self and while retelling their stories, they reinforce or refine their Self (Frank, 1991).

The Use of Disability Memoir to Represent Identity

If narrative inquiry is a researcher's method to collect data using texts created by participants, memoir in research can be considered one form of participants' claim to ownership of their stories. Framing research texts as products in their own rights re-centers the purpose and meaning of why and how texts are used. Memoir is art for art's sake. If disabled people choose to generate memoir, it is their choice and the decision to contribute it to research is a separate one. But memoir offers more to narrative inquiry than simply a paradigm shift. To read memoir "is to witness a self-watching himself, herself, and a theater of the author's own making, but also, spies

and stalkers that we are, to catch oneself being exposed in our assumptions, our desire, our fears" (Mintz, 2012, p. 438). In this way memoir is both a tool of authority over self-expression and an effective research vehicle. I draw much of my review of literature from Couser (1997, 2005, 2011), who is widely recognized as a leader in the analysis of disability life writing.

First, it is important to understand the work that disability narratives do and particularly the social significance of life writing. Drawing from Garland-Thomson's (2007) description that disability narratives "do cultural work. They frame our understanding of raw, unorganized experience, giving it coherent meaning and making it accessible to us through story" (p. 121), Ferri (2011) explains that as counter narratives, life writing can become a type of social critique. However, to serve this function they must exist in contrast to the overwhelming and rampant momentum of ableist and inspiration-based discourses which surround disability conceptualization and its textual documentation (Couser, 1997). To transform the individualized and victim-focused reception of disability narratives, they must become "more dispassionate and more political...and instead of 'why me' it [the message] should be 'why us?'" (Couser, 1997, p. 75). This message is often lost or understated in disability narratives, especially longer narratives like memoir, because the opportunities that disabled people have to write often coincide with convalescence after an event that causes impairment or some other disability or illness-related incident. The danger in these circumstances is that the writer may be presently faced with sudden bodily change, perhaps pain, and is justifiably self-absorbed, which naturally can be part of the disability experience, but does not represent all experiences. Reflections of these circumstances emerge in some disability texts and contribute toward an already-entrenched medical discourse (Couser, 2011). In truth, the disability experience varies and these variations deserve representation and recognition.

An autobiography attempts to relate the tale of most or all aspects of a person's life, while a memoir focuses on singular aspects of or episodes in a person's life (Smith & Watson, 2010). Disability memoirs can become unrelentingly consumed by the topic of disability and when it does, it dismisses the holistic Self and begins to objectify the person as their disability (Couser, 1997). But a more complete disability memoir, with its portrayal of everyday occurrences, comic relief, aspirations, relationships, and any other seemingly, though not actually unrelated aspects of personhood, allows the text to "deflect the gaze from the body that might otherwise trigger stereotypical responses...[and] may enable individuals to cross back over the border into the mainstream or, better yet, to cross out—or at least blur—that border" (Couser, 1997 p. 182). Kuusisto's *Planet of the Blind* (1998) is an example of the kind of memoir Couser describes. In his book, Kuusisto describes his own evolving relationship with blindness while negotiating a context steeped in the prevailing blind-role discourse, thus maintaining a powerful yet whimsical interplay between personal narrative and disability rhetoric. Linton (2006) provides another example. In her book *My Body Politic: A Memoir*, she forges her own treatise about identity processing and her transformation into a disability studies scholar and activist after a car accident. These are simply two examples of a burgeoning genre of published memoir.

Because disabled people communicate in multiple and diverse ways, our assumptions around modes of creating a memoir must be more fluid. Baggs's (2007) aesthetic and sensorial video docu-memoir offers one example of a different mode. Her lyrical monologue haunts the audience, not in relation to her disabilities, but in its solicitation of and demand for transformative language, expression, Selfhood, and dignity, creating a text that is both artistic and discerning. Like I mentioned in Chapter 1 Mukhopadhyay (2011) chooses an alternative mode or representation. While a portion of the text is standard memoir, how he shows the

intricacy of his experiences is through poetry, which weaves language, frustration and beauty into one. He then transforms the text into a series of personal poetic verses. In their more ethereal disclosure of his narrative, these verses seem to eradicate the envisioning of what a memoir is or supposedly should be. Mukhopadhyay (2011) writes:

> I know my name since that moment Who he was I do not know, as he had gifted me just this mind. I cannot see or talk. So I could never ask anybody who he was. Yet I can imagine. I can hope and I can expect. I am able to feel the pains that I cannot cry. So I just be and wait for the pain to subside. I can do nothing else but wait. (p. 168)

All at once, he communicates the difficult beauty of his experience, the intricacies of documenting a memoir when the body and mind do not work in sync, and a lyric disclosure of his own understanding of Self.

Many disabled people have chosen memoir as the mode via which to tell their stories and these memoirs are well represented in publications (Couser, 2011). Adams (2002) found that about a third of two-hundred recently published memoirs focused on the topic of disability. However, researchers must pay attention when they study memoir, because memoirs are often constrained by narrative structure associated with writing about the whole life (or long periods) (Frank, 1991). Writers know that stories have a beginning, middle, and end. They know what makes a good story, including deep description and building to a climax. These strategies do not always mimic reality. Further, chronological memoirs can frequently undermine the author's authoritative right by providing the reader with deductive knowledge about what is to come (Couser, 1997). When readers are furnished with tidy sequential formulaic narrative, they quickly understand that the writer has survived to tell the tale (and has succeeded well enough to participate in authoring memoir) and readers can easily predict the upcoming resolution (Couser,

1997). This implies a comfort and omniscience that the author never had during the events they describe. Chronology communicates a distinct linear coherency that does not mimic life as it is felt, and just as the writer manufactured a beginning of that line, so they must also manufacture an end. But lives don't end, not in this literary sense anyway, so the author is most often coerced by their narrative into tying up loose ends as closure, expounding external indicators of triumph which relate that the character is "okay." An ostensible listing of these achievements (e.g., a marriage, a job, a book) as a means of conclusion debases the process of life with a disability, shifts the locus of control from the self onto meritocratic measures (Scott, 2005), and grants the reader a far too complacent sense of moral rectitude simply for having read the book.

If, instead, memoirists shift between time periods or abandon chronology all together, it may be possible to generate some measure of contingency and disequilibrium, which communicates those aspects of lived experience and discharges authors' obligations to end-cap their narratives. Utilizing vignettes across Narrators and across timelines addresses this concern about omniscience and obligatory scenes. In this dissertation, the Narrators and I document experiences and within those experiences I discuss commonalities. The memoirs that Narrators wrote for or during this dissertation (see Chapter 3) may or may not ultimately be placed in chronological order. That will be the decision of each Narrator, but for research purposes, I resisted representation of chronological events.

Conclusion

I began this chapter by defining identity. Jenkins (1996) defines identity as "the ways in which individuals and collectivities are distinguished in their social relations with other individuals and collectivities" (p. 4). I described how the identity is comprised of three facets: political, cultural, and personal (Almerico, 2014; Fearon, 1999; Wren, 2002). Disabled people's

(and other people who are stigmatized) identities develop within contexts that often render them less than human (Goffman, 1963). It is from this subjugated position that disabled people have come together and have fought to claim their right to equality (Charlton, 1998; Fleischer & Zames, 2011.) Studies of the disability identity seem to be focused on this fight or the political nature of the identity (Barnes, 1999; Brown, 2002; Brown 1995; Cameron, 2013; Dunn, 2014; Evans, 2013; Gill, 1995, Hahn, 2002; Hahn & Belt, 2004; Mollow, 2004) leaving the personal and cultural components of identity neglected.

I also discussed how narrative and memoir can represent disabled lives. Narrative represents our lives and our lives are how they are told (Bruner, 1990). Memoirs are a popular form of disability narrative (Adams, 2002). When memoirs are written in particular ways, they can communicate "why us" rather than "why me" (Courser 1997, p. 75). The authoring of memoir was a priority in this dissertation. Refocusing on "why us" is precisely what this dissertation intended to accomplish, because the disabled identity continues to exist as "other" and the study of it continues to focus on the fight against being an "other."

Chapter 3

Methodology

In the previous chapter, I discussed the existing literature regarding disability identity, the narrative view of Self, and the theoretical foundations of this work. This chapter outlines the methodological decisions and procedures utilized in this research. This chapter begins with a rationale for this research and the questions it addressed. As an emancipatory research project, it was integral that the Narrators and I maintained an awareness of the ongoing benefits and risks. I review the tenets of emancipatory research and how I implemented them in this research. Following this section, I discuss my decisions to use narrative analysis, which includes life history interviews. Next, I discuss my methodological procedures. I outline the criteria for Narrator recruitment and selection. I then describe how I generated data and the multi-step thematic coding strategy I used to analyze the data. Next, I describe how my chosen method and philosophical position shaped how I represented the findings. I conclude with a statement detailing my own subjectivity as it relates to this study.

Rationale

The moments in the Narrators' lives, as well as my own, affect each of us in a myriad of ways, which are often (and perhaps unknowingly) simultaneously positive, negative, and everything in between. Our identities are an astoundingly complex creation of experience, need, comfort, personal decision, context, influences from our environments, the interplay of various identifications, and the synergy of these all including an incalculable number of individual variables. Our moments are our own and no matter what the nature of the social institutions that reign over us, we maintain a degree of agency. The answers to the question "What is disability identity" are necessarily messy and unclear, because lives, unlike manuscripts, are messy and

unclear. I sought to gain intimate understanding of individuals' view of disability identity through a process of creativity and reflection, understanding that each reader may find personal meaning, applications to their own practices or lives, or challenge the conventions of knowledge and its making.

Because the disability identity is complex, choosing how to do research about it was also complex. If I selected a strict methodological approach that didn't permit for individuality of Narrators, the richness of my research would be limited and voices of the Narrators constrained. Much of the previous research about the political disability identity isolates it from the participants' personalities as if, as readers, we are seeing one piece of a jigsaw puzzle. Instead, I chose to follow the needs and desires of the Narrators, so I could obtain a higher quality of data, but also because it permitted me to capture on paper the Narrators as people. Seeing the people involved allows us to see the messiness that is inherent, which resists prescribed rules, perhaps especially when considering Narrators' political identities. The Narrators contradicted themselves, hemmed and hawed, and expressed every emotion from ambivalence to despair to anger. The political disability identity is not just a corner of the Narrators' brains controlling their thoughts and actions, but is tethered to all aspects of their being. This is what this dissertation provides, a glimpse of the political disability identity as it is *lived*.

Given my discussion of the messiness or complexity of disability identities and that scholarship often focuses primarily on narrow views of political identity, my study sought to broaden and contextualize disability political identity as generated by disabled people in and through narrative. To gain clarity about disability political identity as something that develops and changes across time and context, I necessarily had to spend a great deal of time with Narrators and chose life history interviews as a mode of data collection. I understood that it was

important that we become comfortable with one another. In that comfort and time, we could

begin to see through the mess. Narrators had the time to tell all the standard stories they tell

people, but then dig deeper into moments they normally might not disclose, but that ultimately

created the richest data. Because we needed the time to develop this kind of relationship, I

expected to conduct quite a few hours of interviews. In the end, I conducted approximately 100

hours of interviews.

Thinking only about the *amount* of time spent together with Narrators was inadequate. I

also felt that Narrators needed multiple ways to communicate with me so that I didn't

misinterpret information and because different types of data likely would yield different

information. Further, I anticipated that talking or standard interviewing might not always be the

preferred method of participation for some Narrators due to their personalities or various

disabilities or communication styles. In Chapter 2, I discussed memoir or life writing as an

effective way of representing disability identity. I aimed to use memoir writing as a data set that

both enriched the life history interview data and provided a space in which I could capture and

represent Narrators' authentic voices. I understood that multiple sources of data would lead to a

more complete picture of Narrators lives and was, thus, an appropriate choice of analytical tools

(discussed below).

While I had established a multi-pronged method to get a glimpse at the disability

identities of the Narrators, in thinking about the mode of analysis, there seemed to be something

significant missing. I was missing the "Why?" Why does the disability identity matter and why I

am studying it? Very early on in the development of this dissertation, the answer came to me.

We know disabled people are an historically oppressed population and continue to feel the

effects of ableism in a multitude of ways. Given this context, I was compelled to ask how do

disabled people become themselves? What did living in a society that frequently pushed them into the sidelines mean for their thoughts, actions, and Self-understanding? There was one last consideration that I felt compelled to include. In the development of this research, I recognized disablement as a critical part of this study. Consequently, I felt a responsibility for this study to give back to the Narrators who participated in as substantial ways as I could, which I describe in the next section.

Emancipatory Research Methodology

In the rationale above and throughout the research, I frequently discuss the Narrators as knowledge makers. I felt it was crucial to the field of disability studies and to the authenticity of this type of inquiry to participate in a radical shift about how scholars conduct research with disabled people. Much of the scholarship "about" disability has been criticized as misguided efforts to "help" or "cure" disabled people, motivated by fear, pity and assumptions based in deficit models of what it means to experience disability and yet, doesn't consult disabled people or include them in the research process (Charlton, 2006; Oliver 1992; Petersen 2011; Shapiro, 1993). In the realm of qualitative research, scholars note the tradition of stories being told *about* disabled people, privileging the voices of parents or professionals, as opposed to disabled people themselves (Ashby, 2011; Biklen, 1988; Biklen & Duchan, 1994; Blatt, 1981; Bogdan & Taylor, 1976, 1994; Kliewer & Biklen, 1996).

To respond to warranted criticisms of traditional research "about" disability as "a violation of their [disabled people's] experience, as irrelevant to their needs, and as failing to improve their material circumstances and quality of life" (Oliver, 1992, p. 105) emancipatory paradigms have received due attention. Drawing on Barton (1996, 2005) and Oliver (1992, 1997), Petersen (2011) defines emancipatory research methods as "empowering individuals with

disabilities by employing the expertise of the researcher to collaboratively carry out the goals and aims of individuals with disabilities" (p. 294). Scholarship that aligns with this framework must embody the three fundamental principles of reciprocity, gain and empowerment, and the involvement of participants in the research process as a way to create balance and ultimately share power between the researcher and the researched (Petersen, 2011).

As noted in Chapter 1, I attempted to develop an emancipatory inquiry from the very start of this work rather than trying to retrofit a methodology. Scholars before me guided the development of this study, but it was the Narrators who molded the method as we proceeded. Emancipatory research seeks to shift power, control, and benefit about and from research from the researcher to the participant (Oliver, 2002). The pursuit of knowledge and the often intangible or relatively minute social change that research achieves often leave the individuals who participated in research feeling "ripped off" (Oliver, 2002, p. 15). Shakespeare (1996) questions the possibility that truly emancipatory research can exist since the researcher always stands to gain prestige compared with the participants' little benefit. Therefore, I understood that I needed to be innovative and ensure my modifications to standard methodologies were not only symbolic. I also accepted I was possibly pursuing a myth, but had to try nonetheless. Finally, I had to consider what responsibility I had to myself and to disabled people as a group to address how the concept of emancipatory research applied to me as a researcher with disabilities.

I feel it is important to begin any emancipatory research discussion by remarking on the use of terminology. Bogdan & Biklen (2003) describe the life-history interview as a form of case study in qualitative inquiry. The purpose of a sociological qualitative case study is for the researcher to better understand the existence or effects of various institutions. However, the mention of the case study can conjure various alternative meanings by both the disability studies

scholar and disabled people. It is a broad term employed not only by qualitative methodologists, but also by quantitative empiricists, mental health professionals, and medical personnel. With the term's ambiguity and the frequent historical (and even contemporary) exploitation and abuse of disabled people in many schools, hospitals, institutions, and in research, I rejected any framing of this work that might connote injurious intent or messages. Therefore, rather than "participants," I used the term "Narrators," according them with their due authority.

My method utilized Petersen's (2011) model of reciprocity, gain, and empowerment. I addressed reciprocity by positioning myself in a similar role at the Narrators. I understood that participating in this research, Narrators were vulnerable. They relayed personal and sometimes difficult moments in their lives to a stranger and wondered what it would be like for their life histories to be displayed to the public. Therefore, I reciprocated what the Narrators offered. I shared stories with them and included reflexive accounts in the research manuscript (see Reflexivity). I developed the research around the objective of memoir writing to address equitable gain. Narrators received an audience, organizational assistance, feedback, and encouragement to develop the memoirs they already began or wished to author (see Narrator Recruitment and Narrator Compensation and Risks). The research served Narrators' needs, which were independent of the research objectives. Finally, I addressed empowerment. Narrators participated in discovering and documenting multiple critical moments in their lives that represented the three components of identity (political, personal, and culture). I analyzed only the political facet of identity, thus will refer to only that from this point forward. I provided Narrators ample time to revise any memoir contributions they made to the research and we reviewed everything I wrote about them. They maintained the right to suggest changes until I submitted the first draft to my dissertation committee and they took advantage of this authority

(see Data Collection and Data Analysis). I provide a thorough discussion of my emancipatory research objectives in Chapter 7.

Narrative Methods

Selecting the research methods I implemented in this research was a process. I began by choosing life history interviews, an approach foundational to sociological research (see Bertaux, 1977; Thomas & Zaniecki, 1918). Sociologists view life history methodologies as intersecting history and biography, which through personal experiences represent sociological phenomena (Mills, 1959). When research tethers multiple individual narratives to a collective narrative, sociological meanings begin to emerge (Berger, 2008). Disability studies scholars recognize the value of life histories, understanding that life history methodology acknowledges individual agency and provides access to perspectives that are frequently marginalized and which have few venues for circulation, especially in ways that are accessible to disabled people (Perks, 1998). However, stories themselves provide limited meaning, but if they are one kind of data that contribute toward a larger set of data examined together, researchers can recognize patterns and interpret those patterns using various theoretical lenses (Sparkes, 2002). The life history interview is the scaffold on which qualitative researchers can introduce other texts (e.g., images, documents, journals) to enrich and corroborate data, which together create a complete narrative (Chase, 2005; Clandinin & Connelly, 2000). This process of collecting multiple data is one form of narrative analysis.

Narrative analysis is a process of understanding how people, as social actors, perceive and represent their reality (Dorries & Haller, 2001). Recently, disability studies scholars have taken advantage of this method because it provides evocative data and is flexible (Goodley and colleagues, 2004; Lucius-Hoen, 2000; Pearce, 2006; Smith & Sparkes, 2005; Todd, 2006). I

chose the method of narrative analysis because I felt it would be the most effective method to construct a multifaceted and authentic representation of disability identity told through the perspective of the population the research represents. Developing the narrative through both interview and reflective writing enriches the data (Reissman, 2000). In other words, multiple modes of collecting data that included both immediate and reflective processes, created rich data. Not only this, but narrative analysis recognizes that storytelling is a performance and the analysis of data considers what performances "do" (Reissman, 2003; Sparkes, 2002). Integral to narrative analysis is the premise that how a person tells his stories is as important as what his story is (Esterberg, 2002; Reissman, 1993).

As I continued to plan this research, I recognized how well narrative analysis could serve the Narrators and used it to varying degrees. It was important to me for Narrators to communicate to me in any way they felt most comfortable, both for the documentation of their memoirs (including the critical moments) and for the interviews. It was also important that they could ask me to communicate in various ways to them. For example, one Narrator did not read or write, so she chose to paint pictures and describe them to me. Two other Narrators typed to communicate both in real-time and typed and emailed. I provided information and questions in spoken and written forms. For all participants, I communicated to them in the beginning of the research that we could proceed to collect data in any mode, and change as necessary. We did. One Narrator sometimes typed live and other times emailed texts to me. The inherent flexibility, trial and error, and universality of narrative inquiry empowers participants to respond in the ways they feel most expressive and confident, assuming the researcher is receptive to feedback and allows for a mutable distribution of types of field texts, thereby preventing the format from hindering the story and increasing research fidelity.

Lastly, in contrast to data collection that only utilizes verbal and performative modes of participation, contemplative authorship allowed for a more lyrical and engaging representation of the Narrators' life stories. Kuusisto (2005) explains that "claiming disability requires claiming the lyric. If people with disabilities have been exiled by history, by the architectures of cities and the policies of the state, then the lyric and ironic form of awareness is central to locating a more vital language. The lyric mode is concerned with momentum rather than certainty" (p. 161). The selection of a method that incorporated memoir permitted Narrators additional reign over their stories, access to intricate portrayal, and claim to how they wished to be represented.

Research Questions

This research examines the political disability identity of nine disabled adults by using life histories and memoir, focusing on critical moments in those memoirs. My research questions included:

1. What are the political disability identities represented in the narratives of nine disabled people?

2. How did these disabled people enact their political disability identities?

Research Design

I conducted this dissertation from July 2015 until August 2018. In December 2015, my dissertation committee approved a draft of the introduction, literature review, and methodology. In January 2016, the Syracuse University Institutional Review Board approved the research and Narrator recruitment began. Recruitment and selection of the Narrators lasted approximately ten days. For the next fourteen weeks, I collected data, meeting with each narrator roughly twice a week. In April 2016, I completed data collection and by May 2016 completed data analysis. I submitted dissertation chapters periodically, completing the first full draft of the dissertation in

November 2016. Assessment and revisions of the dissertation took place over an additional two-year period.

Narrator Recruitment

I began my recruitment of Narrators by generating printed fliers and an email advertisement (Appendix C). I contacted various professionals with whom I was acquainted asking them to disseminate my advertisement on bulletin boards, newsletters, listservs, and social media sites. About half of the twenty contacts I had were associated with organizations that serve disabled people. Within a few days of releasing the call for Narrators, fifty-five people responded, many originating from a single listserv.

I asked each of those responding to my call several questions followed by a longer survey. The initial questions were related to primary criteria and included asking if the volunteer was over the age of eighteen, identified as a disabled person, and if they had plans to write a memoir about their experiences as a disabled person. The nature of their disability labels, whether they were self-defined, medically ascribed, or designated by some governmental social service was irrelevant. As an inquiry focusing on disability identity, it was important to me to prioritize the definitions and perspectives of disabled people. I also provided a summary of the research process. At this juncture, sixteen volunteers chose not to participate. For the remaining thirty-nine volunteers, I provided the brief survey (see Appendix D). The purpose of this demographic survey was to aid in the selection of a diverse sample. The questions in the survey focused a great deal on socioeconomic status indicators, because I originally considered socioeconomic stratification a significant part of this inquiry. Once data collection was well underway, the data suggested shifting away from a focus on any one aspect of identity.

Using the returned surveys, I selected nine volunteers who represented the broadest

sample of identifications, including: gender, disability, socioeconomic status and background, race, ethnicity, and sexual orientation (Table 1). I met with these nine volunteers either in person, on the phone, or on internet conferencing. They all had copies of the consent form and we discussed each aspect of participation. We discussed the research as a type of collective memoir and how the process of documenting life histories and portions of memoir would be arduous, but hopefully rewarding. I selected six of these volunteers to participate. One of the volunteers I selected saw the call for participants on an online disability group. We had known each other briefly through mutual friends when we were teenagers. Her interest was earnest and her story was intriguing, but most of all I had a feeling she needed someone to listen to her. I selected her.

Of the fifty-five people who responded to my call for Narrators, all but one identified as female and Caucasian. I attempted to address this and sample a more diverse population. I asked Narrators to forward the call for participants to anyone they thought might be interested. I sent the advertisement to my colleagues and acquaintances. In all cases, anyone interested was asked to contact me directly for information. My extended search yielded two additional Narrators that identified as male, which further contributed toward a diverse sample. I had briefly known both males, but lost touch with them some time ago. Aside from adding diversity both in gender and disability, both exhibited great enthusiasm toward writing their memoirs, which convinced me they were a good choice for the research. My sample included a broad representation of categories of disabilities and socioeconomic backgrounds, but race and nationality were limited. While searching for more Narrators, an ASL interpreter working with me mentioned that she had an aunt with a disability who had been talking about writing her story for decades, but needed assistance to document it. Soon after telling her aunt about the project, I had a phone conversation with her and we both quickly came to understand that she (sometimes he) would be

a wonderful fit for the research.

I then contacted the nine Narrators I had selected to discuss the project and began the consent to participate procedures, which included Narrators having time to consider the project and seek out the advice of people they trusted. Narrators learned that they would participate in life history interviews. Each Narrator met with me on several occasions for about 90-120 minutes per meeting. When taken together, the life history interview process resulted in about 10-12 hours of interviews for each participant. The nature of the method is such that one life history interview logically required 10-12 hours of contact time each. Narrators could participate however they preferred and change their mode of participation if they wished. Two Narrators chose face-to-face interviews. Four Narrators talked to me using the phone. One Narrator chose a combination of phone interview, live interview, and shadowing. Two Narrators chose to type their responses to me and did so in both real-time and through email. Nearing the end of the process, we would work together to locate and select critical moments in Narrators' identity development to document in memoir or revise from existing memoir. All but one Narrator chose to type their memoirs. One chose to paint and take pictures. I outline the benefits and risks to Narrators in the next section. Due to concerns about preserving anonymity, one Narrator and I decided it would be best that she withdraw from the research.

Table 1

Narrator demographics and mode of data generation

Narrator	Gender identification	Sexual orientation	Disability	Education/income	Mode of participation	Number of hours interviewed	Number of interviews/communications
Latefor	She Guy Man	Asexual/heterosexual	undiagnosed "retarded or dumb" (self-report)	High school, no diploma/ <$10,000	Face to face interview, shadowing, painting, photography	9	3
Bryluen	woman	bisexual	multiple	BS degree/ <$10,000	Typed conversations, writing	NA Bryluen typed asynchronously	>30
Flora	woman	heterosexual	multiple	High school diploma <$10,000	Phone interview, writing	11	5
Jo	woman	heterosexual	dissociative identity disorder	BS degree $40,000	Face to face, writing	15	6
Felix	man	heterosexual	Hemiparesis, orthopedic	MS degree <$10,000	Phone interview, writing	10	5
Allister	man	heterosexual	Orthopedic, learning disability	BS degree <$10,000	Typed conversations, writing	NA	>30
Gail	woman	pansexual	polio	Ph.D. >$100,000	Phone interview, writing	15	7
Stephanie	woman	heterosexual	spina bifida	MS degree $35,000	Phone interview, writing	10	5
Tim	man	heterosexual	traumatic brain injury	MS degree $38,000	Phone interview, writing	11	5

Narrator Compensation and Risks.

In aiming to design the study with elements of emancipatory research, I sought to accord Narrators comparable benefits and risks to those I also assumed. While there was no monetary compensation for participation in this research, given the extensive and intimate nature of the work, Narrators gained access to a dialog that many described as productive and cathartic. Because a desire to document and disseminate their lives was a criterion for participation, we talked a lot about memoir and ultimately they all made progress in the pursuit of its documentation. Beyond a mode of collecting data, life history interviews served as a way for me to help Narrators develop outlines for their memoirs. I assisted Narrators in breaking down what often felt like an overwhelming project into smaller tasks and we discussed how to prioritize those tasks. Once they generated a portion of memoir, they sent it to me and I provided feedback about my experience reading it. I then provided questions about what I read and highlighted aspects that I did not quite understand. Often, I encouraged Narrators to "take me to the moment rather than reflect on the moment." Frequently, Narrators told me that simply knowing I was waiting for them to generate memoir motivated them to produce it. At the completion of this research, I offered to provide Narrators with six months of further support, in the form of meetings, discussion, and feedback as they continued to write their memoirs.

Narrators, as well as the researcher (or myself), exposed ourselves to several risks. Life history interviewing and memoir writing is necessarily intimate, in ways that have the potential to make us vulnerable. The potential for emotional as well as physical fatigue due to the lengthy research process was substantial. For this reason, Narrators could exit the research at any time without penalty. Narrators also dictated the length of each interview meeting. I did everything I could to anonymize the Narrators. I removed identifying information and applied pseudonyms

for all names. Still, the possibility of being identified exists. The risk associated with being identified include increased stress on any relationships mentioned or not mentioned in the text or perhaps unforeseen problems at work, school, or in the Narrators' communities.

Data Collection

In this research, I collected four types of data, including life history interviews, Narrator-generated memoir, reflexive notes, and portions of my own memoir. Guided by other researchers (Bertaux, 1977; Bogdan & Biklen, 2003; Chase, 2015; Clandinin & Connelly, 2000; Polkinghorne, 1995; Reissman, 2000; Thomas & Znaniecki, 1918), I conducted life history interviews with Narrators as a mode to develop, inform, and contextualize other aspects of the data. In this research, I developed the narrative by using life history, memoir, and reflection on both of these (see Data Analysis for discussion of narrative analysis). I used semi-structured interview questions (Bogdan & Biklen, 2003) to begin the life history interviews with Narrators (Appendix B: sample questions), but then let conversation occur naturally, with the Narrators leading the way. Next, I encouraged Narrators to guide the direction of the interviews (Bogdan & Biklen, 2003). As a life history, Narrators intuitively discussed their experiences in chronological order (Frank, 1995; Goetting, 1995), but I encouraged Narrators to discuss whatever was important to them at any point. After each session, I immediately drafted field notes and reflexive notes, highlighting information, documenting non-verbal data, posing questions to direct the next interview session, clarifying statements, and further detailing the session.

I conducted the interviews in a private room selected by the Narrator or at a location which was amenable to the Narrator. When using Skype internet conferencing or the telephone, both the Narrator and I confirmed that no other people were in our rooms (except any required support personnel) as a way to maintain confidentiality. During each interview, two certified

American Sign Language interpreters were present as an accommodation for me as well as any personnel required by the Narrators. This type of interviewing and document inquiry was time consuming. For this reason, the length and number of sessions was determined by the Narrators in appreciation of their individual scheduling requirements and levels of fatigue, which may or may not have been dictated by their disabilities. Two Narrators asked to conduct their interviews through typed messages as an access need. These interviews entailed both short, live interviews and long emails we sent back and forth. While I began data collection with Latefor over the phone, it was an ineffective mode of communicating with her. She invited me to her house where she showed me rather than told me about her life. She showed me photos, objects, clothing, paintings, and took me to significant locations around her house.

I took lessons from Reismann (1993), who learned in her research on divorce that people resist the fragmentation of their stories into codeable, easily organized snippets, because that is not how natural conversation occurs (Mishler, 1986). Therefore, except for some initial semi-structured questions to get started, I entered each interview session with flexible objectives and tried not to insinuate a structure to our conversations. Narrators tended to start their life histories by talking about their high school years, and so that is where we started. I encouraged a natural conversation that moved through time, but also fast-forwarded and rewound frequently. Generally, I asked questions like "You mentioned your family didn't much like xxx. Tell me about that." I then sat back and enjoyed the Narrators' stories. I wrote down key words or short phrases to remind me to ask Narrators questions whenever they paused. Occasionally, when Narrators ran out of things to say and I ran out of questions, I guided the conversation toward other aspects of the Narrators' lives. Very quickly, I began to look forward to these conversations and to me they felt like I was catching up with old friends.

I conducted a total of 36 interviews plus countless email correspondences, generating approximately 10-12 hours of life history interviews for each Narrator and totaling about 100 hours of interviews, but these interviews generated only part of the data corpus. All along, I encouraged Narrators to write, paint, or record portions of the memoirs they wanted to author. The Narrators and I informally exchanged pieces of narrative we were currently working on to build rapport and help generate conversations during the interviews. Creating a community for memoir authoring, after all, was important to my philosophical approach to this inquiry. Collectively, Narrators wrote or revised approximately 600 pages of memoir, six paintings, and seventy-three photos in this process.

Working with Narrators was a pleasure. Interviews were typically natural and flowing except where I have noted. I asked Narrators semi-structured interview questions. They talked or typed, generally answering the questions and then guiding the conversation in directions they felt were important. When they reached a natural end-point in a discussion, I asked follow-up prods based on statements they made or asked my next question. Memoir documentation varied from Narrator to Narrator. At the end of each interview, four Narrators reviewed with me what they thought they would write about during until I next saw them. Sometimes they asked me what I thought they should write. I resisted answering, but sometimes mentioned stories they had repeated or that seemed to be important to them as good topics. Other Narrators were more independent and even took their own notes while conducting the interview about topics they wanted to explore in their writing. Throughout the weeks, Narrators and I exchanged pieces of writing, paintings, or photographs and discussed them primarily thought email. While I did not provide content-based feedback, I told Narrators how I felt when I read parts of the memoirs. I asked questions like "Does the second paragraph on page two mean…?" and "Can you tell me

more about how you felt at that exact moment. The way you wrote about it suggests it was an important event. Tell me more about that. Slow time down." I approached discussion of memoirs much like standard approaches interviewing. I asked open-ended questions, asked for clarification, and tried not to impose meaning on their words or images. I encouraged them to further explore what they created of to move on to other topics when they felt they had throughout exhausted one. Discussions about memoir documentation also served as a form of member checking. I asked questions like "So, I should understand that to mean…" or "In one of our interviews, you said [insert statement]. Is this connected to that?" These served as ways to improve my process of interpreting and understanding how Narrators communicated, what I understood, and provided opportunities for the Narrators to correct any errors. After I completed the dissertation, I encouraged Narrators to read the dissertation and provide suggestions for revisions to ensure I did not misinterpret things they communicated. I showed them how to search for their names so they did not have to read the entire document if they didn't want to. For Latefor, since she didn't read, she asked her sister to read the content to her. All but one Narrator provided some feedback.

I electronically audio recorded every time I met with Narrators. I immediately sent the file to a professional transcription agency after each session. Prior to the next session with any Narrator, I reviewed the previous transcripts, writing questions, noting areas of interest, and locating statements that required additional discussion or detail. The field notes and transcript review served as a data generating tool for the next session, while still permitting Narrators the freedom to reflect as they wished. I transferred all audio files to my laptop computer, which was password protected and I encrypted the specific files. I kept these files for a period of six months after the completion of research, at which time I deleted them. Only the transcription agent and I

had access to these files. All contracted services are professionally bound to confidentiality and signed a confidentiality statement.

As the research relationship continued to develop and I gained an increasingly substantial awareness of the Narrators' lives, the Narrators and I began to discuss what we felt were critical moments that influenced or effectually demonstrated a given Narrator's identity-in-process. This marked significant moments in our research relationships. Narrators began to shift away from only having roles as data sources. I conducted a cursory review of interview transcripts to note events that Narrators referenced frequently or about which Narrators were passionate.

In our second to last interview, we further discussed the instances I thought the Narrators were passionate about, sometimes discovering they were not significant after all. Narrators remembered other important moments in their lives, which they discussed, and sometimes they remarked about critical moments in their creations of Self, that I had overlooked. At the end of what we felt was the life history interview, I asked Narrators about their political identities and what that meant. While still together, we thought back to some of the politicized events they discussed in previous interviews to initiate conversations about this facet of their identities. Narrators had the task of thinking about moments that had big impacts or forever changed their lives. They thought about these moments and many continued our conversations through email. I, too, went home and read through interview transcripts and fieldnotes highlighting possible critical moments in political disability identity. I primarily did this by looking for stories they repeated or selecting moments when Narrators were impassioned discussing them.

In our final face-to-face interview, Narrators and I discussed the critical moments of identity development they selected and the moments that seemed to me to be critical. Juxtaposing these served as discussion starters. When we picked the same moment, the Narrators

often expanded: "You should have been there…" providing more detail. When we had different ideas, Narrators often justified why they picked their moment, which also communicated to me more about the events. We continued these conversations until the Narrators were certain what critical moments they wanted to document in memoir for each identity category. I never justified the moments I selected and Narrators universally selected their own critical moments. Of the nine critical moments, we picked six of the same ones and three were different.

Narrators returned home and set to work. I did not inquire whether the Narrators had already authored memoir that contained any of the three moments they decided were critical moments in their disability identity development. I only instructed that each piece of writing could be no longer than two pages single-spaced typed or four images (which might be images of paintings or photographs). I also asked them to be descriptive of their feelings and consider writing as if they were living the moment now. As Narrators completed their pieces of memoir, they emailed them to me. I read them and responded with questions about anything that confused me, how I felt as a reader during various parts, and the general tone of what I felt as I read. This sometimes sparked additional email conversations. When this occurred, I asked Narrators if I had permission to include this data in the research and though I had permission, I did not use any of these data. Five of the nine Narrators chose to conduct revisions on their work after discussing my experience reading it and/or sharing it with partners or other people with whom they were close. The exploration, identification, and documentation of the critical moments of the three components of disability identity development in the Narrators' lives, served as a first step in analysis. In a way, Narrators applied a set of rough a priori codes to their lives and used them to organize and select stories to fit those codes. I felt it was critical that Narrators' have the authority to select these moments as way to increase the validity of the analysis. However, once

the selection and documentation of the critical moments was complete, Narrators did not participate in any further analysis.

While accurate, the data collection process above does not fully encapsulate some of the modification I employed to meet the research participation needs of my Narrators. I had three Narrators who participated in alternative ways: Allister, Bryluen and Latefor. Allister types to communicate, so we sometimes chatted online and sometimes he wrote me long emails. Bryluen's disabilities made her unable to meet and she also has an unstable home life. She chose to write emails, sometimes 30-40 pages long each. We also had a few online chats. Lastly, Latefor and I tried two interviews on the phone, but it was not successful for either of us. She asked if I could visit her so she could talk to me. I visited and ended up working next to her cleaning animal stalls while interviewing. Latefor also does not read or write, but she is a brilliant painter. She chose to paint pictures and take photographs with a disposable camera I gave her to document her memoir. She clearly had already been documenting her life via visual means since about 30 small oil paintings showing her in different times and scenes hung on the wall in her house. All of this is to say, the Narrators were different, thus how I worked with them was different. As I have discussed it above, the description of my data collection accurately depicts the process even if not some minutiae. For example, for someone typing, I had to have four interviews compared to one with someone who speaks. For clarity's sake, I described this as one above. Reference Table 1 for actual details.

Data Analysis

To analyze the data for this study, I employed qualitative thematic coding and narrative analysis (Chase, 2005; Reissman, 2008). I used NVivo® qualitative research software to assist in the coding of data. Thematic approaches to qualitative inquiry traditionally attempt to parse out

small consequential statements or phrases to make sense of vast amounts of data. While coding

in this way is a necessary strategy for drawing connections between data sets and meaning

making, it functionally runs the risk of simplifying very complicated and contextualized

accounts. It was crucial for me to pay due reverence to the writing, painting, and photographs

conferred unto me from the Narrators by preserving their histories in the most intact way

possible; fragmenting them would decontextualize them and risk losing meaning (Reissman,

1993). However, this can make analysis difficult. I compromised by fragmenting the data (e.g.

statements from writing and interviews) for analysis in the findings chapters and then presented

the narrative (photos and portions of memoir) in the Appendix A. This strategy of maintaining

Narrator presence, literary character, and natural poeticism reduced the effects of skewing the

lives of a group whose history is steeped in the marginalizing and oppressive effects of research

and social pariahship. Therefore, my analysis focused on stories co-constructed between the

Narrator and me in their entirety or as much as was feasible. In contrast, I coded interview data

by statement or anecdote, using it to support the analysis of the sections of memoir. In this way, I

considered and juxtaposed portions of the narrative as whole units of analysis and interviews

more relationally through micro coding (Reissman, 1993). Below, I detail how I analyzed the

data.

Four-Step Coding Process

  **Step 1: Identifying critical moments in Narrators' disability identity formation to

document.** In what marked a transitional time in this research between life history interviews

and later interviews, Narrators worked with me to select critical moments in their identity

development. Once the life history interviews neared completion, I discussed with the Narrators

the meaning of the political identity (Fearon, 2001; Wren, 2002). Once they were able to provide

their own definition and an example, our next task was to decide what we each believed might be

a or the critical moment of the Narrator's identity formation. At the next interview, we discussed

our thoughts until the Narrators finally made decisions about the critical moments they felt were

most important to their identity development. Narrators then authored additional memoir, which

captured these moments or revised memoir that already captured the moment. I discussed their

memoirs with the Narrators and asked questions. All but three wrote at least two drafts. One

Narrator (Latefor) took photographs and painted pictures to document her memoir. For each of

these, we had a conversation where she explained to me what we were looking at and what it

meant to her. I asked questions and I used her words for analysis (though represent her art). This

process also supported my use of narrative analysis. Throughout the research process, the

Narrators and I pulled apart and scrutinized their stories. Here the Narrators pulled the stories

back together and prepared them to be analyzed and represented in the dissertation. This

construction of the whole narrative from the various texts used in research (life history and

memoir) is a prime feature of narrative analysis (Polkinghorne, 1995; Reissman, 1993; 2008).

  Step 2: Coding political disability identity development. At this time, I took extended

excerpts from the critical moments, which would be used in the research. Using NVivo

qualitative research software, I coded both the sections of memoirs and life histories using

inductive coding. (Bogdan & Biklen, 2007; Thomas, 2006). I developed three codes around the

development or shifting of Narrators' political disability identities, which I used to represent the

findings.

  Step 3: Coding Narrators' enacting political disability identity. Next, I used inductive

coding (Bogdan & Biklen, 2007; Thomas, 2006) with the life histories, which resulted in the

development of four codes. These represented how Narrators enacted their political disability identities.

Step 4: Developing sub-codes of how Narrators enacted their political disability identities. Finally, I coded the four codes, which further assisted me in organizing and representing the findings. I developed two to three sub-codes for each of the four codes that represented Narrators' enacting their political disability identities.

Organization

I present the findings of this dissertation in three chapters. As mentioned previously, this dissertation includes an analysis of the political disability identities of nine Narrators and how they enacted those political identities. In order to represent a satisfactory account of these features, I selected depth over breadth, saving the remaining features of identity for future manuscripts. In Chapter 4, I introduce each of the Narrators, drawing significantly on their life histories.

Chapter 5 begins with a discussion of the political disability identities of the nine Narrators. I present long excerpts of Narrators' narratives to keep their voices strong in the research, but also to strengthen my analysis, which weaves around those narratives. This discussion includes three themes: 1) A breaking point: Reactions to strangers or acquaintances, 2) Political activism in college, and 3) Changes in lives enabling new perspectives.

Chapter 6 discusses how Narrators enacted their identities. As political people, the Narrators expressed their political disability identities in different ways. In this chapter I discuss these. The findings include: 1) Internalized ableism, 2) Self-to-other ethic of care, and 3) Working for change.

In Chapter 7, I discuss the implications of this research. I begin by reviewing the findings

and the key themes. I discuss the implications of the findings and draw upon the findings of other scholars. Next, I discuss the implication of these findings in today's sociopolitical landscape. I also review my level of success at meeting my emancipatory research objectives. Next, I discuss the limitations of this study and make suggestions for future research about the disability identity. I conclude this chapter and this dissertation with a few final thoughts.

Appendix A includes unadulterated pieces of memoir from Narrators. Narrators included them as a way to show their personality. These narratives are not always connected to disability, but the Narrators as individuals.

Subjectivity

"Nothing about us, without us" (Charlton, 1998) has become almost a colloquialism in disability studies, rightfully and thankfully so. This statement communicates the idea that federal and state policy making must not occur without the feedback and representation of disabled people, and numerous disability rights oriented efforts in private business, social organizations, schools, and academic discourses use this motto as well. Like many, I believe "Nothing about us without us" extends to research too. In research about disability, disabled people must take active roles in development, implementation, and analysis of inquiries to promote careful interpretations of the lives of disabled people (Ferguson & Nusbaum, 2011).

As a researcher with multiple disabilities, I struggle with the concept that my identity as a disabled person alone is sufficient to address the appeal of "Nothing about us, without us." Despite vigilant efforts to avoid a medicalized orientation toward disabled people while conducting disability-focused research, research findings frequently have that quality. Participants in the research, Narrators, bear the burden of vulnerability: disclosing personal moments, thoughts, and bodies, which are then fashioned into a more sterile, affable, and

personally removed manuscript for the public to consume. If I remain silent about or cursorily claim my status as a disabled person, I am complicit in maintaining the researcher/researched canon and thus a certain subjugation of disabled people within the able-bodied nature of academic literature. Therefore, I began the research process by first thinking about an emancipatory methodology and second about research questions.

Despite these very politicized statements, I cannot abide the feeling that disability seems almost universally confrontational. Even describing the benefits, beauty, and culture of disability feels as though it exists as a counter-discourse to the overwhelmingly negative broader discourses in which it is situated. I find it very difficult to accept that such a significant portion of my Self must always be at odds. My work then clearly reflects my objective to undermine the conflict-laden nature of being a member and researcher of a subjugated population, not because those arguments are unnecessary, but because I need more, I am more. My hope is that moving beyond the arguments toward descriptive accounts of lives with disabilities somehow addresses the argument in ways we have yet to discover.

Conclusion

In this chapter, I established how I conducted this inquiry. There are two research questions that I used to guide me toward understanding the identities of disabled people and one additional research objective about creating emancipatory research both for myself and the Narrators. I disclosed my rationale for the research and how I selected the Narrators. The remainder of the chapter detailed the four-step coding procedure I utilized to analyze the data.

After introducing this research, reviewing the literature and describing my methods, I dedicate the remainder of the text to research findings and the discussion of those findings. In Chapter 4, I introduce the reader to the nine Narrators.

Chapter 4

Meet the Narrators

In the previous three chapters, I introduced the dissertation, reviewed relevant research, and described my methodological approach to this research. In this chapter, I introduce the nine Narrators who participated in the creation of this research. For each Narrator, I provide an overview of their life. It is important to me that readers maintain a connection to each of the Narrators, even as this becomes difficult as the research process begins to reorient and analyze each person's life history. I encourage readers to take their time reading the biographical overviews and attempt to forge personal relationships with each of the authors, engraving these biographies into their memories, yet still resisting the concept of "knowing" them. I intend these summaries to act as a grounding for each Narrator's timeline, but it is the histories and pieces of nonfiction that do the real "telling." To aid in the development of these relationships, each Narrator provided a short piece of nonfiction or a photograph that sought to portray their personality or daily lives, without any additional prompt about topic or content. I asked each Narrator to simply tell a story that communicates, "This is me." For some Narrators, this proved difficult, so I asked them instead to state two words that described them and then to document a story that illustrated those aspects of their personality. I encourage the reader to consult Appendix A for these "This is me" narratives to get a fuller picture of the Narrators.

The Narrators

Latefor

The moment I began talking with Latefor, I felt completely at ease. At the end of our very first interview, I said to myself, "She's just lovely." Our conversations were frequently interrupted by her dog, visitors, or her cows and chickens needing attention. Her life of labor,

poverty, and pariahship extended beyond any easy understanding of her experience and it was often difficult for me to feel justified in my conceptualization of her life. Still, Latefor didn't emphasize these things. Her anecdotes were unembellished and untheatrical, and in their modest telling, I felt humbled to receive them.

For most of Latefor's adult life, she never heard her name. Isolated from her loved ones and the community, her husband and his family called her "retard," "dummy," or they simply ignored her existence. When she finally started seeing her nieces and they called her "Aunt ----," her own name sounded foreign to her. I felt troubled disclosing to her that in this research, I would once again have to strip her of her name, though this time for her own protection rather than to erase her. As a meager offering, I asked her to pick her own pseudonym. She replied, "Call me 'late for dinner,' it's funny!" and let out a prolonged chuckle. For ease, and lack of confusion, I abbreviate this title to "Latefor."

Latefor was born, raised, and remains in one of the most remote areas of New England. She is in her mid-60s. As a girl, she spent her days doing chores and mucking out her family's horse stable. Her father delivered milk and her mother cut people's hair in their house. The family's income was limited, but they always had a good dinner of hamburger and potatoes and on Sunday they had a roast or chicken. They grew many vegetables and so they had those to eat, except during the harsh winters. The middle child of three sisters, Latefor had a lonesome childhood. She had no toys, no friends, and her father didn't like her very much, a fact he often expressed. She chose a life out of doors exploring and befriending animals, but mostly she worked. She liked the labor of farming and tending livestock.

School was not easy for Latefor. Teachers and peers called her a retard. After being held back in second grade, she went to a special school, in someone's house with four other children

who were "dirty and smelled bad." She never learned anything there, but she did help to buy a set of clothes for a classmate who only owned one disintegrating dress. At age fifteen, Latefor started working at a farm, taking care of cows. Her day began early with the cows, then continued with school, chores, and then more work with the cows, who became her closest friends.

In order to attend high school, Latefor had to move away from home where she continued to work on a cattle farm to pay for her room and board. School continued to be an unkind place for her. It wasn't until she was in high school that anyone noticed that she could not read or write, so teachers and administrators filled her schedule with study halls, which seemed silly to Latefor since she could not study. Instead, she advocated for herself to join all the shop classes where she was the only female. Though the gendered nature of those classes was not welcoming, she discovered a love of crafting, particularly welding. She exited high school at age 21, never having received a disability diagnosis, even to this day. She simply explains that "I am different" and "stupid," and "people felt like they will die if they came near me."

After her school days, Latefor continued to hone her agricultural skills by taking classes at another high school while still working the cattle farm. Soon she met Jake, a man twenty years her senior with a four-year-old son who was also working the farm. Their courtship moved quickly. Latefor had never dated and he said he liked her and wanted to marry her. She accepted. For the next twenty years, the two were farm workers, contract working at one place and living in its farm house until Latefor's husband decided to quit. Then they would move to the next farm. Latefor said that she was a slave. She cooked, took care of the child, and worked. All the couple's earnings were given to Jake and she never saw a single cent. Jake either ignored her or called her "retard," behaviors his son soon learned to emulate.

Finally, they purchased a home and still worked the farms. By this time Latefor's step-son had fathered a child with his girlfriend and both lived with them. Latefor was a stranger in her own home. Everyone in the household denied that she existed. They wouldn't talk to her or listen if she talked, so she just worked. Six years ago, Latefor's husband died. For some time, Latefor's son-in-law visited; he may have stolen money from her, claiming that he needed her signature of various forms that she was unable to read. Now she lives alone, though her son-in-law has been known to barge in and simply take anything he wants from her home. An additional medical concern that she has is that her retinas recently detached. She has had surgeries, but she still occasionally has difficulties with her eyes. She once fell and broke her arm and now has a "pipe" inside of her. Latefor didn't discover the broken bone for several days, because she felt that she simply needed to keep working.

Forty years being married to Jake and caring for his son was very difficult. Jake was controlling, manipulative, verbally abusive, and paranoid about Latefor's relationships with anyone. If she left the house, he would follow her. He dictated everything from what she could wear to what she was permitted to own, and either could be stripped from her if someone else wanted them. Latefor became increasingly isolated and simply "got used to" her life of invisible and dehumanized labor.

It appears Latefor's position as a calf raiser was slowly eliminated for an unknown reason. When Jake became ill before his death, Latefor went to the unemployment office and soon accessed some social services including training, counseling, and job placement. She now has three jobs washing dishes and working at a secondhand store. These are the first non-farming jobs she has ever had. She has made friends with her co-workers at the restaurant, though they never talk outside of work. When she needs help reading something or figuring out how to do

something, she brings her questions to her friends and they help her, creating a local support network. I asked Latefor to take pictures of things that make her happy and pictures of things that make her sad. Her response was, "Since Jake died, nothin' makes me unhappy, so I can't take them pictures. I will take them cameras you send to work and my friends can show me how to work them." Latefor wants very little more in life than what she has, except perhaps a larger farm so she can have more cows.

Because phone interviews proved to be inadequate, I traveled to visit Latefor. Latefor is a remarkable woman. She is tiny, hard, weathered, and joyous. We chose the picture below (Figure 1) to illustrate Latefor's personality. Also, together we tried to map out what to document in this personality piece, but she candidly stated, "I just don't have a personality. I work." In the end, I believe reviewing her daily schedule is the most justified use of this space, because it is her routine, love of work, care for family, and her animals that so acutely define her.

1:00AM Latefor wakes up and starts a long, multi-step process of making hard cheese from her cows' milk (e.g. Gouda, Parmesan, Romano). She cannot consume all the milk the cows produce, cannot sell it due to health codes, and this is the best way for it not to spoil. Her cheese room has well over 100 wheels aging. She then snoozes on her recliner between production steps and watches classic Western movies surrounded by her cats and trusty border collie.

3:00 AM Bakes bread, pie, or cake.

5:30 AM Latefor goes to the barn, where a radio eternally plays music for her two Jersey cows, two calves, ten chickens, and quarter horse, so they don't become lonely. Like naming newborn children after beloved departed family members, each animal has a family name. They are family. She mucks them out, spreads new sawdust, waters them, feeds them, and milks them.

She completes the routine by patting each animal on the rump, kissing them, and saying something along the lines of "You did okay for me today. I love you. Thank you. Tomorrow will be better. I love you." The cows were hot to the touch, so I asked, "What is the average body temperature of a cow?" She responds "Maybe 300 or 250. I don't use a thermometer. I stick my finger in the mouth and know if they are sick."

6:30 AM Walks the dog up a long roughly hewn road to the "sugar shack" where she often helps the neighbor complete maintenance or boil down maple sap for their syrup business. She checks to make sure that everything is secure.

7:30 AM Goes to work at one of three jobs averaging thirty-five hours a week as a dishwasher and as a clerk at a second-hand store. At the end of the day and from various sources, she collects leftover coffee (for her) and vegetable and grain scraps (for the animals) in countless small containers.

4:30 PM Returns home and stores the spoils of the day and collects various items that neighbors have left for her, which is a sort of an unspoken and untallied agreement of exchange of labor, foodstuffs, and lumber. I noticed a half gallon of syrup that supposedly was "unsellable," but I was skeptical that the statement was true.

5:00 PM A repeat of the tending of the animals.

6:00 PM Completes some other labor, which might include felling trees, chopping wood, moving the manure pile, building a split rail fence, or any number of other tasks.

7:00 PM Eats dinner of un-spiced meat and vegetables.

8:00 PM Goes to bed.

She has one day off a week, so she can get "real work" done.

My visit disrupted her routine because Latefor took the day off to interview with me and teach

me things. Her sister accompanied me, who lives six hours away and Latefor frequently held her hand and kissed it. Simultaneously, she humorously and ironically quipped, "We hate each other" or, "She doesn't like me because I'm a dummy."

I collected the two oil paintings I asked her to paint, which turned out to be five: just one more indication of her unwavering commitment to work. Since she lost a day's income, committed so much time to painting, and sent me home with a sack of her cheese, I tried to compensate her with $80. This would not cover the cost of the cheese alone. Still, she refused. "I live cheap. I don't need money. I'm generous and I am cheap!" I left the money on the counter and replied, walking away, "Please feed the cows for two weeks." She took up the money and disappeared, likely stashing it in some secret trove. When she returned, she gave me a long hug that I authentically appreciated.

"You never stop do you," I suggested.

"No, I work," she responded unfazed.

Flora

Flora is a passionate, artistic punk in her mid-thirties. She is White, agnostic, and heterosexual. We have been acquainted for about fifteen years, though only peripherally through social media for the last ten. She is the older of two children. She lives with a son in his early teens, Clyde. She currently lives in the urban Mid-Atlantic home she grew up in, still owned by her parents, who have moved to a new home in the suburbs. Flora is a great conversationalist, which made the life-history interview fluid and easy to conduct. Her pace, detail, and balance were very National Public Radio. Her stories communicated a well-articulated relationship between fiery, raw inspiration and emotion and the realities of everyday existence.

Growing up, Flora's mother was a college administrator and her father an electrical engineer, which provided the family with a comfortable living and the ability to take frequent, modest vacations. Flora remembered her early years with great fondness, particularly holidays. From an early age, she and her brother were both very artistic. Her brother Justin eventually chose the medium of painting, while Flora selected dance. She attended an art-focused magnet school where she honed her dance skills.

Upon graduation from high school, she went to a prestigious dance college, but her mental health faltered, which did not permit her to continue her studies. Flora left and was never able to return. Soon she married the boyfriend she had been dating and they moved in together. She continued struggling to maintaining her mental health, but worked as she was able. The situation came to a nadir and Flora attempted to kill herself. Diagnosed with Bipolar disorder, she began therapy, but resisted medications, fearing that they would destroy her artistic identity. She and her husband became distant and eventually separated. Flora's self-medicating behaviors were risk-laden including binging on alcohol and unprotected sex. Clyde was conceived with one of her partners.

Flora's relationship with Clyde's father was rocky. She moved out-of-state to be with him where he might find work, but it proved disastrous for Flora, largely because of the isolating conditions she faced taking care of an infant in a new town among a family that treated her poorly. It was also difficult for her to be separated from her very supportive and loving parents and brother. After going back home a few times, she decided to stay and it was around this time she checked herself into a psychiatric hospital for the first time.

Flora finally decided that to be the mother she needed to be, she would have to take medication, even if it meant she might lose part of herself. By age four, Clyde exhibited signs of

Asperger Syndrome including difficulty with social cues, fine motor function, and obsessive behaviors. This was difficult for Flora because she knew the kind of social landscape to which he would be exposed, but she has always cherished and loved Clyde's personality, intellect, and kind nature. Kindergarten was tortuous for Clyde and the development of his Individualized Education Program was delayed, so Flora pulled him out of school and taught him herself. The two created a codependent relationship, which, while serving both their needs, could not and perhaps should not last forever.

Meanwhile, Flora experienced a significant number of physically debilitating conditions which were difficult for her, especially considering her dancer identity. She was diagnosed with arthritis in her mid-twenties. She became very ill and had to have her gallbladder removed as well as undergo a hysterectomy. She was constantly tired and in pain and, after years of suffering, was diagnosed with fibromyalgia. Now she often must walk with a cane. Flora gets intense cluster headaches that have caused stroke-like symptoms including weakness on the left side of her body and loss of muscle control and definition on half of her face.

Clyde returned to public education, where he has succeeded. Flora married a long-time friend. Recently, the marriage came to an end because her husband's addiction to alcohol made the marriage difficult to maintain and provided a poor environment for Clyde. Now that life has stabilized for Flora, she is trying to rediscover herself and who she is beyond being a "crazy" and a mother. She still gets a great deal of support from her family and intends to apply to the Social Security Administration (SSA) to receive assistance, because it is impossible for her to maintain employment. Her last experience applying years ago was degrading and ultimately her application was denied. Presently, she lives with the help of her parents, some assistance from

the department of welfare, and some income generated from art, baking, or other tasks as she can.

Flora suggests a significance to the many layers that make up her identities as a woman, family member, and sexual being in her introductory narrative. She thrives on impulsivity and revels in those sweet moments of quiet thought.

Bryluen

I made Bryluen's acquaintance more than twenty years ago through mutual friends, but subsequently fell of touch. She has a certain acerbic wit and a ferocious sense of humor. The accounts of her life were passionate, well-considered, evocative, and included multiple perspectives. Though raised as a Christian, she now practices Shamanistic-Polytheism, a spirituality that tethers her to the natural order of the world. This spirituality provides some solace to Bryluen's troubled days. Our discussions consistently carried a sense of gravitas, because her experiences and moment-to-moment existence was just that—troubled.

Bryluen was born in the late 1970s at one of the several military bases across the globe at which she and her parents would live over the next sixteen years. They identify as a White American family, though they often resided outside of U.S. borders. Bryluen's father made a career in the military, retiring after twenty-one years when Bryluen was still a teen. She described him as a stereotypical soldier: emotionally distant, quiet, religious, and somewhat narrow-minded, but overall a good guy. Her mother sometimes worked as a substitute teacher or as a retail clerk, but largely stayed home. Bryluen's relationship with her mother was and is difficult. She cited religious zealotry and an inability to accept personal fallibility or the existence of Bryluen's disabilities (because disability might mean fallibility) as a major source of

this difficulty. Growing up, her family had consistent income, housing, health insurance, and transportation.

Bryluen's childhood was marked by illness and hospitalization. At a very young age she contracted German measles, which set off a chain of medical events including damage to many of her organs. Bryluen frequently contracted pneumonia and other illnesses. At the age of five, she was administered an aptitude test and scored very high. Her parents placed her in a gifted education program, but it was difficult for her to attend school. Her solitude in the hospitals paired with her aptitude created a condition in which Bryluen developed a strong identity as an independent scholar, particularly interested in the sciences and forensics.

Bryluen's early life was wrought with traumatic events. At the age of six, she was raped by a teenage worker on one of the base's swimming pools. Her parents refused to investigate or validate Bryluen's report of the violence and forced her to return to the pool frequently over the next several months, which further traumatized her. At age ten, she witnessed one of the most horrific air show disasters in history, describing how she watched as a piece of plane debris decapitated a spectator and as body parts were carried off the field. Not long after, she was attacked by a man on the street, who exposed himself and attempted to rape her. The burden of these events weighed heavily on her and she overdosed on painkillers when she was ten. Surviving the overdose, she was hospitalized, which is where she met C.B., a pilot. The two quickly became close and their relationship blossomed into a romance, which Bryluen says saved her life. Despite their significant age differences (she was eleven when they met), this was the first and perhaps only normal, loving, and cathartic romantic relationship she had ever had. But the life of trauma she experienced was not over. At the age of 16, she watched as C.B. died in a plane accident. She was and still is devastated.

Bryluen continued to excel as an independent scholar, earning a bachelor's degree in metaphysical science as well as enough postsecondary credits to equal several advanced degrees. Her true calling, writing, emerged from her relationship with C.B. and the constraints of her disabilities. Bryluen is an accomplished author. She has published more than a dozen fantasy, romance, and mystery novels with countless others in process, but these do not generate much income. She works part-time in an office doing clerical work in the southwestern region of the U.S. and her total income places her just around the poverty line. Her health insurance is wholly inadequate to cover her many medical needs. She has been married since 2004, but the relationship is troubled and often abusive, including emotional torment using Bryluen's disabilities as a tool of control. Though in a heterosexual marriage, she identifies as being bisexual. She primarily spends her time alone writing voraciously, interacting with others online, or simply counting the minutes of painful suffering, which are far too many and unrelenting. Bryluen also dedicates herself to advocating for people with disabilities or who are victims of domestic and sexual abuse.

Bryluen's disabilities are numerous, interactive, and severe. Due to the severity of her Post Traumatic Stress Disorder and Clinical Depression, it is difficult for her to leave her house and form relationships. Combined Acute Intermittent and Erythropoietic Porphyria causes neurological and skin symptoms, including severe pain, decreased organ function, sensitivity to sun, impaired senses, and arthritis. Chronic Legionella causes Bryluen to have respiratory problems, flu-like symptoms, and has resulted in bone fractures, internal bleeding in her gastrointestinal tract, and one of her kidneys. Abdominal adhesions, the scarring of internal organs, cause her great pain and have made her infertile. Over the years, she has also struggled

with bulimia. Due to the nature of her disabilities and her instability at home, she requested that we conduct her life history interview using typed communication.

Unfortunately, during the research process, Bryluen's medical needs became critical. She had numerous spinal fractures and experienced indescribable pain. She was unable to afford prescribed medications, eat, or go to work, exacerbating her already dreary financial situation. She was forced to quit her job after significant problems with obtaining adequate disability-related accommodations, and the stress of this process exacerbated her medical conditions. Still, she chose to continue to participate as a Narrator, which I feel communicates a strong theme in her life of commitment and constitution. I acknowledge her priceless offering and am deeply moved by it.

Bryluen's current life is wrought with struggle. Her disabilities make it difficult to work, leave the house, or maintain relationships. Her husband is misogynistic, emotionally abusive, and belittles one of the few devices that Bryluen has to escape and survive her experiences: her writing. It appears difficult for her to imagine a life free of these difficulties and thus they represent her daily life and personality.

Jo

Jo is a White woman in her late forties, slight and athletic. She laughs often, complains infrequently and her comportment communicates a sense of droll lightness that makes her very easy to be around. She is observant, analytical, and articulate. Jo is a middle child of five, though her younger sister and brother both had different fathers than she and her older sister. It is unclear who the father of the fifth child was. Her parents met in college, where they both earned bachelor's degrees, but separated by the time Jo was two. Her mother was an alcoholic, often violent, and promiscuous, which placed stress on all the family relationships. Jo, her sister, and

her mother moved to an impoverished rural area of the northern Mid-Atlantic, where their grandmother lived. Jo's mother started dating again and they moved in with one of her boyfriends, Fred, but he was abusive, so they left and moved in with another boyfriend named Roger. Roger was the father of Jo's younger sister, but soon her mother returned to Fred. Jo's mother continued to drink and date.

During childhood, Jo and her sister were frequently raped by her mother's friends and beaus. Jo's accounts of ghastly tortures, neglect, abuse, child pornography, and observing the murder of her youngest sister are so horrendous that I frequently became bewildered and speechless during our interviews. The tales stay with me and I feel a great deal of compassion for Jo. Signs of the sexual abuse began to emerge, but no one acted. A nursery school teacher discovered Jo shoving crayons in her vagina. Her mother was placed in a psychiatric hospital for some time and was in and out of drug rehabilitation programs, but in the meantime, Jo's father won custody of the two older children and they returned to the east coast to live in a "commune-like" environment, which Jo enjoyed. At age eight, Jo decided to move back with her mother, after a great deal of guilt her mother made her feel. Jo felt it was her responsibility to care for her mother. Jo did well in school despite her tumultuous home life. Now living with another one of her mother's boyfriends, Gregg, a younger brother was conceived. Gregg worked hard as a low-paid boiler maker supporting the family, but he, too, was mean and abusive. Jo's mother continued to drink and struggle with mental health. The family was poor, the house was a wreck and overrun with pets, and Jo lived a life of fear. She developed severe anxiety, dissociative identity disorder, and depression, which has created gaps in her memories. In fact, Jo remembers very little about her life before the age of eighteen, except a few fragments of the atrocities

inflicted upon her. Many years ago, she was handed her own high school yearbook and not a single image was even remotely familiar.

At age eighteen, Jo fled and attended college where she earned a bachelor's degree in sociology. She never spoke to her mother again. After completing school and in a great deal of debt, Jo decided that she wanted to run a bed and breakfast. She secured a position as a sort of an intern at a decrepit bed and breakfast in Vermont owned by a cantankerous drunk man. In many ways, it felt like her experiences growing up. Her mental health continued to falter and she thought something was very wrong. She sought out counseling. In her mid-twenties, life started to stabilize a bit for Jo. She found a support group. She had a job as a proofreader and fell in love. This was the first "normal" romantic relationship she had and with this man, she had her first consensual sexual relationship, even though her trauma continued to haunt her. With him, she travelled the country backpacking and exploring, truly feeling free for the first time in her life.

Their relationship eventually came to an end, but Jo had a plan. In her adolescence, she had seen a classroom of Deaf students and was mesmerized by them signing. During her college years, she took two American Sign Language classes and loved the language. One of her mentors communicated to her that she had a natural skill for the language. Jo returned to college to earn an associate's degree in ASL interpreting at an all-Deaf university. She struggled a great deal with supporting herself, managing her mental health, and the rigor of the program, but nevertheless excelled. Upon graduation, Jo found her niche in the Deaf community working as an interpreter, which also created financial stability for her. A few years later, she met Paul. They fell in love and married. The two now own a small home and a lake cottage with a combined income of around $80,000. Presently, Jo continues a great deal of self-care though exercise,

holistic medicine, quiet living, and therapy. She has begun work on a memoir, hoping to help others who have experienced trauma, and is considering furthering her education in the field of writing.

In her introductory narrative, Jo shows her love of wordsmithing. She broadcasts her connection with literature and claims her right to live. Though the narrative relays an event from many years ago, this moment seems to stand out for Jo and informs who she is even today. It shows her strength and resolve. Jo has few memories from before this time in her life. This story relays a renaissance for her that resonates.

Felix

When Felix takes up topic, he does so with great gusto, often with colorful language. He enjoys dedicating himself to the moment, not seeming to fear being perceived as overdramatic. It was this feature of our interactions that I enjoyed the most. Felix is sentimental, empathetic, intimate, and frustrated. With great ease, he shifts from disclosing subjective experiential accounts to providing pansophic analysis of the events that occur around him. His accounts carry a certain hopefulness, but I also frequently felt a morose sense of contrition in his words. "Close, but no cigar" is one of his favorite idioms and it communicates a prevailing theme in his story.

Felix, age 38, lives in the Pacific Northwest, where he has spent much of his life and has recently begun a municipal internship focused on improving community access and inclusion for disabled people. He was born with hemi-paresis, which is a weakness of the right side of his body. His right eye is blind and his left eye has a palsy. Fine motor functions on his right side are difficult and sometimes he experiences muscle spasms. He also has a nonverbal learning disability, which has complicated many relationships and learning experiences. Felix holds a graduate degree and completed part of a professional degree. Recently, he purchased a condo

with the help of his parents, who both hold professional degrees and provide a great amount of support to him. Born to a Jewish family, he was raised following cultural and some religious traditions, but does not wholly connect with this aspect of his heritage. Felix has an income well under the poverty line and receives publicly funded health insurance through the state.

Growing up, Felix had a difficult time. Peers were cruel to him, teasing him and picking fights. In school, the special education resource room became one of his few sanctuaries. Later in his secondary education, Felix discovered the power of scholarship as a counter-story and tool to protect himself from abuse. He also began practicing martial arts, which provided a physical outlet for his frustration, a spiritual discipline which led to his embracing of Buddhist philosophy, and a sense of control.

In college, Felix excelled in theory and practice coursework, yet struggled with math courses and standardized exams that included mathematics. For this reason, his path toward becoming a teacher, a long-held aspiration, was barred and he entered fields of counselling, rehabilitation, and disability studies. Felix states that access to dating has always been difficult since his appearance exists outside of standard norms of acceptance. He also can misunderstand romantic social cues and the consequences have been a traumatizing mix of stigmatization, communication breakdowns, and ostracism. Between testing requirements, confrontations with women, and philosophical conflicts, Felix had a particularly difficult time ever finding a "home" in academia and decided to leave it.

Since leaving his professional degree program, Felix has continued to search for his place. He participated in a business program in Southeast Asia, but that did not yield any tangible plans for what he should do with his life. For the last few years, Felix has worked as a parking

attendant, continued his martial arts discipline, and looked for relevant work in his fields of counselling and disability rights or access.

Felix is a funny guy. Comedy is important to him and he wanted to show that in his introductory piece. In some ways, it seems comedy serves as deliverance from some of the more deleterious aspects of having disabilities, a kind of approach toward coping that Felix utilizes throughout his life in different ways.

Allister

Allister and I typed together for our interviews. He uses an Augmentative and Alternative Communication device on which he types and it generates a voice. We discussed how we would approach communication and since him generating voice was unnecessary for me as a Deaf person, we agreed to live typed interviews. However, Allister quickly shifted to typing me long stories and thoughts when we were offline as well. He described that he often woke up at night thinking about things he wanted to tell me. Allister responded to interview prompts with the precision of a historian, complete with detailed chronologies, contextual background information, and citations. It took me some time to get accustomed to his clinical approach to describing his life, though it was wholly adequate and complete. By the end of the life-history interview, I very much grew to appreciate Allister's personality and the complexity of his accounts.

Allister is a native of New Zealand, but moved to the United States when he was two years old. He was born with an orthopedic disability that affected his ability to produce speech as well as with some motor/balance difficulties. He also has a nonverbal learning disability. In adolescence, he acquired a moderate hearing loss in both ears as the consequence of complications of long-term infections. He grew up and now once again lives in one of the Plains

States with his parents. Now in his early thirties, he and his family maintain strong ties to the Episcopal Church. His mother is a deacon in their local diocese.

Though he was identified as gifted, Allister lived his school years in the shadow of his high-achieving sister. Assumptions about his disabilities connected to intellectual capacity and speech created many barriers for Allister, which further emboldened him to excel in his scholarship to prove educators wrong. Allister resisted connections to other people with disabilities and attempted to avoid stigmatization as much as possible, which was largely successful for him. His well-educated, affluent neighborhood was very supportive as was his school. He has always been a sportsman, particularly interested in baseball, running, and hiking. Though a prominent feature, disability is not Allister's master identity. He values his individuality, scholarship and sense of command over his fate, though he recognizes the social forces at work. Allister earned two master's degrees in English and a disability-related field, but has had a difficult time securing employment. Like Felix, Allister feels that he has never had the opportunity to explore romantic relationships. He is hopeful and identifies as heterosexual, but currently feels frustrated with the reality of dating culture. Presently, his parents provide housing and medical insurance. Allister has located a part-time job as a writing tutor and continues to search for additional work.

Allister chose to depict himself as grateful, ruminative, nostalgic, and prepared to move forward. I agree that this captures how I, too, perceive Allister. He is at a crossroads in his life, searching for his career and wondering what will happen next. I enjoy the nonchalant tone and pace of this piece. He has captured himself well.

Stephanie

Each time we interviewed, Stephanie greeted me with a great deal of energy and infused the whole interview with positivity. I quickly learned to try and schedule our sessions during my longest work days when I needed the boost. Like all the Narrators, Stephanie showed a very strong commitment to providing quality data and making regular meetings, but her story differed from the others. How it differs unfolds throughout the remainder of the text, but it was this difference that drew me to Stephanie and caused me to further question what I expected to find in this research.

Stephanie is a White female, aged twenty-six, who lives in a small city in the Mid-Atlantic States. She grew up in an affluent suburban neighborhood, where everyone supported one another. Her mother was a preschool teacher and then a stay-at-home mom, while her father was an executive at a large restaurant chain and holds a bachelor's degree. Their income exceeds $100,000 a year. After Stephanie was born with Spina Bifida, Stephanie's parents quickly jumped into action, developing connections with educators, doctors, and support groups. By the time Stephanie entered school, she had many friends with Spina Bifida, knowledgeable parents, and receptive teachers.

Stephanie had very enjoyable school years. For the most part, she lived a life free of stigma, despite reporting that it was obvious she had a disability. She wore and still wears braces on her legs for support, had several surgeries, and struggled with incontinence. During those years, she was active in various sports, piano playing, and choir. While she popular in school, she also and felt an extra sense of community with her peers with Spina Bifida.

In college, she studied special education and during her student teaching practicum in a rural and impoverished coal mining town, she came to understand the intricacies of poverty, education, and disability. She received a master's degree in special education and met the man

who she would eventually marry, the only person she has ever dated. Eventually, Stephanie found a job at an independent living center, while her husband Dave is a teacher's assistant. Together, their annual income is about $35,000. They have health insurance through Stephanie's job and own vehicles. Presently, they are searching for a home to purchase and are trying to conceive a child. Overall, despite Stephanie having one of the more severe forms of Spina Bifida, disability simply is not an omnipresent aspect of their experiences together.

Stephanie struggled writing this first piece. She wasn't sure that she was a writer, especially a reflective one. She was unsure of how to describe her personality. Many times, during the life history interviews, Stephanie mentioned that she prefers to live in the moment and focuses on moving forward rather than unpacking the past. I found her struggle to ruminate, scrutinize, and dissect some of her past refreshing, because it seems to be all I ever do.

Tim

Tim and I quickly became friends. He was always very conscientious of my needs, enjoys conversation, and was curious about my own life story. I felt that he entered the research seeking out an emotional connection and we easily connected in a very visceral way. Coincidentally, Tim acquired his disability just a few days before I became Deaf. Frequently, he began a thought with the statement "Let me tell you Steven…" and I always knew that whatever words came out of his mouth next were going to be heartfelt, intense, relevant, and personal. Tim is simply an upstanding, kind gentleman.

Tim is a male in his mid-fifties and of Scottish descent, a cultural heritage with which he feels a strong connection. He grew up and continues to live in the same mid-sized Midwestern city. Tim has four siblings and grew up in a house with an emotionally distant and alcoholic father. His mother was "somewhat abusive," berating the children and hitting them with electric

cords. Financially, the family was quite comfortable. His father was an aerospace engineer with a graduate degree and his mother a secretary, providing the family with a combined income of about $110,000 a year. While in high school, Tim was a fine student and enjoyed sports, particularly hockey. Upon graduation, he went to college for science, but was unsuccessful due to a "psychotic break" that included hearing voices and depression. He took an apprenticeship making aluminum die casts and eventually at age forty-two went back to college to get a bachelor's degree in history. His personal income grew to about $70,000 a year and he made several investments. All through his adolescence and early adult life, Tim struggled with substance abuse. Eventually, he sought help and now has been sober for twenty years.

Tim's family faced three separate traumatic events. When Tim was young, his older brother went missing. Later, his body was found and the coroner ruled that he had drowned. Another brother was in an accident, which resulted in massive brain damage and hemiplegia. He was in a coma for a year. Communication and self-care is difficult for this brother and he presently resides in a care facility. At age forty-five, Tim himself was in a horrible car accident and sustained a traumatic brain injury and multiple bone fractures throughout his body. He was in a coma for a month, followed by two months of amnesia and a long rehabilitation. While recovering, he married the only girlfriend he ever had, but the marriage lasted only a few years. She had bipolar disorder and had been hospitalized several times.

Currently, Tim walks with a limp and has speech aphasia, learning disabilities that make it difficult to comprehend or retain information, and depression, partly connected to how his damaged brain now processes emotions. After he recovered from the injury, he returned to work and was able to do die cast designing work well, because his body/mind remembered the routine, but it ceased to satisfy him. Instead, he opted to return to school, joining a history master's

degree program, but soon made connections with a disability studies scholar. His graduate

assistantship and a nomination to a local board that dealt with disability-related issues sealed his

connection to disability studies and he completed a graduate degree in the field. It was very

difficult for him to navigate his new experience and figure out how to learn again, especially

given the dense theoretical nature of his discipline. He struggled a great deal, often emotionally

immobilized, or as he put it, "crying without tears."

Not long after earning his master's degree, he found a peer-support job that required

employees to have a disability and in this role, continued to crystalize his own disability identity.

Soon this work led to a position as a mental health case manager, where he continues to work

today. His income of about $35,000 a year is about half of what it was while a die cast designer,

but the work is much more satisfying, meshing well with and contributing toward his own

experiences as a disabled person. Recently, he has purchased a condo and owns two cars. He also

is the founder of an organization that promotes undistracted driving, which he continues to

support while serving on the disability-related board mentioned previously.

The months following Tim's accident changed him forever. He continues to adapt as his

newly wired thought process confronts new challenges and environments. It was important to

Tim that his personality piece communicate those ideas of fragmentation, discovery, confusion,

and alienation that have shaped his present-day personality.

Gail

Gail is a joy of joys. Very quickly, Gail and I forged an intimate research relationship.

Although quite a complex woman, she and I shared a kind of inelegant humor that made

interviews and correspondence a great pleasure. Our interviews were very conversational and we

frequently emailed one another between sessions to discuss feelings, clarifications, and to tell one another about interesting things that happened during our days.

Gail is a White woman in her early seventies who identifies as a lesbian, pansexual, or bisexual. Born in urban New England, Gail had a loving family. She contracted polio as an infant, so her father gave up a successful career in the military and became a high-ranking official for the state to take care of her. He also made several good investments. Her mother took care of the family including Gail's older sister and later became a librarian. Both had advanced college degrees and generously shared their wealth.

Gail's early life was marked by numerous surgeries, therapies, and long stays in a Shriner's hospital ward, which significantly shaped her identity and dominates her memories. She attended a Catholic grammar school, where students frequently teased her about her polio-induced limp, but as she moved toward high school, the bullying eased and she became more popular. In high school, Gail's sexual identity emerged, one that she relayed with refreshingly little shame. She had a boyfriend and experimented with women.

During that era, the expectation for women of her caste was to go to college for teaching with the primary objective of finding a husband. This was not for Gail, so she studied sociology, but did in fact meet the man who would become her husband and soon conceived a daughter. One of Gail's strongest identifications is that of a mother. Social work wasn't the right job for her either. She enjoyed working with drug addicts and prostitutes, but working with disabled people was unfulfilling. Though still good friends with her ex-husband even today, the marriage did not last. Gail dated a few women, and before long met the woman with whom she would live and love for the rest of her life.

Gail continued her education to earn her master's and doctoral degrees in sociology at prominent universities. Securing a sociology professorship in the Midwest, Gail moved with her partner Lilly and her daughter Jill. The family continued to flourish. Gail became chair of her department. Lilly directed a pro-bono legal consultation service, and Jill went on to earn a Ph.D. As the years passed, Gail's physical health deteriorated. She begrudgingly began using a cane, crutches, and finally a wheelchair. Some years ago, she was diagnosed with lung cancer, but after treatment is now in remission. It was around this time that she retired and, with Lilly, moved to Florida. Her household income is around $200,000 and she received a sizeable inheritance from her father when he passed away.

Gail stated "I am funny and I am smart. That's what I want people to know about me." That is exactly what she accomplished, infusing a bit of sensuality, love, and blitheness in the process. Undoubtedly, Gail the woman jumps off the page.

Conclusion

In this chapter I provided an introductory sketch of the Narrators' lives and the Narrators themselves demonstrated their personalities. Within these summaries, we see specific events related to impairment, disability, and psychology. The summaries include a general review of the Narrators' backgrounds including their various identity markers and socioeconomic locations. In this chapter, the chronologies move very quickly over the decades as a means of portraying the big picture. In the subsequent research findings chapters—time is slowed down for analysis of how Narrators created their identities. With the clock slowed, there is time to ponder, dig, feel, and hopefully in some sense, experience the critical moments in the Narrators' lives.

Chapter 5

Critical Moments in the Shaping of Narrators' Political Disability Identities

In this chapter, I present and discuss critical moments from the Narrators' memoirs, which captured what they believed to be the most crucial moments in the formation of their political disability identities. Throughout the research, the Narrators discussed their political identities as disabled people. As we progressed in the research, I centered on the critical moments the Narrators felt impacted the development or evolution of their political disability identities. Six of the Narrators explicitly told me the memories of these critical moments remain strong and guide their political identities. The remaining three Narrators signaled these moments a bit less explicitly by saying things like "Well, if you really want to know how I became so bitter…" (Allister regarding ableism). Or, for example, while discussing what critical moments to select, Jo stated, "I am constantly changing. I am not the woman I was yesterday, but I am still the woman who experienced this moment [described below]. It doesn't go away." I organized the contexts in which these moments occurred in three themes: 1) A breaking point: reactions to strangers or acquaintances; 2) Political activism in college; and, 3) Changes in lives enabling new perspectives.

A Breaking Point: Reactions to Strangers or Acquaintances

Many disabled people cope with the pitying, curious or deleterious stares and comments of strangers, but eventually reach a breaking point. To illustrate the movement towards these breaking points, several of the Narrators directly or indirectly drew on Miserdino's (2014) concept of Spoon Theory, which is a metaphor for how sick or disabled people have comparatively fewer physical or emotional resources than able-bodied people and thus must choose how to allocate their "spoons" or limited resources. For example, someone with

agoraphobia might have to choose between going to the grocery store and going to the doctor, because they cannot abide being outside their home for long periods of time. Some Narrators discussed the idea that they, too, had varying numbers of metaphorical spoons to use each day. Their disabilities required the use of spoons to navigate medical treatments and contend with ableism. Once Narrators used all their spoons, they were exhausted, perceived themselves to be at risk, or noted that they may behave in ways they normally would not. Bryluen and Flora both discussed this concept of spoons directly, while for others this metaphor seemed to reflect their experiences quite well. For example, Bryluen told me "Are you familiar with Spoon Theory, yes? Well, I refuse to use any spoons with the Significant Other. I need to save them for dealing with the bank who is going to repossess my car." Though Gail did not bring up this particular metaphor, her story (included below) about wanting the fulfillment of being with the Girl Scouts she so much admired, but was often met with pity exemplified it. Gail expended her spoons in efforts to feel normal, be accepted among her peers, and maintain her family relationships. Bryluen spent most of her spoons simply trying to stay alive. Anything left, she dedicated to her writing and coping with a relentless amount of paperwork, so she could receive support from the Social Security Administration. Flora used most of her spoons to take care of her child, cope with her disabilities, and fight with public assistance.

By the end of the day, the Narrators sought out support in different ways. Bryluen and Flora often turned to the internet for that support, accessing disability specific support groups, but also sought out broad social media platforms. Out of spoons, Flora and Bryluen described they were often at their wits end by the time they went online in the evening. All three noted that they were bound "to reach a breaking point" (Flora), but perhaps as uncomfortable as these events were for them, they were also critical moments in their lives, and in the development of

the political identity of these Narrators.

Bryluen and Flora relied on the internet for support because the co-mitigating factors of poverty plus the manifestation of their multiple disabilities limited their participation in life outside the house. They generally reported appreciating the ease of the Internet, even though they missed the physical experience of being around people. Bryluen explained that the speed at which information moves and our lack of awareness of where it ends up is not always desirable. She continued "It's not like screaming into the wind. Other people actually see what you post on the Internet." Both Flora and Bryluen commented on the lack of filter or general thoughtlessness that permeates the virtual world, thus leading them to critical moments in political identity development. Bryluen saw a social media post by an acquaintance who knew of her disabilities, but purported how an individual can be healthy by making good choices and positive thinking. She couldn't bear it any longer, so Bryluen belted back:

> I will fucking hand you my pain. I will hand you my deteriorating skeletal structure, my breaking down nervous system, my diseased and dying body organs, and you can damned well experience my life... And while you do, remember this:
>
> I was born with Porphyria… I was born with RA… I was one year old when I was exposed to German Measles, which nearly killed me, and left me with approx. half of my body organs mangled with scar tissue… I contracted Legionnaire's most likely from the place I work… Now you sit there any tell me how I fucking chose this. I dare you. And, maybe the next time you think about posting something about how a person's health is entirely their own choice, you'll stop and think about the people who never chose anything.

All Bryluen's rage from seeing countless insensitive posts, peppered with ableism and ignorance,

burst as if through an opened flood gate. Bryluen let it flow. She explained that the release of this anger was therapeutic, but more than that, she felt she was fighting back. She spent far too long being quiet, a learned behavior from her military-like family culture that was reinforced by her current partner. In this critical moment and afterward, she expressed herself and did so confidently. Bryluen self-studied disability laws, sociology, and sought to understand her own body and people's perception of it so she could be well armed to "show the world my disabilities in an intimate way. After all, most discrimination comes from people's ignorance and fear." Her tactic is one of educating people by exposing her own body and disabilities for public display. Later she posted images online of her legs covered in sores and provided vivid details of life with disabilities. This first explosion, reacting to friends and acquaintances in her online community, marked what she reflected upon as a crucial moment in her development as a political person.

For a long time, Flora utilized various Internet platforms for friendship and connection. She maintained journals, which she let close friends access. Just like Bryluen, the Internet was a place to be social and share. She used the Internet for support, but often was not satisfied with how she felt. She was unsure if it was the nature of online support, her Bipolar Disorder skewing her feelings, or if it was the ways she reached out to people. Regardless, she learned that her friends were only there until "scary Flora" came out. She meant that when she was the most manic or the most depressed, many of her friends disappeared. There was a limit to how much drama or passion they could bear. Then there was an opportunity, an outpouring of support for people with mental illness after Robin Williams committed suicide. She read posts by family members, friends, and Internet acquaintances that stated various iterations of "If you ever need me, at any time, I will pick up the phone." Flora was distraught over the loss of the actor, but thrilled over the good it brought. Flora wrote:

In the days after Mr. Williams' passing I took to Facebook as I often do. Friends posted

meme after meme with Robin Williams' face and messages about awareness of

depression. Some of the memes had the phone number for the suicide hotline on them;

others spoke of removing the stigma of mental illness… Things changed after Robin

Williams' death though. I sought to no longer lie for what did I have to be ashamed

about? Yes, I am bipolar, but I have followed a treatment plan for over 10 years and in

that time have had my ups and downs, but more time than not have been "stable." Why

should I not reach out to family, friends and community for support? And so I did. The

next day I posted that I was so terribly depressed and again, not a soul could be bothered

to reach out to me. Then I got on the offensive. I posted three consecutive posts that were

nonsense. They were filled with jokes and off-color banter, and wouldn't you know,

everyone crawled out of the woodwork to respond. I pointed out the response to the

nonsense versus response to my calls for help; no one could say a thing. I deleted it all

and went to sleep to shut down all my emotions.

After confirming her suspicions about her online community, Flora stated that although

disappointed in her "friends," she nonetheless felt empowered. She explained that the power of

feeling correct, coupled with how insincere the people in her online communities were about

supporting people with mental illness, incited her to "do something about it." That "something"

was no longer hiding her disabilities, but instead claiming them as a source of pride for herself

and a teaching opportunity for others. She hoped that by being more conspicuous and educating

others she would help affect change in suicide rates and the stigmatization of people with mental

illness.

While Bryluen and Flora experienced critical moments in the development of their

disability political identities interacting with people on the Internet, Gail described a particularly strong memory of a childhood experience that still resonated sixty-five years later. Gail reflected upon how this singular instance in the Shriner's hospital communicated to her that she was neither a person nor a girl.

> We've been told that this Wednesday a group of Girl Scouts will come to our Ward. I'm looking forward to it and I think I'm not alone in this. Finally, it is Wednesday and I begin to have doubts. I can't pinpoint why, it's just some feeling, some uneasiness, some fear. They come in, about 10-15 of them, accompanied by the leader, an adult distinguished, in addition to her age, by more badges on her green uniform. The uniforms are green with yellow sashes and are graced by ribbons and pins. Some of the girls have more uniform adornments than others. They range in age from 7-8 to 14. They stand at attention when the leader holds up the flag and then they sing the National anthem, a song which makes me cry and still does (except now I cry for the loss of America as it was supposed to be, the values it used to represent, and our ruthless discrimination of all kinds of difference. Instead of the America we were seeking, we have violence, greed, and hatred.) The Girl Scouts sing other songs and do a dance I don't recognize but the song has a good beat and I wish I could get up and dance. But even those of us who could are not allowed to get out of bed. I feel as if I'm in boot camp. Suddenly, and it is quick, my anger, my embarrassment, and my sadness appear. It has something to do with the manner of the scouts and the leader. Maybe I'm imagining it, but I suddenly see the real scouts, and they transform from just a group of girls to the enemy. They feel sorry for these pathetic, crippled kids, they are better than us and fail to realize they could be us.

The Girl Scouts represented what Gail wanted to be, "I saw their badges and I dreamed about all

the adventures they had earning them. I would never get to do that." She was angry and hurt, but then there was a transformation that she recounted, as well. For the first time, Gail possessed a consciousness about her position as a disabled girl. Gail explained she didn't have the words for it then, but she was not mad at the Girls Scouts. She was mad at the world for "letting the Girl Scouts become what they had become. Oh, and Jerry Lewis too. So clueless and pitiful, I mean pitying, or maybe both." At the age of thirteen, Gail had an understanding that the issue of disablement extended far beyond the girls in front of her. She knew that having a disability was a social problem. From this critical moment forward, she explained, "I never again saw any interaction as simple. They were all messy and [they] all included my disability."

In each of these cases, Narrators responded to a flawed symbolic representation of disability. Bryluen lashed out at an acquaintance because this person perpetuated the idea that people have control over their health. Bryluen recognized the reality of temporary able-bodiedness, while also attempting to dismantle the cultural tools like the aforementioned meme and endless health gimmicks we see on television that people have devised to protect themselves against their fear of disability and death. Bryluen described cultural tools like breathing, exercise, and nutrition, provide a sense of security and a sense of control, even if they have limited or no actual benefit on quality of living. She also noted how these pithy constructions also do not consider the sudden onset of disability. Through personal, sharp rhetoric, Bryluen struck back and in doing so made a step toward her own self-knowledge and disability political identity. Flora, too, confronted what she saw as empty and superficial offerings of support that circulated in popular culture. Specifically, she called out the charade of those who make half-hearted, sporadic commitments of support for people with mental illness. Flora explained, "It's very popular now to wear ribbons and crap to raise awareness for mental illness, but true compassion,

well that's hard work and hard to come by." Flora understood that authentic support involves emotional labor that most are not willing to do. Both women characterized these explosions of anger not as the consequence of one occurrence, but in response to repeated messages on the Internet, television, and in magazines telling them they were inadequate or deserving of pity, but not respect. They could only tolerate so many of these kinds of messages.

Finally, Gail's story about the Girl Scouts, who purport to honor, help, and duty to the community were in many ways like those well-meaning actors in Bryluen and Flora's stories. The Scouts in Gail's narrative likely intended good will. However, they came to represent ableism, by positioning Gail as the "cripple who needed their pity." Gail was under a great deal of pressure to fit in with her peers in the ward and please the nurses. For these reasons, she looked forward to the recreational event so much that when she experienced the Girl Scout's treating her like an object of pity, it overwhelmed her. The nurses communicated an unequivocal message to Gail, "You are not one of them." Pushed beyond her limits, she felt crushed, lost, and angry. Gail explained:

> The Girl Scouts story…turned my head around so long that when I became a social worker, I found normal people boring. I wanted to work with the outcasts. First it was drug users and prostitutes and a little later, disabled people. Shriners experiences really made who I was as a scholar, especially once I entered sociology.

It appeared Gail's time in the hospital reinforced a desire or a commitment to identify not with those in the dominant group who she saw as boring, but to reorient herself to those in the margins. Over the course of our interactions, Gail relayed various iterations of the Girl Scout story and her entrance into her career. Clearly, it was an important moment that she wanted me to understand. No longer did she see herself as a "normal" person, nor did she want to be. Instead

she began aligning herself with other marginalized populations, which she found more interesting and more fulfilling in her career as a social worker.

Political Activism in College

While Bryluen, Flora, and Gail experienced critical moments in the development of their disability political identities during interactions with strangers and acquaintances, Allister, Felix, and Tim felt as though they truly understood themselves as political individuals when they first participated in activism. For these three Narrators, this did not happen until they were in college. Throughout childhood, all three dealt with inequality and maltreatment as or of disabled people. Allister and his family struggled to obtain an appropriate educational placement for him. Classmates frequently bullied Felix because of his appearance and Tim's brother, who had quadriplegia and other disabilities, almost died due to neglect in a nursing home. When these three Narrators participated in social activism in their college years, they discovered something new in themselves. That feeling of discovery is palpable in Felix's words:

> I immediately joined a group designed to advocate for people with disabilities. As a member of this organization, I learned to listen carefully to problems as well as be able to ask questions toward solving them. One thing that I quickly learned was there is solving a problem that faces you immediately and others that are too big and systemic to tackle. I learned to use listening as a powerful political act; an act of defiance and empowerment by helping people voice their lived experiences in their entirety. The good, the bad, and the complexity. Listening is a lost art because people are taught that they are right and others who don't agree are wrong. I strongly believe everyone matters in a participatory democracy. A great leader listens to all thoughts on an issue and find ways to make suggestions toward moving forward. I learned to listen and draw people out so that

people felt heard and that the committee was useful to better the lives of people with

disabilities. One issue that became clear was transportation and how people with

disabilities were being erased by some transportation providers.

Felix conveyed that he was simultaneously frustrated and calculating. He understood activism as shaking fists, conducting sit-ins, and yelling, but in this moment, he learned that much of activism is done sitting at tables and talking, trying to help others understand "the right thing to do." Within this critical moment and a new conceptualization of activism, Felix developed a sense of how he could act in political ways.

Tim's initial knowledge of disability activism was limited to vague memories of television coverage of the 1983 ADAPT demonstration for accessible transportation and the 1988 Gallaudet University protest, Deaf President Now. However, these memories were far from his mind while he was recovering from a TBI. For a couple of years after Tim's TBI, he existed first in a state of shock and then in a state of re-learning the world around him, including how he processed information and feelings. He explained, "My damaged brain didn't have cognizant thoughts. It was, and to a certain extent still is, a mass of raw emotion without much ability to interpret it. I was guided by vague, but strong feelings." As Tim's life became stable again, his thoughts turned toward reducing distracted driving, which was the reason he got in the accident. He began a committee to develop training materials and information. Tim explained that he also began hanging around with other TBI survivors. However, Tim didn't "feel he was with his people." Tim survived, but he didn't want to define himself only as a survivor. He was "Tim the guy with a TBI or Tim the guy with a disability, or maybe just Tim." He felt that he was becoming something much more than a consequence of his accident and thus sought out other disabled people, hoping he might figure out what that was. For Tim, the TBI community was too

focused on the past. He began having conversations with a college professor about disability, eventually enrolling in the college where the professor instructed. In college he had a graduate assistantship that focused on disability pride. Mistakenly, a woman came to his desk and inquired about some dumpsters covering accessible parking spots. Though not Tim's job, he sprang into action to ensure those dumpsters were moved.

> I learned a great deal about myself. First, when confronted with visual evidence of the construction crew's absence of regard for those with mobility impairments, the university's facilities management team compelled the crew to change their conduct and the accessibility around the site improved. Maybe, the construction workers realized removing the dumpsters was the right thing to do; perhaps the change developed in response to shame, but the crew could not ignore the situation when I involved university accessibility specialists. While I am glad, the university directed the construction crew to improve their conduct; these events signaled a fundamental change in me. Never before had I engaged in accessibility advocacy efforts. However, as I imagined the woman struggling to cope with the thoughtlessness of the construction workers, I resolved to act to make life easier for a fellow wheelchair user. While I do not require a wheelchair to navigate the world I encounter, memories of the time when I used a chair remain a powerful reminder and I empathized fully with the woman. This, my first advocacy effort, signaled a major change in me.

In this critical moment, Tim reported experiencing empowerment and felt in control of his fate and the fate of other disabled people. This was the feeling of "something more," a phrase he often repeated, for which he had been searching. He felt part of a people. A minor action of standing up, walking over to another building and demanding that the work site be evaluated for

accessibility, stayed with Tim. He explained how it simmered inside him and grew, "I don't know. I just felt…I don't know, like I was actually doing something that made the world better, even if not very much better. I wanted more of it!" Later, he expanded his quest for social justice, publishing articles and attending conferences, but he returned to this critical moment several times mentioning "that's where it all began…again," highlighting it as significant in the development of his political disability identity.

Felix and Tim found spaces in the academy that promoted disability rights, initiating political actions to right what they felt was wrong. Like them, Allister reflected on an incident during college that marked what he felt was his emergence as a political activist. Unlike the others, Allister's political act was more of a symbolic one, challenging ableist institutions regarding voice, speech, and technology. He recounted an experience he had at an academic conference:

> My paper is on doing ethnography with a speech disability. There are other individuals on my panel who have speech disabilities as does the moderator. There are revoicers present, but I also have a speech generating device (the other individuals are using revoicers) as well. I am welcome to start using the revoicers at any moment, though. I am starting to run out of time typing, so I switch over to revoicing. I am able to get through all of my presentation that way something that, quite likely, would not have been possible if I had typed everything out. Communication devices cannot always solve all problems in all situations. I am probably relatively able bodied amongst AAC users, so I recognize I do have some privilege in saying this, but I would have prefer to use my device the way the evaluating speech therapist suggested which is as a way to deal with communication breakdowns

Allister's past shed some light on why claiming his right to communicate in a way that worked for him was so critical in his development of his political disability identity. Though he cited the importance of the above critical moment in developing his political disability identity, Allister had been political from a young age because his parents included him in decisions about and advocacy for a quality education. He participated in acts of politicism early on, such as walking out of his segregated special education classroom to go to the library where he could authentically learn. The moment he described above was different. For the first time, he was in a position of authority rather than a subjugated disabled kid fighting back, which is how he described his experiences. Allister's protest was one of preference over how he represented himself. He described that he felt, "powerful and in control over my body and my voice. I wasn't fighting them, I was letting me out." Particularly for Allister, but Tim and Felix too, this highlighted that the most significant moments in the development of their political identities were not necessarily connected to the magnitude of the politicism represented in their narratives. Instead, the critical moments were more connected to personal processes, which brought about a change of political disability identity from within that we get a glimpse of on the outside in their stories.

All three of these Narrators expressed that they felt more accomplished and satisfied by recognizing opportunities to act in political ways that furthered what they felt were the needs of the disabled community. In other words, advocating on behalf of others made them feel a sense of personal growth. The Narrators highlighted that it was significant to them that they purposefully chose to take up roles involving activism and the fact that this was a conscious choice was the linchpin of why this moment was important to them. In other words, it was the act of choosing to push back against ableist structures that was instrumental in shaping their political

identities. They found these acts fulfilling, which marked moments in their lives as independent political figures and thus affected their political identities.

In considering this first section, I think it is worth noting that several of the Narrators took up the idea of responding to circumstances involving other people as influential moments in their developing political identities. In this section, I discussed physical forms of activism, including going to various offices, presenting at a conference, and representing the Narrators' political positions. This type of event was highlighted by several Narrators who saw these acts as instrumental in their understanding of themselves in political ways. Interestingly, this perspective was expressed by three male Narrators. In the previous subtheme, "A breaking point: reactions to strangers and acquaintances," critical moments in the formation of disability political identities were expressed by three females Narrators. For these women, two who had participated in explicit activism, it was the process of suffering, an internal discourse about the able-bodied world, and finally deciding to release their built-up angst that designated a critical moment to them. All three described that there were little recognizable positive outcomes to their actions, but the process was integral to their knowing themselves.

Changes in Lives Enabling New Perspectives

In this section, I discuss how changes in the Narrators' lives forged paths that led them to changes in or the development of their political disability identities. Jo, Latefor, and Stephanie narrated childhood experiences characterized by either subjugation or privilege. At various junctures of life, these Narrators gained new perspectives about their childhood experiences and prospects, thus affecting the development of their disability political identities. Jo was abused and frequently dissociated as a "defensive mechanism." Latefor was neglected and ostracized. In contrast, Stephanie experienced a loving family in a community with little strife. Life changing

events that precipitated Jo's escape from abuse, Latefor's new found independence from her family, and Stephanie's foray outside the insulation of a loving family meant changes in how these Narrators viewed their worlds. They perceived that their lives could be different, realizing they could affect positive change for oppressed peoples. Thus, in these critical moments of self-realization and change, they developed their political disability identities.

Jo escaped an abusive home life for college, discovering new things upon which to focus, like coursework and socializing, rather than a day-to-day maintenance of her own safety and security. As she acclimated to college, she grew more courageous and sought to figure out what the world might hold for her. She said, "After all, I have never experienced the world outside my dark, crumbling corner."

> When I left home for college, I spent the first two years struggling to come to the fore of my life. I had no means by which to self-navigate beyond the borders of my own skin. I knew my own mind and had no problems academically, but I floundered outside the perimeters of the classroom. I changed majors four times, unable to envision myself in any of the social positions for which I was being prepared: Teacher, Social Worker, Writer, Psychologist. Real Person. In my junior year, I stumbled upon an eccentric group of professors in the department of sociology, lugubrious Marxists and Socialists whose ideologies resonated with me in obvious ways. Alienation, exploitation, expendability – these terms hardly needed to be explained to me. I finally moored myself to a platform, a political identity by which I could define my own contours in relation to the outside world. A desire for equality, social justice, and an end to all suffering would shape my every choice from there on out, as I slowly made my way into the land beyond the shelter of my gloaming interior.

Jo discussed this moment in time as signifying an immense change in the core of who she was. She noted, "The fog was lifting and I was seeing myself as a woman for the first time. I met a boy, but what was truly liberating was there was a sense of autonomy that was never there before." For the first time, she was exposed to a body of knowledge and scholarship, which represented at least a notion of the experiences that she had growing up. In the narrative above, Jo latched on to various faculty members and the sociological theories they instructed in her classes. She felt enlivened and consequently became more of a political individual. She began a painful process of drawing from her own experience: "I just had to start writing. It flowed from me and I knew deep inside that there had to be some good to come out of such evil. I was or am responsible for ensuring that good is not wasted." Jo began writing her memoir long ago and hoped that somehow people reading it would affect some amount of reduction of abuse. As she and I discussed this time in her life, we attempted to excavate what was so political about it. Her conclusion was that for the first time, all the thoughts, fears, power struggles, insecurities, potential futures, and her own present reality were moving outward rather than inward. Before this critical time, all these aspects of her life moved inward "like a black hole." As she pushed outward and influenced those around her, she also changed, becoming a political actor.

Like Jo, a critical moment Stephanie's political disability identity development also involved a drastic change in environment, resulting in the recognition that she could and should try to be an agent of change. Growing up, Stephanie's community was supportive and affirming of her as a disabled person; thus, her political awakening took place under a much different set of circumstances. At the end of her college program, she left her middle-class, White neighborhood to complete her student teaching requirement in a low resource coal mining community. Upon arrival, she didn't immediately see disabled students, but instead witnessed extreme poverty and

a school system that prepared students to work the mines after high school:

> Walking into the elementary school, you would not see the poverty at first until you
>
> spoke with the students and understood how a lot of them live. More eye-opening for me
>
> however is my view on coal mining. Prior to this experience, I had always considered
>
> myself an environmentalist, which I still do, but that always meant being against coal
>
> mining. That view however was before I met children who rely on coal mining for
>
> survival. One day this week we were talking about coal mining in relation to exploring
>
> mars because space is the theme for science. Mrs. Roark asked the students how many of
>
> them had a family member who is a coal miner. Every hand in the room shot up. While I
>
> was not completely surprised, it struck me that when we talk about the coal mining
>
> industry and how bad it is, we often forget about who is doing all the work.

Stephanie felt conflicted between our needs as consumers and her ethical position about energy sources. We talked at length about what would happen to these children if coal was no longer used as fuel and the underserved families of her students were without work. We talked about the culture of coal communities and the men in the shafts, while their wives tried to get the dust off the next day's uniform. She told me, "No one really wore white, because it was just asking to be ruined. School was all dark colors, black, gray clothes." In following up about the absence of disabled students, Stephanie noted that:

> Oh, it was obvious that there were students with disabilities, but they were not labeled.
>
> Unless they had a disability that prevented them from working in coal, they likely were
>
> not diagnosed. The school didn't have the resources or will. It wasn't the culture.

She went on to further discuss the school-to-coal mine pipeline for disabled students. They were "…prepared to go to the mines just like the others. Perhaps *more* likely to work in coal than the

others. The others [able-bodied students] might have the opportunity to do something else, but with no skills or money, what were these kids with major disabilities going to do?" In this case, inclusion was working in a strange and not necessarily good way. It seemed that education wasn't the focus for any of the students and the disabled students were being prepared to enter the same professions as their peers. Stephanie began, "To say this was complicated…To say I felt confused…I don't know." The moment agitated her because there was no simple textbook solution to solve the problem, like she experienced in her coursework. One thing was clear to her. She was changing. She saw and felt the people's experiences:

When I went home and saw my neighborhood, it felt a bit flat. I was asked to present about my experience and I mostly talked about the coal industry and its effect on the environment. I couldn't talk about the kids yet. I was still processing it all. I mean none of their needs were being met in any kind of way and I couldn't do anything about it.

Ultimately, the one of multiple causes that deserved attention (e.g. poverty, special education, human safety, renewable fuel sources, and gender roles) that drew her professional, political, and personal attention was special education. She described that the disabled students were not the first part of the experience that struck her, but they stayed in her thoughts. She felt the students' bodies reflected back at her own disabled body and she couldn't ignore that. A short while later, she enrolled in a special education graduate program.

Upon entering college, Stephanie and Jo experienced drastic changes in their lives that precipitated the development of their political disability identities. However, Latefor became the "political guy" (she uses pronouns fluidly) she is today a bit later in life, around age forty. At that time, her neglectful and abusive husband's health began to fail, diminishing his control over her. As his health failed, she began claiming power, noting that prior to this time,

I didn't know how to do nothin' on paper, so I got my niece to teach me to sign those

checks and learn the bank and stuff…and when I get a letter or a bill I take it down to the

restaurant to have them read it to me. If need something I find a way to get it.

When Latefor's husband eventually died, she realized she was, "…free from being a slave and

[gestured a key locking her lips]" signaling to me that she was no longer being silenced or

locked. However, because of her cloistered life up until this point, she did not possess all the

skills she needed to live independently in a modern bureaucratic society. Understanding she was

free to learn what she needed to survive was critical for her, because she now had a reference

point and reflected back in time with resentment. Latefor's painting (Figure 1) demonstrated how

she felt during her 20-year marriage. There is a look of hardness on Latefor's face. The hard-

angled lines of her face reflected the hard labor and general toughness she needed to survive.

Latefor used all warm colors inside her cell and a cool blue and gray on the outside, which could

signal her feelings about her husband and stepson on the outside versus her own very different

sense of self.

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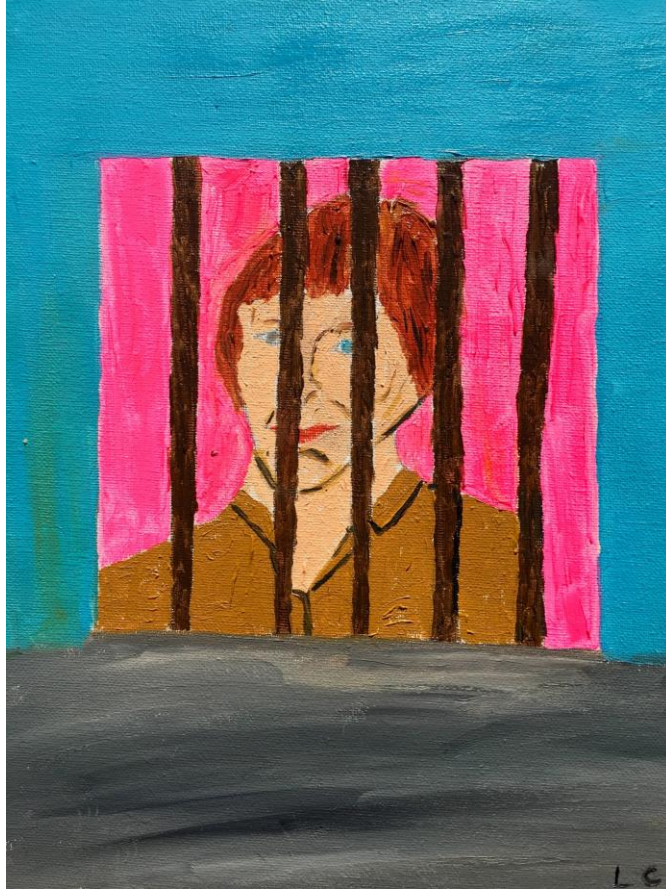
Figure 1: Latefor's critical moment of political identity development. The doors to her

metaphorical prison opened.

When her husband died, the door of her prison opened. I asked if she would marry again, she

responded, "No way, never again! I've got my dog. I can walk out that door there and go, come

back when I want. I can sleep in the chair if I want. It's strange. Good. Still strange." She had

never been alone before. It took experiencing this moment to understand how bad it was for her

before. Her sisters tried to help when Latefor's husband was still alive, but Latefor didn't allow it

because she did not know how to accept this help and because she worried that her husband

would "give me hell…and I would be paying for it for a long time. He was a mean son of you

know what." She also adopted a silent sufferer persona. She said, "If I just stayed quiet and did

what I suppose to do, I could get by." With her husband dead, she gained a new consciousness

about the abuse she had endured. She also gained freedom from people who called her names, questioned her competency, and kept her in a veritable prison. Before then, she had no context to define freedom. According to Latefor, in her early 40s she came to understand her political position: "Women don't get much power. Special people [sic] neither. We are all kept pushed down in the closet. You know that too [points to her ear to highlight that the researcher was Deaf]."

For all three of these Narrators, drastic changes in their environments created the conditions under which their political disability identities began to take shape. These changes remained in their memories and, based on their descriptions, continued to guide them. For Latefor and Jo, they crossed boundaries into relative physical and emotional safety, thus providing the impetus for recognizing their political disability identities. For Stephanie, her boundary crossing was from a familiar to unfamiliar space, which sparked her political identity development.

Conclusion

In this chapter I discussed the critical moments in the Narrators' lives that they felt shaped the development of their political disability identities. To represent these critical moments, I included mutually agreed upon text and an image from Narrators' memoirs. Generally, the Narrators described these times as days of transformation. They were days that marked new lives or new ways of thinking about their relationships with their Selves, others and society. For Flora, Gail and Bryluen, their critical moments were ones of claiming a right to exist and ceasing to be quiet about their often-painful lives. For other Narrators like Felix, Tim, and Allister, their critical moments were marked by engaging in political actions. Consequently, they felt empowered by their identities as disabled people. Still, there were more quiet, internal

processes that brought about both peace and disability politicism for Jo and Latefor. These two

Narrators gained freedom from their respective tortures, at least the physical components, while

the psychological components of their experiences may stay with them always. It was during

these critical moments described that both Jo and Latefor realized that their lives could be

different. Reflecting with contempt on their pasts fueled their hopes and actions for a better

future for all people. For Stephanie, observing the poverty and poor-quality education for

disabled students incited new feelings of politicism. Stephanie was aware of various problems in

the world, including poverty and inadequate education for disabled students. It wasn't until she

worked among people who experienced poverty and saw disabled children neglected that she

developed a new perspective and political motivation. Her feelings grew stronger and rooted in

experience rather than talking. The change in environment changed her, which she reflected

upon with both fondness and disdain. She felt disdain being unable to affect change as a student

teacher, but fondness because this critical moment of disability political identity development

enabled her becoming the woman she is today.

This chapter discussed critical moments in the development of the Narrators' political

disability identities. Chapter 6 will show how the Narrators enacted their political disability

identities. Organized around key themes, I discuss the multiple ways in which the Narrators

sought to make changes in their worlds, on scales both large and small, public and personal.

Chapter 6

Enacting Political Disability Identity

In the previous chapter, I centered on critical moments in the Narrators' lives. These were moments in their lives as disabled people that they felt changed them or helped them come to develop, shape, or acknowledge their political disability identities. I say critical, because all the Narrators stated that politicism was integral to their lives as disabled people. In addition to memoir writing, they joined this research because they felt their participation acted as a counter-story to the many stories told about them. In this chapter I examine how the Narrators enacted their political disability identities. That is, in what ways did the Narrators show the identities they described in Chapter 5? I discuss how the Narrators enacted their political disability identities through the following themes: 1) Internalized ableism, 2) Ethic of self-care, and 3) Working for change.

Internalized Ableism

Internalized ableism is a learned reaction to oppression, resulting in the oppressed disliking themselves and their peers (Rossenwasser, 2000). Consequently, the oppressed may blame themselves for the oppression rather than those who enact it. In the case of disabled people, internalized ableism manifests in two major ways: disabled people distancing themselves from one another, and emulating ableist norms (Campbell, 2008). In this section I show how the Narrators enacted their political disability identities in ways they hoped would create equity for both disabled people they knew, and disabled people broadly. As they enacted these identities, they simultaneously represented ableist norms or shied away from disabled people. Sometimes, Narrators described relationships between their internalized ableism and how they enacted their political disability identities, and other times they did not indicate they were aware of the ableist

ideas they communicated to me. I organized these findings into experiences in schools, hospitals, and within their social relationships.

Schools

Early in their school years, all but two Narrators learned to feel shame about disability. To look, act, or speak differently exists outside of the norm, so the Narrators attempted to pass (Goffman, 1963) as able-bodied or divert attention away from their disabilities. They also relayed instances of enacting their political disability identities. For example, Stephanie shared how she kept her scarred, differently-shaped legs covered: "I was in sports, a couple, but I always wore sweatpants, even in the summer…never changed in front of other people." Though she hid her disability in school both because she feared her peers and because she wanted to be normal, she was active in "a youth group of kids with SB [Spina Bifida] that went around talking about pride and other stuff. Now I am a leader." Stephanie recognized that she didn't want people to feel they had to hide their disabilities. Being a leader helped Stephanie reconcile some of her past experiences, but she continued to make internalized ableist comments like: "No, I mean like those kids were really disabled." It seemed Stephanie could harbor ableist ideas while concurrently enacting her political disability identity to the aim of helping other disabled people. Stephanie enacted her political disability identity by doing advocacy work and mentoring other people with Spina Bifida. She hoped to reduce the complexity of receiving public assistance.

Gail, too, tried to obscure her legs and her gait: "I just couldn't take all those eyes on me, so I used the railing to support myself or waited until everyone was already in class to go into the halls" One time, her father said to her at a young age "Can't you just try to walk normally?" His words were soft, but she carried those words with her for a long time: "I didn't want to be disabled, see disabled, hear disabled or anything else. That was it for me for many years. I was

not right, so it was best to hide it." The idea of "not right" is one Gail felt represented her and she said it often. An interesting thing happened after she chose to go to college: "Sex, choosing not to marry and go to work, and pot. I don't know what it was, but it got the gears in my head and heart going. It would still be a few years until I really faced disability." To that point, Gail quashed her political disability identity or at least kept it confined to her thoughts, but at age 18, she discovered the freedoms of feminist thought, the sexual revolution, and drugs. She claimed these enabled her to confront her fear of her own disability:

> It was just me and I knew me. My lovers knew me, and we were starting to feel free, so I sort of had this conversation with my body and said, 'I'm alright', so I started telling people that and I wanted other people with all kinds of bodies to do that, but I still wasn't going to go to the movie with another disabled person.

Despite her claim of confronting her dislike of disability, the internalized ableism of not having a so-called normal body persisted. Gail and Stephanie enacted their political disability identities while also behaving in ways that represented ableist understandings of what the body should look like or be able to do.

Other Narrators adopted different approaches to enacting their political disability identities. For example, Felix, no longer able to cope with high school bullies, began to act the trope of the disabled as monster: "They [schoolmates] treated me like a beast and [so] I was one." He noted how he began acting aggressively, growling at people when they approached him and lurking in the dark corners of the hallways so that he might not be seen. Consequently, "I felt like Quasimodo. You know, the gentle, but scary monster and I did scare them." This tactic was only marginally successful at reducing the abuse doled out to him by the other students. It also represented embodiment of the very thing his oppressors made him out to be, a monster. Felix

internalized ableist stereotypes of what disability is. Because he felt like a monster, he soon struck back: "You know, instead of saying fuck off, I learned to say, you know, hegemony, neoliberal, et cetera." Wielding these words as verbal weapons bewildered the assailants and empowered him: "That's why I started in this field [social justice/education] really, as a way save myself."

Though Allister did not experience a great deal of bullying, he nevertheless experienced marginalization in school. He had few friends and was passed over for opportunities in sports and academics. One of his biggest complaints was always being grouped with disabled people for activities. He said, "Why should I have to be with other disabled people? I wanted to be in the advanced classes and could be, but I was always fighting against being placed with kids that looked disabled." Allister highlighted his school's poor inclusive practices and what it meant to look disabled, while also noting how little he wished to be around disabled people: "This is where people say I am not very disability studies, because I just have no interest in being around other disabled people just because we have a similar attribute. Seems like segregation." While Allister's comment about what disabled people look like exhibited internalized ableism, his reaction to being denied certain opportunities uncovered another layer: "At least I actually am smart, so I have that and when people do listen to me, I can do things to help other people with disabilities." Allister leaned on traditional assumptions about intelligence to separate himself from *real* disabled people, reinforcing intelligence as a primary indicator of ability and the ableist norm that it is okay for you to be disabled/dumb [sic] as long as I am not. And yet, Allister used his writing and philosophical skills to further disability rights and improve public understanding of disability. He felt that he always had to develop and showcase his academic skills to diminish how disabled he appeared and thus utilized these internalized ableists ideas to

enact his political disability identity. Resulting from his participation in this research, Allister completed his memoir and continued his graduate studies, noting that: "Everyone disabled or not should have the opportunity to succeed or fail and too much of all this [disability rights movement] is about giving disabled people more than that." Allister disregarded that all people need help at some time in their lives. He also neglected to recognize that success is rarely an individual pursuit. Allister recognized that stigma existed and that it constrained disabled people, but regardless, he felt it was up to the individual to ensure his or her own success. In other words, disabled people should overcome their disabilities.

Throughout their schooling, the Narrators exhibited internalized ableism while simultaneously enacting their political identities in ways that criticized society's marginalization of disabled people. When Bryluen was in junior high school, her notoriously sadistic gym teacher forced her to run a mile. It was snowing and Bryluen's body was permanently weakened from German measles and her other emerging disabilities. Nevertheless, he pushed her to run more until she collapsed, unable to breathe.

> I remember the huge, lumbering man yelling at me to keep going. My body, all the scars, my rapist, and [gym teacher]. They were all one saying the same thing, 'you are worthless' and I agreed. I just laid there as he said it over and over.

Bryluen was often unable to separate her disabilities and her traumas, because they were so closely linked in her mind. In our conversations, Bryluen often wrote "I am worthless." Apparently, she has said this her whole life and, when I asked, "Why do you think you say that so often?" She responded "I get the irony. How do I help other victims of rape or oppression because of their disabilities, when I can't see my own worth? Shrug. I do my best. That's what I do." Bryluen's "best" meant she tried to remain alive, which she meant literally as her

disabilities became increasingly severe. She was motivated to stay alive so that she could continue to help disabled people and victims of rape or abuse.

These Narrators enacted their political disability identities in tandem with internalized ableism they developed while in school. As American culture is largely organized around able-bodied norms and schools are spaces where young people learn how to be citizens, it is unavoidable for disabled students not to internalize ableism to some degree. However, the Narrators could maintain these aspects of their personalities and continue to do work that attempted to dismantle ableism.

Hospitals

Western hospitals are not known for their humanism. Patients may feel lost as a constant flow of strangers come in and out of their rooms, poking and prodding. In a place so focused on repairing the body, an emphasis on able-bodiedness is unsurprising. After spending time in hospitals, the Narrators internalized some of the norms to which they were exposed. Simultaneously, the Narrators developed understandings of themselves and the systemic ableism in the medical field against which they later used as a springboard to enact their political disability identities.

When Tim was recovering from an accident that caused a TBI (traumatic brain injury), he also had to quickly learn a new set of rules associated with the rehabilitation hospital. His body didn't work well and his mind couldn't hold thoughts together. His memory was temporarily gone. He explained, "The only thing I had. I mean literally the only thing I had was emotion. A big ball of incomprehensible emotion that meant nothing to me." Gradually, parts of his body and mind healed. Yet, when he tried to move, the nurses prevented him from doing so. Tim explained, "This is when I knew I was different. I mean I already knew my body was different,

but this moment I learned I had to act different, maybe forever...I could no longer just be Tim. I was disabled." Tim had to submit to moving when nurses said to move and sleeping when they said to sleep. The more he chose to follow the rules, the more freedom he got, such as going to the bathroom, using the recreational room, and eventually going home. Even after leaving the hospital, he reflected on playing the role of a helpless disabled person, noting: "I have been playing the role ever since." Tim explained:

> I couldn't go anywhere without people knowing or asking about it [his TBI]. I couldn't go to class without professors asking about what they needed to do. Disability always was there even when it didn't need to be, like when going to a restaurant and a waitress asking all kinds of questions. Just let me eat!

Tim understood the superiority of able-bodiedness. The role he identified is one of a disabled subjugate: "I feel like I am always asking permission to exist." In a later interview he said: "I have to keep myself in check. When I go to a public meeting or present at a conference, I have to say 'Tim you are here because you are disabled [intended as positive in conversational context] and have something to say about it. I have to put those normals in underwear, so I can feel equal." Tim was referencing the age-old trick of imagining an audience in their underwear to feel less nervous. Unlike the Narrators above who were ironically motivated by internalized ableism in schooling, Tim recognized the need to push against this internalized ableism thus enacting his political disability identity.

Feelings of subjugation, worthlessness and needing permission to exist permeated other Narrators' lives. Forced to incessantly repeat her psychiatric history to countless doctors, Flora reflected: "Each time I tell it, I become more detached. It's not my story anymore. They took it from me, but not the pain only my personality…and I guess it doesn't matter 'cause I don't

matter." Flora internalized the bureaucratic process that prioritizes forms, order, and redundancy over people, and in doing so, felt irrelevant. A young Jo reflected on feeling stripped of her personhood too when visiting her mother in a psychiatric ward:

> There was a man in there slumped over a cup of coffee moaning. I wanted to help him, but what could I do? I wondered if when I was 'not there' [referring to her dissociation], people looked at me the same way. Was I not worth helping? I guess not. No one had.

Jo started to question herself, her value, and the value of people who have severe psychiatric disabilities. At first, Flora washed her hands of dealing with her doctors. She simply stopped going so she didn't have to think about it. Jo did this too. As she began dissociating less frequently, she chose not to talk about it: "It was ending and I didn't want to be that any more, so I simply started my life anew and locked that away." As Jo and Flora had a bit of respite from these experiences, they chose to talk. Flora told me: "I may not be able to do anything about it [the medical system], but if I talk long enough to enough people, maybe just maybe something changes or at least I feel I did something." Similarly, Jo said: "I thought about all those other little girls, boys too. If I don't tell my story, then I feel I am complicit in their abuse."

This ongoing compliance with rules about how to act as disabled people was also reflected in how Narrators' political identities were habituated through interactions with various social systems. During her long stays at the Shriner's hospitals for polio treatment, Gail experienced an ecology built around illness and disability:

> We got up, washed, dressed, ate, had treatments, had visitors, and had rules. It was always exactly the same, like robots, and if you stepped out of line they'd tell you 'you are not going to get better if you do that,' so we did that, whatever it was.

Within the hospital there were specific rules, a lexicon, and a well-defined social stratum among

the girls, all to which Gail quickly became acculturated. She knew, for example, that if she did not participate in hazing another polio patient who had an intellectual disability, that she would never get to move into the "popular girl section" of beds. Gail did participate in the hazing and it haunts her still, seventy years later:

> I will always hate myself for that. I can't take it and I can't undo it, but I vowed to do good for others from then on. Why didn't I make the connection between my disability and hers? I was just a little girl, but ughh.

Despite her guilt or perhaps because of it, Gail recognized how much this event shifted her political compass and her feelings about disabled people. Her response to bullying the girl was simply assimilating into the hospital culture and internalizing ableist norms of bodily hierarchy. However, in the aftermath, she self-evaluated and understood how one moment would affect her for many years. The shame she still felt:

> I used it to keep me going when others stared at me and later I used it to teach my daughter about seeing people with disabilities. I don't know. It became that moral guide or how I assessed situations about disability and then I'd act. Funny since I have so many examples I could use, but my head always goes back to [girl with the intellectual disability].

A single ableist incident seventy years ago seems to have had a profound effect on how Gail enacted her political disability identity. Her thoughts returned to this time frequently, which motivated her to teach her daughter about disabled people and develop a disability studies minor before retiring. Nevertheless, she chose the Girl Scout narrative in Chapter 5 as a critical moment in the development of her disability political identity. The Girl Scout story of the troop coming to the ward and earning their "pity merit badge" appeared to elicit anger and motivation in Gail,

which she stated are feelings she associated with politicism. When reflecting on the time she

bullied the girl, it elicited reflection and evaluation, which she felt was more personal.

Both Bryluen and Flora spent time in psychiatric wards when they attempted suicide. Flora told me, "You have absolutely no power in there. They take your shoes and your freedom. It makes you go even nutser [sic]." This powerlessness, which she told me was also perpetuated by her psychiatrist and the Department of Welfare, left her believing she was powerless when she left the hospital: "I couldn't cook for myself or feed my baby. I couldn't work or be creative. I couldn't do anything. The hospital made it worse." Flora internalized her supposed worthlessness as a person with mental illness. Bryluen said: "I didn't have any control in there and lack of control was one of the reasons I tried to off myself." Like Felix's response to bullies by acting the part of a monster, Bryluen became enraged in response to the memory of her rapist and the confines of the hospital: "It was even worse in there than it was at home. I searched for anything I could kill myself with. I became agitated and desperate. I raced around going mad." She felt compelled to become the trope of the raving lunatic and, by internalizing institutional ableism, Bryluen suggested that the hospital's environment contributed toward her actions—the cure for the crisis causing the crisis, perpetuating a traumatic cycle. Feeling powerless caused these Narrators to make changes in their lives outside of the hospital. Flora described: "Well, I could see what the hospital did to me and Clyde needed me and if I was ever going to do anything about how people react to mental illness, I needed to start by getting out of bed. So I did." Bryluen told me: "Some say I need to go back to the hospital. There are many days I can't get out of bed or even type, but on the days I can, I force myself, because my pen is my sword. It is the only one I have." These Narrators demonstrate that being political need not (and often cannot) be what might be considered activism. Sometimes enacting the political identity means making the choice to flip

open the computer or deciding to get out of bed.

Social Relationships

Narrators also evidenced internalized ableism in their social relationships. Allister felt torn about his disabilities: "I'm alright being disabled, but I don't want to be disabled, because people are ableist." He did not state he liked his disabilities, only that he was "alright" with them, suggesting he would be rid of them if it meant escaping ableism. Eliminating disabilities represents dominant able-bodied thinking and an internalization of that idea. However, Allister's words remind us that internalization of ableist norms is a response to oppression as a stimulus, rather than a poorly-made individual choice. Church was important to Allister. In his congregation, he and his family had friends they had known for decades. Allister wrote about attending church on a day where people could be blessed by their minister, noting: "I say I don't really want healing for my disabilities so much as I want to have the strength in order to deal with my disabilities." Perhaps in contradiction to this sentiment, he then expressed his desire for a life not defined by disability: "I just want to live my life and be judged only for my merits, not my body." Allister approached his church, his community, and the places where he has worked in the same ways:

> I go in and act like there is nothing to see. I perform the best I can and don't ask for anything. Sometimes it works and people more or less disregard my disabilities. If you go in and show competence, you don't need to prove it.

On one hand, Allister enacted his political disability identity by exhibiting that disabled people can accomplish things and that there is no need for awkwardness or pity. On the other hand, he reinforced ableist norms in his description, attempting to erase the presence of disability and disregarding accommodations that others may need in various contexts to participate.

Felix and Allister also talked about not having access to romantic partnerships, though evidence of ableism persisted in their commentary. Felix has never had a girlfriend and was lonely. He explained, "Steve, it's just so hard man. I have so much love to give. I have so much to say." As we talked, I came to understand how heavily this weighed on him and how substantial of a problem he felt this was for disabled people. He told me: "Standards of beauty. What is it that makes blue eyes or big biceps—or whatever—a nice pair of whatever more appealing?" When the conversation went in this direction, he often became sullen, but when I asked him what interests him in a woman, he replied:

> No, I guess I'm just like everyone else. It's fucked, ya know. I'm not against the idea of dating a person with a disability, but, I don't know, I just don't really—Dude! I am the problem! I am no different! What the hell?

In envisioning himself with an able-bodied woman, Felix realized how he had internalized able-bodied standards of beauty. What he neglected to recognize was that my question about characteristics was not intended to mean bodily characteristics, but perhaps interests or humor. His default answer was one connected to the body. At one point, Felix established an online discussion group about the topic of disability and dating, which was not so much a dating site as it was a place "to discuss the problem of dating for people with disabilities, but of course that lasted about a day before people wanted to find a date. Funny thing was, it was all guys! Yep. It died real quick!"

Allister had been unsuccessful cultivating relationships with women. This difficulty frustrated him even more when: "These bullies thought I was gay. I mean, they mistook my disability as gayness. I don't know how. I am not gay and I don't know how anyone could think that? I just can't find a woman because I am disabled." Allister defended his heterosexuality at

the cost of lambasting disability and homosexuality. He accepted that his lack of success with women was wholly connected to his disability, reinforcing his belief by repeating it over and over. Both Felix and Allister thought little beyond the body—perhaps because of repeated rejection because of their own bodies, or because they held able-bodied beliefs, thus demonstrating the ramifications of internalized ableism.

In this section about internalized ableism, I discussed three sub-themes about the contexts in which Narrators enacted their political disability identities: School, hospitals, and social relationships. In most examples, Narrators enacted their disability political identities in ways that promoted equity and disability pride while also maintaining ableist ideas. In schools, Narrators hid or diminished their disabilities while advocating for other disabled people. Felix felt so overwhelmed by bullying that he personified the monster peers made him out to be. However, this act became a catalyst for him to develop a scholarly knowledge of ableism as a new mode of fighting back. In hospitals, Narrators learned about ableism as part of institutions and as part of people, using this knowledge as a foundation for enacting their political disability identities. These included political acts like giving presentations about disability, but also acts like summoning the energy to open a laptop and plug away at a blog post or respond to disabled peers. Finally, there were personal relationships. Allister enacted his political disability identity by trying to show people that disabled people are: "No big deal and can do anything we want." His words are both political and show his internalization of ableism. Romantic relationships were also areas of contention. Felix and Allister reinforced ableist and perhaps misogynistic and homophobic notions of romance, sexuality, and bodies. Felix had a moment of clarity, realizing he contributed to systems of ableism. He wished to do something to change or at least bring various disability-related topics out into the open. Even as his attempt quickly devolved, it

represented an enactment of his political disability identity. The Narrators agreed on what ableism was. They agreed that there was a relationship between lack of financial security and disability. They also agreed that attitudes of people systematically marginalized them and there was little hope of seeing significant change in the near future. For each of the Narrators, reflecting on the critical moments discussed in Chapter 5 and other important moments in their lives resulted in feelings that they must do something about ableism and they did.

Ethics of Care

From an ethic of care standpoint, all people live in a state of temporary able-bodiedness and the natural need for care should not reduce a person's autonomy, social rank, humanness or right to dignity (Kittay, 2011). The dynamics of care within all relationships can and should be thought of as reciprocal rather than unidirectional. Within disability frameworks, scholars and activists both point to the need to value interdependence over independence—noting that we are all, disabled or non-disabled, dependent on others in important and mundane ways. In this section I discuss the care dynamics that existed in the relationships between the Narrators and their friends and family, as well as how Narrators developed a different kind of ethic of care between Self-and-Other as a part of their political identities. Narrators, for instance, often enacted an ethic of care in response to their personal experiences, which served not only as ways to care for themselves, but also as ways to care for other disabled people. In this way their political identities were directed toward change, but also out of a concern for both self and others.

Friends and Family

Latefor described what I saw as her ethic of care, as demonstrating both dignity and equity. As described in Chapter 4, Latefor held a subjugated role in her family while her husband

was alive and stepson was living with them. Although she contributed a great deal to the family through her paid and unpaid labor, she was perceived as a "dummy," "worthless," and "not worth lovin'." Equity simply did not exist in the household: "When he said cook, I cook. When he said, sleep, I sleep. When I asked to go to, um whatever that store is, he said no, so I didn't." Latefor talked about always knowing that something wasn't right and that her treatment was unfair. When I asked "Well, what could you have done about it" she replied, "Nothin' just keep workin' and keepin' my head down. Eventually, I'd come up." For forty years there was little reciprocity in their relationship and when her husband died, Latefor enacted her political disability identity in a way that seemed to speak back to her experience of being taken advantage of. She described:

> My animals give me milk. I make more cheese and eggs than I can use. Can't sell it, cause them laws [related to the sale of unpasteurized milk products]. Could give it away. I do, but still too much. I think of them old ladies down at the center. Everyone could eat and then have money to live on too.

The women she referenced were disabled women employed at a sheltered workshop where Latefor sometimes worked and volunteered. She told me they did not earn much money. After years of understanding her inferior position in her family, Latefor hoped to nurture relationships with the women she thought of as vulnerable and needing aid. Her words about sharing excess resources with others communicated her generosity, dignity, and reciprocity. She considered the women at the center her friends. Her words also communicated her general political perspective about disabled people: "They should all have food, all a house, all love and family." In these simple actions, Latefor enacted a political disability identity by creating the kinds of relationships she never had because she felt it was the right thing to do. Latefor's ethic of care

related primarily to equity and dignity. The women at the center likely had some additional support needs and they were not paid a fair wage, despite working hard. Latefor understood that their compensation should not be any less because they had disabilities and sought to rectify their low wages by contributing what she had. In this way she responded to what she saw was an unfair, or possibly exploitative, situation by making cheese with surplus milk she had at the farm.

Bryluen desired an ethic of care that was reciprocal and promoted dignity. Like Latefor, Bryluen was the disabled partner in her marriage who tended to contribute the most but was respected the least. She chose to call her partner "Significant Other" because the quality of their relationship had deteriorated to the point that she "rather not think of him more than necessary or in real terms." Though Bryluen needed significant support because of poverty and her multiple disabilities, her Significant Other placed onerous demands on her:

My Significant Other has entered the room. Now, he stares at me with that haven't you wasted enough time [with writing] look and repeats, 'Are you going to be done, soon? You need to make dinner.' Resentment flashes through me. He's an adult. He could make his own dinner. We've been down this road so many times, I've grown exhausted with even bothering to comment. It only results in more screaming and attitude from him, and I'm just not in the mood, right now.

The idea of care extended beyond that of the partnership. Bryluen's Significant Other did not make much money and he did not share it with her. Recently, Bryluen was forced to quit her job due to her deteriorating health and had been attempting to qualify for Social Security Disability Income (SSDI). She relied on the internet fundraising tool "Go Fund Me" to help pay for medication and for her car, which was recently repossessed. She described the experience as:

Completely and utterly demeaning. Every document I submit is questioned. No one ever

responds, so you spend hours on the phone and never get anywhere. The other day a clerk

had the gall to ask me 'Why do you think you deserve money from the government?'

Conceptualizing an ethic of care as part of citizenship suggests that as a people, we should

promote the dignity of individuals and act to reduce suffering. Not only was Bryluen neglected at

home, but she felt the government willfully made disabled people suffer unnecessarily. This

angered her: "I am going to die. Perhaps the sooner the better as far as they are concerned. The

government doesn't care. I don't know why I bother." The government reduced their bodies,

time, self-esteem, and their lives to mere numbers. An individual cannot provide care unless

they, too, are cared for. In this case, Bryluen was unable to provide self-care. It is these kinds of

relationships between individuals and government organizations that contribute toward

maintaining a system that rarely permits disabled people dignity or the ability to reciprocate care.

Bryluen had little energy, no money, and very little motivation to do anything, but she

spent her time writing social media updates about the process of applying for SSDI so that others

could see what it was like and perhaps avoid the paperwork pitfalls. She felt, "This may not do a

lot, but it's all I have to fight with. If I ever get enough [money] to survive on, I will have to do

something about this awful process." Bryluen felt she had little power, compounding her

suffering due to inadequate health care and other resources, but what little power she had she

directed toward trying to make sure others might be helped by sharing what she learned in

dealing with the system. In fact, it was her lack of power that compelled her to do something

about it—hopefully helping others to not have to go it alone like she had to. In both her

relationship with her Significant Other and with the Social Security Administration, Bryluen

experienced condescension and dismissiveness, exacerbating her already strained existence.

These demeaning relationships made it difficult for Bryluen, but these difficulties turned into a

political act, fueling her desire to care for others who might benefit from her experiences navigating difficult social service systems.

Some participants redefined care in ways that creatively enacted reciprocity and mutual support. Flora's relationship with her extended family was loving, supportive and equitable. However, applying for public assistance placed her in a demeaning position. As with Bryluen, Flora reported draining experiences applying for SSDI:

> Appointments—I pay for the bus, I go. I go. I go. So many appointments and so many of
> them pointless. The irony is that if I had the energy, money, clarity, and mood to do all
> the things I need to do to get Social Security, I wouldn't need it.

Flora described the process of securing benefits as exhausting and defeating. She felt that being able to take care of her son and herself should not be so difficult and that she should not have to feel like a beggar to receive supports. Unlike any of the other Narrators, Flora lived near her parents. In fact, her parents sold her the home she grew up in on long-term rent-to-own terms. They also visited often, helped with the care of Clyde, and provided some food and money. She stated:

> I don't know how I would do it without them. We are like three-way parents and I don't
> feel they look down on me in any kind of way. It's a good thing we have going on if I
> could just contribute more.

Flora challenged the notion that caring for oneself and for one's child must be a solitary effort. In sharing responsibility of care, her parents were able to all provide supports in ways that did not diminish feelings of equity. Flora noted, "I do what I am able to do, which might be cook on Monday and wash clothes on Tuesday and I do stuff at their house too. The parents pick up what I can't do." Despite these rewarding and reciprocal home relationships, Flora did not always feel

like she was contributing enough because she was "required by the government to feel subhuman. I sometimes think I'd be better off not applying for SSI. The process fills me with self-doubt about my worth as a mom and daughter." Because of Flora's negative experiences with the Social Security Administration, she enacted her political disability identity by criticizing the government on various social media sites. She also taught her son, who has Asperger Syndrome, to advocate for himself, knowing that he may someday need to seek support from government agencies. Flora's family's ethic of care engendered a sense of equity, support, and love for both Flora and Clyde. Flora contributed as much as she could and located any diminished capacity to care as resulting in outside forces, rather than her own capacities. She also saw it as her parental, but also political, responsibility to help her son advocate for himself.

As the only other parent in this research aside from Flora, Gail often talked about being a pansexual, disabled mother. Gail and her wife always had adequate resources to care for their daughter, who was born during Gail's first marriage. Disability rarely affected their early life until one day: "I saw her walking down the hallway like I walked. I was so mad and embarrassed, but she said, 'I thought you'd be proud of me for walking the same as you.'" Gail did not think her family was affected very much by her disability. She also did not think that it mattered that she rarely talked about her disability. Her daughter's naivety in that moment caused her to reassess her approach to discussing the topic. Gail said, "From that point onward, we were totally open talking about sex, love, race, bodies—disabled and not, and all the hate in the world people have about these things. She didn't get it then, but we tried." When Gail accepted a professorship in the late 1970s, she and her family moved to the Midwest, where she experienced some of the hatred she had talked about with her daughter: "To be a lesbian and a cripple in those days and in [that area] was a lot to put on my family. I had to teach people, but

also learn when to back down and hide." Gail felt bad because she knew her daughter would feel the brunt of oppression from both her parents' marginalized identities. For example, when attending a neighborhood picnic, other adults said to Gail's young daughter: "Tell your parents, this is a family event, so maybe you should go home." Gail spent the next two decades working to make change through advocating and challenging community policies, such as where disabled people could sit in the movie theater. She also carved out a space for her family, but:

> In the end, I still felt bad [about what my daughter had to experience]. So, we took every last cent we had and sent her to [famous liberal arts college]. It didn't fix anything, but it made me feel good to sacrifice for her after she sacrificed for me for so long.

Gail could not take away the fact that by having to move for her job, her family experienced marginalization from neighbors and the larger community. Although her disability and sexual orientation was a problem for the people in her neighborhood, Gail recognized this and tried to reconcile it by educating her daughter, fighting for equality in their town, and ultimately sending her to a university they could not afford. Gail felt guilty about some of the bigotry she and her family experienced. I asked her why she felt so guilty and she said: "Well it was because I chose to bring her [my daughter] into this awful world of bigots and haters." In trying to carve out her family's space, Gail emerged as a more deliberate activist and "became more so as I gained seniority at the university." Being a disabled parent meant having to act in political ways. Most discussion about ethics of care are centered on the disabled body and creating relationships which replicate entrenched ideas of what care means (e.g., to be a burden). Gail discussed how as a disabled woman she was also a care giver. She made sacrifices, both financial and social (e.g. hiding her sexual orientation) to make up for the ableist and homophobic experiences her daughter endured because of her mother's multiple marginalized identities. While Gail was

enacting her political disability identity by trying to increase awareness and acceptance in her Midwest town, she also pointed toward a common perception about care. We think of care as a more capable person providing care for one less capable. An authentic ethic of care recognizes that care is mutual. In this example, Gail attempted to make sure her family did not feel the brunt of oppression and in so doing, merged her political or activist work with sacrifices for her daughter.

Ethic of Self-Care

An ethic of care forms not only from relationships between people but also the relationship a person has with self-care. The Narrators' early experiences shaped their understandings of and reflections on how they were cared for. This included experiences ranging from painful medical treatments, to bullying, to abuse. Reflections on these events led Narrators to develop new ethics of self-care. They also shared or spread this enactment of self-care with others, making this an integral part of their political disability identities.

Stephanie described two events representing this ethic of self-care. She shared an experience in elementary school when:

> I didn't want to pee through a tube anymore. I wanted to go to the bathroom like my friends, so I would go in the bathroom and rip it [catheter] out and reinsert it later. I was used to it [the discomfort]. My parents wondered why I soon had an infection.

While the act of removing and reinserting the catheter may have been medically inadvisable, Stephanie claimed a right to "pee." She told me this was a significant moment of self-determination and self-concept, giving her a sense of empowerment. When "the doctors or your parents make all the decisions, it feels pretty darn good to do something for yourself." Today, rather than pulling out catheters in bathroom stalls, she worried as she tried to become pregnant.

She and her husband had been trying for a few months to conceive a child:

> I am what they call a 'high risk' pregnancy. Do you know how hard it is to get an
> OBGYN for a girl with SB [Spina Bifida]? It's absurd. I think I am going to have to
> deliver it myself at this rate. As if I didn't have it bad enough, 'cause women with SB can
> have a hard time getting pregnant. This system needs to be better. I'd be better going out
> of the country.

Though having trouble accessing the care she needed, Stephanie exhibited a certain confidence. She cared greatly for her health and the health of her future child and pleaded for equitable treatment. When I last asked her, she continued to make calls to doctors and contact various Spina Bifida groups to help her access appropriate medical care. Meanwhile, Stephanie redoubled her efforts at work to ensure her clients didn't experience the same inequities:

> So many of our clients have the most medical needs and the least insurance. It is the first
> thing I try to help them with, particularly disabled women whose reproductive health is
> often ignored. I gently encourage them to follow up on specific things like mammograms
> and paps, but then I don't want them to feel like I am trying to act like mommy.

Stephanie's examples highlight the tension between her desire to direct her own care and her role as a cautious advocate (though not "mommy") to assist disabled women in doing the same. She reflected on the times when she felt people made all the decisions for her, yet also conveyed her desire for disabled women to have access to and take advantage of the healthcare system. Through these actions, she enacted her political disability identity and spread an ethic of care for other disabled women.

After earning his graduate degree, Tim accepted a job as a home health aide, eventually expanding to a career as a caseworker. He explained: "I recovered as much as I was going to

from the TBI, [partner] left, I studied about the sociology of disability, so I guess it was time to do something with it." During the time he was a home health aide, one of Tim's clients was a woman who used a wheelchair and did not use speech to communicate. This challenging position caused Tim to question the connection between theories about disability and practice:

> I was frustrated. I didn't know what she wanted. All the things I learned about independence and self-determination were going out the window, but then she purposefully rolled her chair right over my feet. I think I told you this, but it hit me. She was communicating and I wasn't listening. Until this point I hadn't really let people know I often process thought only as emotion and only went to the therapist, well, not enough. Just like her and other people, communication happens in different ways. I wasn't telling people either.

Tim's epiphany was two-fold. He understood that to facilitate others' understanding of him and thus have his own care needs met, he had to be more explicit about sharing how his thought-to-communication process worked. He also learned a lesson about communication with other disabled people. He continued: "…and it's the ones in the worst situations like institutions or bad group homes that have the least communication, which make them angry, which ya know, goes in a circle." Tim understood that many bad reactions to disabled people who had unreliable communication systems were the result of inaccessible environments. He began to apply his work experiences to his own ethic of care, because: "I was really struggling with depression and finally understanding her [woman who used the wheelchair] showed me how to feel better." Tim described how is ethic of care changed. From that point forward, he recognized that disabled people are experts about their own bodies, so when he provided care at work, he always consulted his clients before acting. Tim also made purposeful efforts to be clear about his needs,

taking a more active role in his own care. Tim then "…went to my TBI support groups and tried to share what I was learning. It felt so necessary. They didn't really get it." As Tim claimed a more active and mutual role in his care, he enacted his political identity by trying to educate his peers with brain injuries.

Jo's childhood experiences were characterized by atrocities of neglect, torture, and sexual abuse including child pornography. She described how she had little choice but to develop strategies for survival because the parents who were charged with her care sought her destruction. She explained:

> I developed an immense power of inward concentration as a means of surviving the brutality and debasement of my childhood. My core experiences were lessons in abject helplessness and powerlessness, but within my head I held a tiny turf of secret sovereignty. I built an unbreachable soul keep there, at the farthest reaches of my mind. This enabled my survival.

She described the dissociation above and as a fog that overcame her, not as a mental illness, but as a survival technique or self-care. Since no one else was going to help, no matter how vulnerable she was, she had to be the one to ensure her survival. When she finally left home, discovered her political orientation in college, and moved into adulthood, the concept of care became central to her person:

> First, I have to take care of me and I do with exercise and good eating. Of course, I take care of my husband, but the thing we both do is the protection of all animals. Big, small, human, or insect—they do not deserve to suffer.

Reacting against her early experiences, Jo designed an ethic of care that abandoned her childhood of inequity and destruction, to an adulthood filled with peace, security, and politicism.

Jo participated in an extensive list of self-care activities. They include: frequent

meditation, meditation retreats, veganism, homeopathic medicine, running and other exercise,

acupuncture, acupressure, massage, organic and gluten free eating, reading self-help books,

psychotherapy, and participating in Quaker Meetings. She described:

> I will be healing my entire life. I won't be able to tip the scale back to balanced, but I
>
> have been able to claim, 'I am done with that' to parts of my life. I built a life so I can do
>
> these things for me. I need to do them to be okay and to be healthy mind, heart, and soul.
>
> It's a lot, I know, but I can't feel bad about pushing back against half my life trying to
>
> overtake me.

Jo understood that her early life stripped her of any dignity, equity or selfhood. She realized that

there was no recompense for her past, and thus her purposeful pursuit of self-care provided

security, comfort, and health. Through these self-care acts, she also reclaimed her dignity. As

self-focused as these behaviors appear, Jo was an advocate for the reduction of waste, the

elimination of meat as a food source, and a more flexible health system, which includes

homeopathic options. She also explained:

> There is a connection between all the natural and cathartic things I do and people. I can't
>
> abide the idea of people suffering. I think the more suffering I see in the world, the more I
>
> do to stop it. I help out with centers for domestic abuse, particularly Deaf and [husband]
>
> and I do so much work for [organization for the protection of animals].

Jo created a relationship with her world that achieved reciprocity, dignity, and shared

responsibility. Born from her traumas, Jo's ethic of care evolved into an ethos characterized by

care for vulnerable beings such as other disabled or disenfranchised people and animals. By

enacting this type of care, she redefined herself and expressed her political disability identity.

In this section I discussed how Narrators developed ethics of care as responses to their experiences, facilitating the enactment of their disability political identities. Often characterized by discrimination, debasement or trauma, the Narrators relayed their understandings of what care meant and how it manifested in their relationships with family and friends, with institutions, and with themselves within their respective life contexts. Although we don't necessarily see care work as activist or political work, the stories of the Narrators show that when directed at marginalized groups or oppressed individuals or even towards one's self in ways that refuse subject-object dualisms and enact mutual respect and reciprocity, care can be integral to one's political identity.

Working for Change

The Narrators all hoped for and worked to change how disabled people are treated. Though looking different for each Narrator, I interpreted the idea of working for change as efforts to affect change in not only thoughts but also actions. Some Narrators selected or came upon professions where they could enact their political disability identities as part of their work. Other Narrators engaged in disability advocacy or awareness-raising as modes of politicism.

Choosing Professions that Supported Disability Rights

At one point in their lives, six of the nine Narrators were employed in jobs directly connected to disability. The political scope of these jobs ranged from general care giving to advocating for disability rights. In these positions, the Narrators were able to enact their political disability identities while simultaneously earning a living.

In their endeavors to work for change within the disability community, Stephanie and Tim chose similar types of positions—positions that paid less than their previous ones. Stephanie's career went in a direction she did not initially intend. She earned a master's degree

in special education, because she thought, "I could do it well and serve as a positive role model for students." After a few jobs, she settled into working as a services coordinator and coach for disabled people. When I asked her about the lower pay she responded: "Well, money. We do okay and while I would make more teaching, this is where I am needed. Here I help empower our people and I see immediate results." Stephanie was very clear about the sacrifice she made so that disabled people might have better lives:

> I do this because most of our clients are young and don't know what they are entitled to. So much paperwork and navigating the system. I think that many would end out sick and poor without the advocacy we provide. I like to think and I do know some actually do go on to college, have jobs, and secure places to live.

Stephanie was even more explicit about how her work aligned with her political positioning: "They [her clients] become the proof we need to fight oppression. When they succeed we are that much closer to solving the problem." What she meant was that the more disabled people who have jobs and resources, the more likely there will be change, because they will be more visible and hold more power.

Tim selected a job as a case manager, ensuring disabled people received the services they needed to live as they liked and make decisions about their care. Tim said:

> Sure, I could go back doing di cast work or drafting and make three times the amount of money, but this is me. This is my career that connects to who I am as a person. Am I going to move mountains as a case worker no, but I will make a difference in these people's lives every day.

Additionally, Tim served on a regional disability rights board, presented at conferences, and published papers, so perhaps his "moving mountains" comment undervalued the contributions he

truly made. Like Stephanie, he chose to make his life about affecting change by selecting a career that was both satisfying and relevant. In both of these examples, the Narrators felt the importance of working directly with other disabled people because, as Tim said: "These are my people. I can't do anything for them without also being with them."

Earlier in this chapter and in Chapter 5, I discussed many of Gail's contradictions: struggling with her identity as a disabled person while wanting to do social work with various marginalized populations such as the LGBTQ community. At the end of Gail's career, that struggle ended: "I couldn't hide it anymore. I had to use a wheelchair. I was obviously disabled. Colleagues began asking me all the questions about the student with disabilities. I said, 'okay let's do this.'" Gail told me it was her legacy. She finally abandoned her reservations and: "came out—as disabled. They already knew I was a lesbian." While a faculty member at a university, Gail developed and implemented a disability studies minor. She explained:

> I wasn't trained in this. I went from social work to sociology. I have a disability. I read a
> lot of books. I did it not because I thought I could, but because I knew the university
> needed it. I didn't do half bad. I asked some people in the field and they said, 'hell yes.' It
> was really one of the last things I did. Then the cancer came. The lungs, the brain.

It took a lot of time for Gail to adopt a public political disability identity, one which spanned her personal and professional life. She was proud of this effort, which I found striking. Gail was in the field of sociology for over forty years, accomplishing a great deal: "Aside from being a mother, it [the minor] was the most important thing I did." Her words convey a simultaneous shift in her identity as a disabled person and as someone working for change up until her retirement.

Allister and Felix hoped for careers that involved disability advocacy work. The two

discussed how the system was set up in a way that made their dreams feel unattainable. Felix told me: "Ya know, I was never going to make it. The job interview, writing, whatever. The system to help people with disabilities is a system by the able-bodied for the able-bodied. What a joke." Allister had this feeling too: "I don't know. My brain is fit for it, but people just can't get me or won't get me. Higher education is broken. It really is." Both Felix and Allister worked part-time menial jobs, which paid just above minimum wage. However, throughout their participation in the research, both continued to search for jobs connected to disability rights and delivered advocacy and awareness-raising presentations. Toward the end of the research, Felix accepted a volunteer position on a local disability rights board. Felix told me: "I don't know what I am doing now or in life, but it is going to be in disability." The two continued to advocate for improved conditions for disabled people, even if only sometimes that work paid the rent.

Teaching Others About Ableism

Not all the Narrators had careers which paid them to promote disability-related causes. Jo's career as an interpreter for the Deaf was clearly connected to disability (the deafness as disability conversation aside), and her job had certain advocacy aspects, such as securing equitable access for Deaf people. However, she developed this role out of her cultural affiliation with Deaf people. When off the clock and among Deaf people:

> I sign about disability rights, laws, self-advocacy, and stigma. It's disgusting how many
> Deaf people have been denied a basic education about their own rights. This is the kind
> of stuff that should be in 4th grade social studies classes and here are adults with so little
> access to this information. This is the gap. This is why hearing say Deaf are not smart,
> because they close them out of the world and then blame them for it.

Because she recognized Deaf peoples' experiences with structural oppression, Jo chose to spread

awareness through her social circles. I asked her how she thought this affected the people she chats with: "Well, I hope they remember it and spreads the word, but in any case, I feel I make a big impact because other people out there are preaching often to the choir or a brick wall. This feels tangible to me." Empowering Deaf people seemed to take priority over trying to educate ableist people, perhaps because Jo "avoids confrontation in anyway I can."

Bryluen and Flora can't work due to their disabilities, but it was important for them to work for change by educating others beyond only internet postings. Flora noted:

So, what would this world be like without bipolar people? It would certainly be a lot less colorful. There'd be less art and poetry, acting and music. We'd lack some of those geniuses that invent and shape our world. In short it would be a bore…We are [supposedly] shooters, rapists, and druggies. We have to fight for our right to even live, nevertheless be valued.

I asked her how we change this view of people with mental illness and she responded: "Well, me, I talk to everyone who comes over to my house about it." Though Flora did not go out very often, friends and family came over to visit her son, Clyde, who has Asperger syndrome. Flora required all visitors to read a book about Asperger syndrome and a pamphlet about Bipolar Disorder. She said:

If they can't take it, we cut them out of our life, but I think it does a lot of good, not just for us but for all the other people they will meet. I mean how many people have Asperger's or Bipolar out there? A gazillion, right? Maybe not severe like us, but still maybe they will be more understood.

Flora worked to affect change in her family's life and the lives of those with whom she shared disability labels. She described that a world without people with Bipolar Disorder loses "an

important chaotic passion" and that she hoped the work she did reduced not only their

marginalization but also "how many of us kill ourselves."

Bryluen used her literary talent to write blogs. She told me her research about her own

body and illnesses "…ignited an insatiable curiosity into bodies, medicine, forensics, and all the

lore that surround them." She applied this curiosity to helping people, primarily on an emotional

level, but she also did fact finding and resource collecting. She explained, "Disabled people are

on the bottom rung and I did and do what I can when I can in my writing and online." Her

contributions to online communities included hosting disability-specific discussion groups led by

self-advocates. She countered hurtful or misguided posts with meticulously-researched facts. The

Internet is rife with ableist ideologies and Bryluen commented on her rationale for contributing

to Internet forums: "Because people don't think they need to consider their words or be polite.

Really I think people show their true colors and they are nasty." She also wrote disabled

characters into her books: "They may have disabilities, but the disabilities don't represent

criminality. They are just part of people. It makes my books more authentic." Bryluen used her

written voice to work for change, enacting her political disability identity to ameliorate the

treatment of disabled people.

In this theme about working for change, I highlighted how the Narrators enacted their

political disability identities. Five Narrators had advanced college degrees. Tim and Stephanie

elected to work in lower-wage fields because these jobs fulfilled their needs to contribute to the

disabled population, and because they thought this contribution would lead to a reduction in

ableism broadly. Gail conducted one final and powerful act as chair of her department by

developing a disability studies program, which was both about personal transformation and

making an impact on how the students of her university perceived disabled people. Allister and

Felix enacted their political identities when they could and where they could. They searched for long-term careers that would permit them to affect change. Bryluen and Flora, unable to participate in the formal labor market, worked for change through Internet-based applications and disseminated literature about disabilities. These acts were integral to enacting their political identities. Bryluen said, "It goes back to the spoon theory [discussed in Chapter 5]. I have so few and yet I still advocate. You can't just stop."

Conclusion

In this chapter, I examined how Narrators enacted their political disability identities. I began by looking at how Narrators internalized the ableism to which they had been exposed for years. This discussion included internalized ableism in school, hospitals, and in social relationships. Though ableist norms were entrenched in the Narrators' beliefs. the Narrators' also enacted their political disability identities in ways that attempted to dismantle ableism and promote a greater quality of living for disabled people. Next, I discussed the ethics of care in relation to family and friends and then self-to-other. Some Narrators experienced long periods of time when they had no autonomy or dignity. When they finally did experience these aspects of care, they sought to embrace it and worked to ensure other disabled people enjoyed reciprocal relationships of care both with individuals and institutions. Finally, I discussed how Narrators enacted their political disability identities by working for change. Some Narrators found careers that permitted them to earn income and participate in either policy changes or general quality of living improvements for disabled people. Other Narrators contributed to change by teaching others via experiential education or internet discussions. In Chapter 7, I return to my research questions and discuss how I addressed them through the major themes discussed in Chapters 4, 5 and 6. I contextualize my findings in relevant literature.

Chapter 7

Discussion and Conclusion

In this chapter I discuss the major themes presented in the two previous data chapters: 1) A breaking point: Reactions to strangers and acquaintances, 2) Political activism in college, 3) Changes in life enabling new perspectives, 4) Internalized ableism, 5) Ethics of care, and 6) Working for change. I put these themes in conversation with extant scholarship to help me answer my two research questions: 1) What are the political disability identities of nine disabled people? and 2) How did these disabled people enact their political disability identities? Next, I discuss the implications of the findings of this research and suggest directions of future research in the study of disability identity. Finally, I conclude this research.

What Are the Political Disability Identities of Nine Disabled People

In this dissertation, the Narrators told and retold stories about their lives, punctuated by critical moments in the development of their political disability identities. Our lives are narratives themselves, and how we live those narratives and refer to them become who we are (Vice, 2003). Chapter five presented themes related to these critical moments, representing the Narrators at specific moments in time, which they deemed significant and that revealed their political disability identities.

A Breaking Point: Reactions to Strangers or Acquaintances

The first theme discussed in Chapter 5 related to critical moments in the development of the Narrators' political disability identities recounted moments when they reached their respective breaking points and reacted to discriminatory behavior from strangers or acquaintances. The Narrators reflected on experiences in which they, like other minority groups, were labeled as malcontent or as agitators (Alcoff, 2006; Balsam & colleagues, 2015; Phenice &

Griffore, 2000; Siebers, 2011). Bryluen and Flora's experiences responding to problematic

internet posts contributed to the development of their political disability identities. However,

both Flora and Bryluen conceded that their ire reinforced what they understood as common

stereotypes about whiny disabled people (Steele, Spencer, & Aronson, 2002). Flora also wrestled

with being viewed as an unstable or unsafe person because of her Bipolar disorder label (Collins

& Mowbray, 2005; Lloyd & colleagues, 2005; Pachankis, 2007; Smart, 2009). Berdhal (2008)

found that oppressed groups that acted to reduce oppression reinforced negative attitudes toward

their group yet they also reported experiencing feelings of personal vindication because they

were also able to affect long-term change. In these examples, as in related scholarship, the

dominant group blamed the minority group for their own oppression (Davidson, 2008; Ryan,

1976; Shakespeare, 2012; Shakespeare & colleagues, 2017).

Allister and Felix, too, cared little about what others thought and consequently were

viewed as malcontents in their schools and communities. In identifying critical moments in their

experiences that shaped the development of their political disability identities, they both

identified an irony that in spaces where they were encouraged to rebel against ableism, they were

demonized even more because they had disabilities. As discussed in Chapter 5, Allister chose to

shirk off his school's disability services office and use a communication system he felt was more

appropriate. He described that after that, the office became passive aggressive in their

communication and less responsive to his access needs. Felix attended a university program that

studied disability rights in the context of social work and another university for special

education. In both places, he met women who misunderstood his intentions toward them. He

explained that the misunderstandings were likely connected to his nonverbal learning disability

and when he tried to advocate for himself, he was pushed out of the universities and branded a pariah.

As members of various identity groups gravitate toward one another, lines of demarcation begin to form between "us" and "them," creating social orders. When these social demarcations are formed between able-bodied and disabled people, they often relegate disabled people to deviant status (Hacking, 1986). As noted by Goffman (1963) and Tremain (2005), both disabled and able-bodied people contribute to the creation of these social orders.

The findings summarized in Chapter 5 demonstrated how the Narrators participated in the creation of an "us" versus "them" mentality. All the Narrators (except Flora, Bryluen, and Gail) went to college specifically for professions connected to disability (although Gail, too, eventually pursued a professional path that related to disability). Narrators also participated in protests that further divided them from able-bodied people, confirming Heerdink & colleagues' (2015) findings that once labeled as divergent, people often further resisted conformity because they were already rejected.

Powerful groups have the privilege to make their own ideologies the norm (Castells, 2011; Foucault, 1980). The significant difference between able-bodied and the disabled people creating social orders is that disabled people have access to far less power. When disempowered, a group has fewer and fewer options until they must break or rebel (Alinsky, 1971). We see this play out in the data for this dissertation. Six Narrators had few resources, little power, and when pushed beyond their limits, they reacted, sometimes forcefully. That reaction to oppressive conditions was most often the experience that Narrators reflected on as critical to the formation of their political disability identities. Davis (2001) claims that disabled people need systemic changes to achieve equality and consequently their disability identity must be tethered to

activism. While I maintain that there is more to the disability identity than political activism, the findings show that explicit instances of political activism was a major component to the Narrators lives as disabled people.

Political Activism in College

The second theme I discussed in Chapter 5 focused on data from critical moments in the Narrators' memoirs and life history interviews that highlighted how participating in political activism in college contributed to the development of their political disability identities. As Van Dyke (2014) found, who studied protests from 1930-1990, historically, there have been many links between institutions of higher education and political protests. College is a place in which young people converge and it provides the means for people to engage in political organizing. Because college students often have access to resources, even if it is only a roommate with a car or the affordance of time, they are more likely able to attend protests. Second, students at schools that have research centers or programs connected to historically marginalized populations and other contentious fields of study often initiate protests about issues that may lead to the development of a political consciousness (Van Dyke, 2014). These findings complement the findings of Cunnah (2015) who found that when disabled people go to college they are more likely to develop understandings of disability that are not based on deficit, but instead based on diversity and identity. Further, when disabled people claim disability identities, they are more likely to increase their understandings of disability rights and interact with more disabled people. My findings aligned with this scenario. Jo, Tim, Felix, Stephanie and Allister all participated in protests during college in varying magnitudes. They all had studied fields that were directly connected or peripherally connected to disability and all were marginalized as disabled people as well as identifying with other stigmatized identities. Negative views of disability are reinforced

by society through derogatory language (Longmore, 1985), public health campaigns warning against acquiring disability (Wang, 1992), warnings about risky behavior during pregnancy that could lead to disability (Armstrong & Abel, 2000), and the abuse of public funds allocated for the disabled (Russell, 2000). Narrators in this study worked to combat these and other issues related to disability rights and advocacy.

Not only did Narrators fight for particular causes, but as discussed in Chapter 2, they worked in ways that could "foreground the material conditions that can enable academia and activism to work symbiotically in the struggle for unexpected and evocative possibilities of living productive and celebrated lives" (Erevelles, 2014, Section 3). In other words, if Narrators' struggles were also embraced by their school through coursework, campus activities, and college-wide training, it opened a wide range of potential political and employment futures. For example, I discussed Tim's assistantship in college was working with an institute that studied disability. The philosophies held at his job positioned him to advocate for the clearing of accessible parking spots, which in turn led to Tim celebrating his disability identity and the sense of strength it provided him. Together these contributed toward him choosing to transform how he approached his career. The political activism in which the Narrators participated and the politically charged futures represented these Narrators' disability political identities being shaped, which was substantially affected by their academic environments. While Gail's years in higher education were far more than any other Narrator, she was not an activist until later in life, though her philosophy about disabled people aligned with disability rights activists. For Gail, internalized ableism, in this case shame, was a stronger influence than her training. In their political and advocacy work, including Gail's, Narrators worked for change, the final theme I review below.

Changes in Lives Enabling New Perspectives

The third theme presented in Chapter 5 highlighted critical moments in the development of the Narrators' political disability identities in which stark changes in their lives enabled them to form new perspectives. The types of changes Narrators experienced varied. Jo and Latefor escaped abuse to better lives, while Bryluen left a situation in which she was subjected to rape, assault, and the violent death of her partner to a life in which she continued to experience the effects of physical and emotional suffering due to her impairments and ableism. Tim became disabled after a car accident and while that was a significant change, it was negotiating his new brain function, leaving the mechanical world of engineering, connecting to disability studies, and connecting with other disabled people that presented opportunities for him to develop new perspectives. Stephanie experienced change in a way that was different than the others. She was sheltered from the world growing up, but during her student teaching practicum in an impoverished coal mining community, she instructed severely underserved disabled students, enabling her to access new perspectives about disability and ableism. The common thread in these experiences involved recognizing and feeling that change had occurred. Those changes in Narrators contexts enabled them to affect change in their own lives and identities. Identities not only can change, but must change, because as we gain new information, have new experience, or ritualize behaviors, who we are shifts (Burke, 2006). For most of the Narrators after their contexts changed, there was a time of reflection that they realized they, too, were changing. Hall (1996) discussed a violent hierarchy of identity, meaning that oppressed people sometimes shape their identities by vehemently claiming what they are not, thereby becoming something else. It was important to Jo, to Stephanie, and to Bryluen not to be who they were before. They could no

longer permit themselves to be victimized and in their newly found power to escape victimization, hoped to help empower others.

And yet, the Narrators did not cease to be who they were. Identities can be said to "define us because they contain traits, personal characteristics, roles, and our ties to social groups, and they can be focused on our past (what was true once), the present (what still is true), and the future (our wishes, expectations, and fears)" (Oyserman, Elmore, & Smith, 2012, p. 26). Burke (2006) discusses the relationship between the social construction of disability and disability identity. Disability identity is tethered to the social role of disability in a society. The Narrators could not cease participation in the subjugated role of the disabled, but my findings suggest the Narrators recognized that role, how it was socially constructed, and then chose to move in what they believed to be positive directions. Disruption of the lives to which they became accustomed initiated these changes.

In summary, Narrators expressed a range of disability political identities. They forged those identities in response to diverse experiences and circumstances—often quite harrowing ones—and at different life stages. What connected them all was a sense that they had a responsibility to themselves and others to enact change, to advocate, to push back against ableism and discrimination, and to shift people's thinking about disability.

How Did These Disabled People Enact Their Political Disability Identities?

Chapter 6 presented data that highlighted how the Narrators enacted their political disability identities. In analyzing the Narrators' memoirs and life history interviews, I found the following themes: 1) Internalized ableism, 2) Ethics of care, and 3) Working for Change. This section discusses these themes in conversation with extant scholarship.

Internalized Ableism

Save for Allister and Bryluen, the Narrators developed their political disability identities later in life. Like many disabled people, the Narrators were the only disabled people in their families; many experienced isolation and abuse. Only Stephanie had sustained access to other disabled people. It was a seemingly able-bodied world. People's private worlds are governed and influenced by public and political ways of knowing. Thus, power in the private realm reflects political influences (Foucault, 1982); as the feminist adage suggests, the personal is political (Crenshaw, 1991). Because the Narrators were raised in worlds with pervasive and covert ableist norms, they sometimes expressed ableist ideas and language, even while enacting of their political disability identities. However, as mentioned, most of the Narrators felt these identities were constantly-evolving works in progress, rather than a singular achievement.

Burstow (2003) tells us that, "oppressed people are routinely worn down by the insidious trauma involved in living day after day in a sexist, racist, classist, homophobic, and ableist society" (p. 139). As described by the Narrators, disabled people can be worn down as much by pervasive physical and attitudinal barriers as they can be by aspects of their disabilities. When disabled people have low self-esteem, it is commonly the result of feeling they are unable to compete with the able-bodied norms or some other form of internalize ableism (Hahn, 1997; Shapiro, 1993). Worn down and acculturated into American society, they, too, emulated able-bodied norms. Sometimes people internalize ableism by "passing" (Goffman, 1963), which reduces public presence of disability thereby further compromising disabled people's position in society (Linton, 1998; Michalko, 2002). In this context, we begin to understand that the dominant able-bodied population sustains its power not only by their own actions, but also the actions of disabled people who have internalized ableism. Butler (1997) explains: "The operation of foreclosure is tacitly referenced in those instances in which we ask: what must remain

unspeakable for the contemporary regimes of discourse to continue to exercise power?" (p.136).

Although internalized ableism of others is easy to recognize, it is not so easy to look inward and

see it in ourselves or those close to us. The "unspeakable" that we may be afraid to find and

name in ourselves, is our own internalized ableism. When this happens, ableism flourishes.

Campbell (2008) suggests that a disabled person distancing themselves from other disabled

people is a way of denying the significance of the role of disability in one's own life. Where my

findings diverge from Burstow (2003), Campbell (2008), and Rossenwasser (2000) is that these

authors describe a single way disabled people respond to or are conditioned in the able-bodied

world. This kind of representation doesn't leave much room to recognize that though individuals

may internalize ableism, they simultaneously develop ways to combat ableism both internally

and externally. Narrators enacted their political identities in states of conflict, both influenced by

ableism and shaped by their political responses toward an ableist world.

Sometimes Narrators' expressed internalized ableism in relation to the body. Felix and

Latefor internalized the roles those around them dictated. They saw themselves as monsters or

silent sufferers. Allister and Felix also stated they envisioned themselves dating women who

were able-bodied. Internalizing the attitudes and roles of the able-bodied individuals may put

them at odds with their own identities. Felix recognized this and had an "ah-ha" moment during

one of our interviews, possibly precipitating a shift in his disability identity. He commented on

how the feminine body has a socially constructed form and that he regretfully conformed to an

ableist interpretation of it. Berger and Luckman (1966) discussed the connection between

identity, roles, and conceptions, noting that, identity demarcates a particular location in the world

and that a coherent identity requires one to incorporate various roles and attitudes associated with

that world. While I don't intend this to excuse ableist views of the body, it is not surprising that a

disabled person might conform to attitudes and understandings that he/she is exposed to. How people express the oppression they have internalized or the extent to which they have been exposed to it varies, because people's experiences vary (Fujiiura & Rutkowsi-Kmitta, 2001; Watson, 2002). I highlight Narrators' ableist attitudes and behaviors not to measure or compare how much they have internalized these views, but rather to expose their existence and to tell their respective origin stories. These data show that although internalized ableism exists, Narrators are nonetheless working to dismantle these forces for their own and their collective futures.

Ethics of Care

The second theme presented in Chapter 6 includes data from Narrators' memoirs and life history interviews that highlighted how they enacted their political disability identities in their understanding of and relationship with the concept of care. The Narrators continued to develop their political identities, while also healing and growing. They reframed and redefined their respective ethics of care within their lives and relationships, often wielding care as an outcome of their newfound politicism. Their actions, especially Latefor's and Jo's, sought to enact Noddings' (2013) claim that "there is a form of caring natural and accessible to all human beings" (p. 27).

For some, the realization of an absence of an ethic of care meant they had to "keep at the system until it changes" (Flora), while for others, it meant defining what care meant to them and attempting to share their experiences with others. Though politicism often summons ideas of advocacy or protest, many expressions of politicism came through care. Narrators sought jobs that paid poorly because it meant they could care for other disabled people in equitable, empowering, and dignified ways. They could nurture while at the same time fight to protect the rights of disabled people. Narrators developed ethics of care as responses to destructive

relationships in which care was withheld or wielded as a weapon. They sought safety and equity in contrast to those experiences. A problem in the discourse about an ethic of care is that it is still primarily discussed in a personal way, typically between an individual and their life partner or personal care assistant and not about public care of people (O'Brien, 2005). Addressing the needs of individuals may not encourage change of an entire system built around a fear of disability. Some of the Narrators knew this and sought to share what they learned about caring and being cared for with other disabled people. They politicized very personal aspects of their existence for the betterment of their own people. Bryluen, Jo, Flora, and Gail frequently commented about how government agencies like the Social Security Administration and the Department of Public Welfare not only demeaned those who needed assistance but made sure to communicate to them that their time was worthless and so were they. Further, restrictions on income, inflexibility about timing for appointments, and bureaucratic red tape decreased the likelihood that disabled people can ever work or return to work. These comments and experiences represent both the intentional and unintentional ways institutions develop policies that diminish the power of those who are different (Berger and Luckman, 1966; Garber, 1991; Wolfensburger & Thomas, 1983) and the ways that care or the need for care diminishes one's ability to push back against oppressive systems of support, be those personal or institutional.

Many (or even all) of the close relationships a disabled person has, especially when young, are typically not with other disabled people. As a result, disabled people may have a difficult time recognizing and challenging the able-bodied values and judgements applied to their lives (Morris, 1991). If a disabled child is not taken care of, abandoned or institutionalized, it may be difficult for them to learn or know how to take care of others (Noddings, 1995). Moreover, because disabled people may be taught that they are weak, needy, or that they are

always to be taken care of, it can be difficult for them to establish an ethic of care for others.

They may internalize the beliefs of those close to them (Jenkins, 2004; Mead, 1934). Negotiating

relationships of care can therefore be complicated or difficult to establish or negotiate. Ideally, an

ethic of care is characterized by reciprocity, dignity and equity (Gilligan, 1982; Held, 2006;

Kittay, 1999; Noddings, 1984). Previous scholarship suggests that in the United States we are not

doing a particularly good job at achieving this kind of ethic of care. Because they live lives often

characterized by frequent and pervasive care relationships, disabled people are experts in

navigating the politics and ethics of care. Since many temporarily able-bodied people privilege

independence and supposed autonomy, navigating old age or temporary illness might be

shocking and challenging. The Narrators understood this. Jo and Latefor committed themselves

to spreading what they believed to be a quality ethic of care. Bryluen and Flora challenged the

governmental systems to provide care and support in ways that maintained their dignity, while

creating opportunities for themselves to meaningfully contribute to society. Tim negotiated an

ethic of care with his clients, while he simultaneously promoted improvements in the healthcare

field through publications and presentations. These efforts were not just actions of the Narrators

for their own benefit, but rather they used their expertise on this subject to also help others

navigate these systems.

Working for Change

The last theme presented in Chapter 6 focused on how Narrators enacted their political

disability identities through their formal and informal labor. When the Narrators were most

downtrodden, they still found ways to educate others. They were disability activists, yet

sometimes harbored ableist ideas on their continuous quests toward self-determination and self-

actualization. Early in life Jo, Bryluen, Latefor, and others to a lesser degree reported feeling

isolated or misunderstood. For these Narrators, one of the benefits of age and education was a broadened understanding of what disability meant on a social (not just biological) level. Either through work or personal pursuits, these workers for change hoped to spread principles that we might align with a social model of disability or a social justice orientation. Abberley (1987) suggests that discussing experiences of oppression can highlight essential differences between the lives of disabled and able-bodied people, sometimes causing more harm than good. I feel this kind of rhetoric as akin to saying, "If we don't talk about the problem, there is no problem." The Narrators wanted to talk about how to affect change and how to counter the flawed notion that they were either completely different or "just like everyone else." Instead, they saw themselves as more complex and nuanced.

Stephanie, Jo, Gail and Tim all recognized how ableist attitudes exacerbated systemic problems, like already-inaccessible work places that were built with able-bodied people in mind. All four of these Narrators had the educational and social capital that allowed them to pursue professions that enabled them to work to dismantle these structures and reframe what a disabled worker could be. Jo conducted this work in two ways: by serving as an ASL interpreter supporting access and by helping to educate Deaf people about their rights. Stephanie helped disabled people access basic needs and job training, because she felt it was the best use of her time, despite it paying poorly. I'd argue that these kinds of efforts, which continue to bring disabled people into the public sphere and provide to them the tools they need (and/or have often been deprived of) to succeed in an able-bodied world, are a powerful form of activism and change. They are also powerful because disabled people increase their visibility and public influence. Many of the actions undertaken by Narrators "begin the radical task of transforming" themselves "from passive and dependent beings into active and creative agents for social

change" (Morrison & Finkelstein, 1992, p. 22). However, the notion that a "better" disabled person is one who participates in the formal labor market risks further deteriorating the positions of disabled people who cannot work in presently conceived and constructed able-bodied workspaces. In fact, the general ethos of American life is that your work is your identity and of course, that means paid work (Galer, 2012). For many disabled people, work is impossibly complicated, because in most cases they must either function as an able-bodied person or not work—the latter turning themselves into commodities that benefits those already in power (Greer, 2016). Therefore, the work of the Narrators moved beyond simply their employment into their activism. That the work of affecting change is so often viewed as inconsequential, signals to us that it is even more necessary and valuable.

Resistance theories consider the how minority or disempowered populations sustain themselves and their identities despite overwhelming oppression or marginalization. Parrilla (2008) suggests that in most cases, subjugated individuals must resist dominant discourses that permit them few alternatives for a positive identity. Yet where there is power there is also counter-power (Castells, 2009). Acts of resistance open new paths of experience and on these paths, individuals discover, analyze, and question their realities, leading to revision of social identity and autonomy (Peters, 2006; Runswick-Cole, 2013). Therefore, while Narrators worked for change, they also revised their own identities and became self-empowered.

For many disabled people, institutions of education, places of employment, transportation, means of independent living, and participation in leisure activities remain inaccessible due to physical and attitudinal barriers (Miller & Colleagues 2006; Siebers, 2011). Because dominant culture maintains prejudice toward disabled people, these barriers persist (Shakespeare, 1994). Those in power function as gatekeepers, relegating disabled people to

marginal lives of dependency without opportunities to define their own identities (Barton, 1993). Claiming that little has changed since Goffman's (1963) findings nearly a half a century before, Swartz & Watermeyer (2008), note that disabled people do not meet the necessary requirements to be considered fully human in the eyes of the dominant culture. Therefore, the Narrators were not simply reacting to individual wrongs, but rather larger societal forces that shaped their political lives. Similarly, their acts of resistance were not only acts in response to individual wrongdoings but acts on behalf of the minority population of disabled people

Implications

At the inception of this study, I set out to explore how disabled people understood and narrated their own histories and to identify what critical moments in those histories contributed to the formation, development, or crystallization of their political disability identities. The cited challenges in investigating a concept as nebulous as disability identity is well documented (Alcoff, 2006; Balsam & colleagues, 2015; Fearon, 1999; Hall, 1989; Shakespeare, 1996; Siebers, 2011). Therefore, in approaching this question via life histories and memoir and analyzing them through a disability studies lens, I hoped to discover new understandings of how disability identity manifests in the lives and histories of disabled people. As the dissertation progressed, I realized that exploring multiple facets of identity (political, personal and cultural) was too big a task for this inquiry. Therefore, I decided to narrow my focus and center the critical moments in the Narrators' lives that contributed to the development or recognition of their political disability identities. The findings from this dissertation have far-reaching implications. Below, I discuss these implications relating to four arenas: Policy, Practice, Methodology, and Scholarship.

Implications for Policy

The experiences of the disabled people in this study exist within a larger political context, shaped by a collective political history. The trajectories of the Narrators' lives were charted alongside historical and political topographies characterized by the activism of the Disability Rights Movement as seen in the 504 sit-ins of 1977, the Denver Transit Authority protest of 1978, and the 1988 Deaf President Now protests. Those who engaged directly in these protests hoped to change how people and policies in the United States addressed disability. The 1990 Americans with Disabilities Act (ADA) achieved important gains toward making public spaces more accessible and reducing discrimination for disabled people. In 2010, the Affordable Care Act was passed, expanding Medicare, long-term services and support, and multiple other clauses that supported disabled lives in public and private spaces. However, in 2017, the federal government moved to repeal the Affordable Care Act, while in early 2018, at the time of this writing, the U.S. House of Representatives passed the ADA Education and Reform Act, seeking to limit the power and reach of the ADA.

Recent disability activism has demanded attention as the nation became increasingly polarized during this unique political moment (Dimock and colleagues, 2014). Politico (2015) reported that Republicans were targeting Social Security Disability Income while MSNBC and other mainstream news outlets observed that the traditionally-bipartisan approach toward disability policy was no longer the case under President Trump and congressional Republicans. This moment necessitated political action. We are all temporarily able-bodied and interdependent. My objective here is not to spark a debate about national politics, but to highlight the need for disability politicism that seeks equity, especially if we may be entering a new era of oppression. The Narrators largely discussed their political identities as cause and effect relationships. Their disability political identities emerged and were enacted because some

perceived wrong was done to them and they reacted with outright protest, changes in personal philosophy, or changes in behavior (e.g. care or work). The political facet of identity for the Narrators was one built out of experiences with ableism more than it was learned from family, friends, or books. These findings suggest that in this tenuous political moment when disability rights are at risk, disabled people will resist their own elimination or marginalization if given access to other narratives of resistance. Certainly, the national media coverage of ADAPT protestors in response to threats to the Affordable Care Act illustrates this point. For the Narrators and other disabled people with similar experiences, this research demonstrates that resisting and refusing to yield is woven into the fibers of their upbringing. Their political disability identities are not tied only to particular political actions or thoughts, but are integral to what makes disabled people who they are. Thus, the implications of this work for policy are twofold. First, changes to disability policy was the direct result of disability activism. These policies have allowed more disabled people to enter the workforce and live independent lives. Second, threats to these policies have and will be met with resistance from disabled people, who find their power to resist and refuse to go back to a more subservient existence. Thus, disability marginalization and disability activism and political identity are forever intertwined.

Implications for Practice

The findings from this dissertation reframe how scholars should think about and investigate politicism and what material outcomes for disabled people may be possible as the result of their scholarship. When examined not as a set of actions, but as one part of an individual's identity, we gain a deeper understanding of individuals' motivations for participating in social change. We can also begin to see patterns in disabled people's lives that have implications for practice in both education and social services. For example, understanding

the political disability identity could inform how educators approach curriculum and pedagogy to foster access to and participation in schooling for disabled children. In some cases, knowing those critical moments that the Narrators identified as significant in the recognition or development of their political identities may help parents and educators foster opportunities for similar moments, without the substantial struggle and abuse that many of the Narrators experienced, or at least help disabled students understand that good things can come from bad experiences. Understanding the disabled person's identity, particularly the political identity, could contribute toward understanding the recruitment and retention of disabled students in postsecondary education. Additionally, knowing how disabled people develop understandings of themselves as political actors could inform programming seeking to educate disabled youth about dating, sexual relationships, self-esteem and self-representation. Many Narrators reflected on key experiences navigating social service agencies that shaped their political identities. This dissertation's findings have the potential to educate government entities such as the Department of Welfare or the Social Security Administration about the often negative or even traumatic experiences of their disabled consumers. Spotlighting how disabled people's identities are shaped by their interactions with these large structures will hopefully have the potential to contribute towards larger systems change that recognizes the humanity of social service recipients. Lastly, as Narrators shared experiences about their care relationships, the findings herein could inform the training of professional or familial caretakers, creating new models of care that highlight our collective interdependency.

Implications for Methodology

Doing narrative research with disabled people as a disabled person uncovered many salient methodological implications. As I noted in Chapter 3, the access requirements and

preferences for me and for the Narrators shaped how the interviews happened, informed the relationships that we developed and thus contributed to the data generated. For example, to accommodate and support Latefor's communication preferences, I traveled to her farm to conduct our interviews in person and engage in participant observation. I helped her feed and clean her animals. We milked the cows and made cheese from their milk. We looked through a trunk of old things, her only space for personal belongings while her husband was alive. We drank thrice-boiled coffee and laughed. These interviews and her paintings yielded rich data, but it was my time spent in her space that pulled it all together. There were three other Narrators with whom I had once been acquainted. Even my limited time with them prior to the study seemed to help me contextualize and humanize their data, countering the trope of the detached, "unbiased" researcher. However, our previous interactions and brief shared experiences could have informed how they entered the project, or affected what kind of information they elected to share. That is, the information these three Narrators shared about their histories and their experiences with disability identity development was no doubt changed because we knew each other previously. Bryluen's stated discomfort with face-to-face or voice-to-voice communicative interactions moved our interviews to a digital space, as did Allister's use of alternative and augmentative communication. While Bryluen and Allister's typed communication may have been considered accommodations "for them" or "for their disabilities" in other contexts, my identity as a Deaf researcher reinterpreted this as merely a choice of modality that worked for both participant and researcher. Additionally, I did not require an interpreter when interviewing Bryluen and Allister, thus removing the presence of a "third person" within the interview encounters. Jo's profession as a certified sign language interpreter meant that our interviews took place in American Sign Language (ASL) with voiced English for the purposes of the CART

transcription. With the rest of the participants, I accessed the interviews with the support of a certified ASL interpreter, thus creating a unique interview dynamic where there were three people rather than two. It's impossible to know if the content of the interviews changed because of the presence of a third person, but though ASL interpreters are bound by a strict code of professional conduct emphasizing confidentiality, the Narrators may have participated in the interviews differently because of their presence.

Gathering various texts and constructing the narrative required flexibility and breadth. The Narrators often became fatigued due to the time-consuming data collection methods employed, supporting my approach of incorporating additional texts to ensure authenticity. However, I question how we come to "see" and describe identity. Though this research introduced other data as needed, it focused primarily on words (life history and memoir). Can words alone represent the disability identity? The spaces we build around us and our behavior within them also represent who we are. This research would have benefitted from the inclusion of some more interactive data such as: shadowing, participant observation, examining and discussing personal artifacts, and perhaps most of all sitting together over a few long meals. Future disability identity scholarship might employ smaller sample sizes and longer data collection periods to enhance researcher fidelity and cultivate deeper relationships between the researcher and Narrators.

In purposefully seeking a diverse sample, I selected willing Narrators who represented different disabilities, genders, socioeconomic backgrounds, sexual orientations, and ages. However, my sample was not racially or ethnically diverse, despite an effort to select the most diverse sample possible. Though the Narrators shared diverse experiences, especially in terms of disability diversity, the small sample size made it difficult to draw specific conclusions about

other markers of diversity or how those markers interact with disability. For example, we know disablement exists and disabled people often resist, but we don't yet know how people who experience poverty and have mental illness enact their identities. The complexity became even more difficult because I did not choose to focus on studying a specific disability label or category of disability. Studies that do may discover disability-specific findings about political disability identity development.

A Review of Emancipatory Research Objectives

This dissertation has its roots in emancipatory research. The emancipatory orientation grew from my earliest experiences with schooling, employment and social services. I chose methods that represented the three principles of emancipatory research, which describe that participants: 1) are empowered and experience gain, 2) participate in a reciprocal research process, and 3) share power with the researcher in the creation of knowledge (Petersen, 2011). Though I am not the first researcher to experience this, I felt and feel beholden to the Narrators. As intent is not the same as outcome, I will review my emancipatory objectives.

By empowering my Narrators to participate in ways that best worked for them and ensuring they gained from participating, I was able to bring a disability studies-informed approach to my methodology. Though the concepts of "empowerment" and "gain" are loaded ones, as they threaten to reproduce a hierarchical dynamic between the researcher and the researched (Petersen 2011; Shakespeare, 1996), it was the Narrators themselves that noted that they gained from the experience, particularly the opportunity to work on writing their narratives. The Narrators authored portions of memoirs and, in the case of Jo, Allister, and Gail, completed nearly 200-page draft memoirs. Bryluen, Flora, and Tim reported having written over 100 pages of narratives that were not yet organized or linked, while Stephanie and Flora learned that they

really did not wish to author memoirs at all. Flora did mention that this research motivated her to paint again and perhaps she would tell her story in that way. Finally, Latefor thought she would keep painting "but not of me. I don't like painting people, just animals and field and stuff and now I can cause I have paint left." Given her story and communication preferences, Latefor's paintings served as an accessible form of memoir.

As we were saying long goodbyes, I asked Narrators about participating in the research process. Many responses were short and included words like: "fun," "tiring," "inspiring," "good," and "thought provoking." However, some elaborated or emailed me later. Some Narrators commented how the dissertation process contributed to their own productivity: "I'm so happy I did this with you. I had all but given up on writing and now look what I have" [Gail], and "Because of your dissertation, I'm almost at the end. I can see the light at the end of tunnel. Are you sure I can still send the whole thing to you to read?" [Allister]. Others conceptualized gain differently: "It's nice to sit here and tell my story and know that someone, you, were actually listening" [Felix]. "I think I now have my head wrapped around [my?] disability and can use to it help people rather than run from the idea" [Jo]. "I don't normally bother trying to explain myself to people, because they don't ask because they don't really want to know. I'm happy you wanted to know" [Bryluen]. It appears the gain and the empowerment overlapped. Narrators cited and evidenced how productive our work together was, while simultaneously fulfilling needs to share their stories and have someone witness them. Empowerment can sometimes express itself like Jo described, as a way for her to move forward and claim control. Other times, being seen or recognized when you have felt invisible, can be empowering in itself.

I attempted to make this dissertation reciprocal and shared this hope with the Narrators. Despite the significant achievements Narrators made in their memoirs, I understood that I had

something greater to gain from the completion of this dissertation. I believed that if I was transparent about my own disabilities and represented myself in the dissertation, that I could also share in the necessary vulnerability of participation. I talked to Narrators about my life and shared stories when appropriate. Initially, I included a great deal of my own narrative in this dissertation, most of which I ultimately chose to remove during editing. The reality was that I could not fully share in the vulnerability. I was the researcher and, in this role, knew what to expect, controlled what data was represented, and, for the most part, am surrounded by family and colleagues who understand disability, which was not the case for the Narrators.

Sharing power in the research process was another objective with which I struggled. Narrators were welcome to select any mode to represent their memoirs. To me, this was integral to emancipatory research. During the selection of critical moments in their identities, it was the Narrators who ultimately selected moments they would capture in memoir form. In the consent process, Narrators learned portions of their memoirs (the critical moments) would be represented in the research in their entirety. This provided the Narrators with power over how they were represented. Because of representation logistics, I removed three and a half narratives from each Narrator and moved one to the appendices. This decision was necessary to increase the clarity of my research, but nevertheless may have weakened my emancipatory objectives since ultimately, I had to make editorial decisions about what narratives to keep and which ones to remove. After data collection ended, when I completed sections of writing, I shared them with each Narrator. Sometimes they had minor corrections or felt comments were taken out of context. I revised my writing according to their statements. Still, I hold no illusion of equitable power. I was the researcher and for me to claim this dissertation as research, I had to conform to various research protocols and disciplinary standards. I had to lead the project.

My effort to conduct emancipatory research resulted in marginal success, but not for lack of want. I maintain that there are ways to get ever closer to emancipatory research but concede that Shakespeare (2000) may be right in claiming that emancipatory research is not wholly attainable. I feel conflicted for having visions of an equity that I could not deliver. The only conclusion I can make is that regardless of whether the concept of emancipatory research is a fallacy, it behooves researchers to try to enact it, because it mitigates at least some of the most significant concerns raised about the researcher/researched relationship. It is a reneging on a commitment, but at least for this project I must accept the proverbial "Something is better than nothing."

Limitations

Like all inquiries, this research had limitations. In purposefully seeking a diverse sample, I selected willing Narrators who represented different disabilities, genders, socioeconomic backgrounds, sexual orientations, and ages. However, my sample was not racially or ethnically diverse, despite an effort to select the most diverse sample possible. Though the Narrators shared diverse experiences, the small sample size made it difficult to draw conclusions about other markers of diversity or how those markers interact with disability. For example, we know disablement exists and disabled people often resist, but we don't yet know how people who experience poverty and have mental illness enact their identities. This research did not contribute toward further understanding any specific disability population and might have benefitted from a stronger focus on specific demographics

As I noted above, I knew three of the Narrators before conducting this study. Though our relationships were not close, it represents an additional limitation. Our previous interactions and brief shared experiences could have informed how they entered the project, or informed what

kind of information they elected to share. That is, the information these three Narrators shared about their histories and their experiences with disability identity development was no doubt changed because we knew each other previously.

When prospective Narrators volunteered, it was clear that they were interested in this research because they did have something they wanted to communicate. They had a story they wanted to tell. They were not simply seeking to document memoirs for posterity, but because they lived lives in the margins as disabled people. They felt not only did the world deserve to know what that was like, but that their experiences could teach the world something, possibly affecting positive change. I felt conflicted about this because the gap I located in disability studies literature and that I had hoped to fill was one that moved beyond the purpose of affecting change and instead focused on descriptions of Self-process beyond arguments and counter-stories. I now understand that it is difficult to separate the notions of Self-creation and acting in political ways for the Narrators. Though that was not my intention, even focusing on the idea of "Yes, but what else?" is difficult, because disabled lives, at least of those who volunteered for this research are still so steeped in ableism.

The implications and limitations seem to overlap here. We witness some particularly personal moments in Narrators' lives and see the processes in which they participated to become themselves. This may be particularly evident in the narratives included in Appendix A. The experiences show the political Selves of Narrators coming into focus, which was the objective of this research, but at times, they are so obfuscated by the agendas of the Narrators that they seem to reflect the extant literature about political disability identity. To me, this does not suggest that I imposed questions or ideas that were irrelevant or unimportant to move toward a next step in disability discourse, but that issues raised in previous literature and the experiences of the

Narrators have yet to reach any point of resolution. The findings seem to demand, "How can we shift the topic if nothing (or little) has changed?" The enthusiasm of disabled people to participate in this study may suggest that they still feel they do not have equitable space to voice their concerns and have yet to gain sufficient enough security in a society to move forward. For the nine Narrators, their participation in this research could be added to the chapter 6 as a form of their enacting their political disability identities. An even loftier hope or framing of this research is that it serves as a way the Narrators can help other disabled people document memoirs and feel empowered as they affect change rather than the agenda of affecting change in this research existing as a limitation.

Another intersection of the implications and limitations of this research is my status as a disabled researcher. While I reflect on this in my review of the emancipatory research methodology, I feel it is important to mention again. My status as a disabled research helped to quickly establish a rapport with the Narrators. They made statements like, "That's what it's like for people like us, right?" I feel being disabled helped me to understand institutions connected to disability like the public assistance and education. At the same time, my own experiences as a disabled person sometimes placed me a little too close to the experiences Narrators described. Consequently, it is possible I inadvertently assumed information about some interactions or influences that an able-bodied researcher might have asked about, which increases the possibility that I misinterpreted information. My own experiences also acted as a liability because I empathized with Narrators who had traumas like my own more than I did those with different or nonexistent traumas. This affinity for some Narrators may have constrained my analysis, despite my efforts to keep it in check.

Recommendations for Future Research

This dissertation contributes to the field of disability studies and disability identity research by showing how political disability identity is not only the consequence of sociological, but also political forces. That is, disabled people become political actors as individuals reacting to their experiences and as members of a larger identity group as they begin to recognize that other disabled people share some common sets of experiences. This research suggests that there is an individual process to becoming a political actor that is neither straightforward nor clear, but instead sinuous and obscured. Entangled in the political identity are the personal and cultural identities, refining the political identity while also contributing to the identity of the group. As the data show, political identities can take many forms. Political identities are enacted within people's thoughts and actions, ranging from how they care for themselves, to why they choose their jobs, and to if and how they participate in public protest. These data also show that the disability political identity can emerge in different contexts, from freeing oneself from abuse to leaving a privileged childhood and experiencing a different social reality. Further, when we discuss identity, we humanize disabled people, the very thing I strived for in this research. The conversation is no longer about "those people protesting again," but about the story of a person's life which leads to protesting with many other storied lives. This idea of "individuals together" will help researchers maintain a balance and quality to their research about disabled people.

The findings from this dissertation suggest that future disability identity scholarship ask new questions which I discuss below. Foremost, identity may be too broad of a concept to investigate. Regardless of the model used to analyze identity (in this research it was a three-component model), it behooves identity researchers to focus scholarship on individual parts of identity so that they may better understand the whole. As this dissertation adds to the already-existing conversation about political disability identity, further scholarship warrants investigation

into the other components. As noted in Chapter 2, political disability identity is a prevalent topic in the literature reviewed for this study, therefore new questions can and should be asked about the personal and cultural facets of disability identity. A shift or broadening of the body of disability identity scholarship beyond politicism may provide new narratives about disability that thus invite new understandings of the disabled experience. The current literature's focus on politics, though particularly salient in this historical and cultural moment, may inadvertently reinforce a vision of disability as only a minority identity shrouded in angst, rather than the rich multifaceted identity that it is. Exciting questions that focus on common behaviors and common thought processes found among disabled people will give researchers a clearer perspective of disabled people as a cultural group. Studying artifacts such as art and medical devices (especially personalized ones) made and used by disabled people show the products of identity enacted. In short, moving beyond the rights of disabled people helps us to see the people behind the fight. Researchers should also consider the personal disability identity, focusing on how individuals can maintain autonomy while simultaneously participating in identity groups that value cohesion and similarity. These kinds of questions have the potential to uncover previously-untold stories.

Initially, this research proposed an intersectional approach to analysis, particularly in relation to socioeconomic stratification. It is difficult to talk about identity without paying due consideration to how various identifications (both privileged and marginalized) create new and unique experiences. People's disabilities do not exist in a vacuum, but rather take up a space entwined with their other identifications. Simply saying more intersectional identity scholarship should be conducted is insufficient. Like this dissertation, I feel the work that needs to be done are intersectional analyses that implement frameworks substantiated in fields of study that have long traditions of identity analysis (e.g. sociology, anthropology for collective identities, and

with the right framing, psychology), compared to providing a description of people and labeling it an identity study.

What Does This Mean for Disability Identity Studies?

Much of the issues I raise in this dissertation revolve around representation of disabled people. First, I raised concerns about emancipatory research. Are disabled people empowered by and in the research and do they have some control over how they are represented? Is the research relationship reciprocal? I also queried if disability identity scholars have sufficiently expounded the disability identity as both expansive and ever-changing. Further, has the literature recognized the interconnectedness between political identity and other aspects of identity? The research I reviewed (Brown, 2002; Cameron, 2013; French & Swain, 2000; Mollow, 2004) discussed their research questions, participants' contexts, and then their findings. Hall (1989) warns us that the identity is not a fixed point, but an unresolved place shifting in various ways because of various stimuli. If disability identity is ever-changing, documenting it necessitates studies that are perhaps bigger in scope, or that follow participants over extended periods of time. What my research accomplishes that many journal-length studies cannot are the stories of lives and identities. This is not to say that previous research has ignored identity studies, but rather has been limited by methodological conventions—this work demands time and space. In longer formats, scholars can show the process of becoming oneself, but I fear too often we recognize social influences and participant outcomes, accepting the line from point A to point B as whole when it is only the surface. Again, because identity is always in motion, examining and documenting how disabled people enact their identities is a dynamic approach that captures a dynamic process.

In addition, claiming that the political disability identity *is* anything is problematic. Some of the Narrators had early lives filled with pain, destruction, and fear. Others had privileged childhoods. As Narrators grew older, some experienced ableism in schools, while others internalized ableism by trying to "pass" or perpetuated ableist ideas in their remarks and actions. Some Narrators experienced physical or emotional pain. Other Narrators had scarred bodies or visual indicators of disability. Through this manifold, I could make only tenuous connections, because identity resists labels and attempts to organize it. Disability confounds the neat borders of identity (Davis, 2001). Shakespeare (1996) describes that disability identity is neither a single event nor a metamorphosis, but is the process of living as a disabled person. As a researcher, I feel the need to take away something more concrete than what I describe above. Fortunately, there is an answer to what the Narrators' political disability identities are, actually two. I have thoroughly discussed both. At some juncture, life as a disabled person necessitates a political response to the oppression he or she experiences whether it is great or small. After all, marginalized identities develop in conjunction with societal conditions (Salazaar, 2005). It is these experiences in the margins that "provide the conditions with which the oppressed can begin to develop their own consciousness and identity" (Weeks, 1977, p. 33). The second "what" is something much more personal. The Narrators' political disability identities often engaged systematic problems that maintained the structures that oppress disabled people. However, there is also a personal component of the identity that is made up of the sum and interaction of each individual's experiences. This individual component is the tears, anger, or stoicism that disabled people experience. It is the anxiety of reflecting on past experiences while in the present. It is the productive and destructive relationships disabled people nurture. Watson (2002) stated that the individual disability identity is still in the early phases of scholarly development. My research

contributes to the study of individual disability identity by suggesting when we analyze political disability identity, we must consider it in three distinct but related ways: The political identity representative of disabled people, the individual political identity, and how the individual identity interacts with the group identity. By doing this, we gain a more complete understanding of disability identity.

Final Thoughts

The Narrators knew they had strong political identities. Not only were the moments that Narrators chose to discuss and document powerful ones, but the way they told these stories was purposeful. They were expositive because they knew sharing them here and now was not simply a reflective exercise, but a mechanism of change. I stare at Latefor's painting of her behind prison bars, which, at her request, now hangs in my office, and it demands change. I reread the political narratives from Felix, Jo, and Allister and I know that when I enter my class to teach I have a responsibility to my students to spread the Narrators' messages. Each Narrator, to differing degrees, expressed how much they hoped that this work will improve the lives of disabled people through awareness, understanding and political pressure. I return to Melucci's (1989) definition of political identity for marginalized populations: "[It] reclaims the right to define themselves against the criteria of identification determined by an anonymous power" (p. 51). That is exactly what the Narrators have done herein.

The disability identity is not a *thing*. Our identity is a concept that represents who we are and how we see ourselves for our own sake and in relation to the world around us. Alcoff (2006) stated that identity is a way of "inhabiting, interpreting, and working through, both collective and individually, and objective social location and group history" (p. 42). Together, the ten of us rolled up our sleeves and toiled to accomplish this work. I dare say that in this effort we "worked

through" our identities in the process, molding them because the identity is malleable by nature. We "inhabited" these documents and the substantial amount of memoir not included in this dissertation. Simply seeing my work and the Narrators' work in print and taking the time to pause, consider, and refine, changes how we see ourselves. And still we live on these pages. It will change how others in our lives to whom we show this work see us and, as a result, we become someone new. We worked "collectively and individually" and as we exit this research we can be proud that we contributed toward the group history of the disabled people. I think Tim's words sum it up best: "We're disabled. That's it." I read this statement several times and, likely had it not been isolated as the first line on a page of transcription, I might have passed it over. The simplicity and complexity represent the disabled experience. This is it and it is everything.

Appendix A

Sections of Narrators' Memoirs They Felt Represented Them

Latefor

Figure 2: Latefor's pictorial memoir. She represents herself in a picture of her chickens

in a stall with ancient chicken wire in the foreground.

Flora

Mohawk bound high, face painted thick, and drenched in sweat, I poured out of the club

with the other revelers. High on life, full of spirits, holding on to the last of the night, we laughed

and hugged as one by one friends headed home. "Hey, dude, can we drive Zane home?"

"Yeah, shouldn't be a problem." Piled into a 1989 Ford Saturn, two people were in the

front and four in the back with my smallest friend, Pixie, lying across us. Oingo Boingo, Devo

and Depeche Mode blasted from out the speakers as we made our way down 5th Ave.

We arrived at Zane's house and he and I spilled out of the car. "I'm staying here," I said. My brother asked if I'd be alright to which I responded, "Yeah, I'm cool." They drove onward to the homestead. Across the street from where I stood was the Henry Clay Frick Mansion. Its grounds were pristine and I recalled how beautiful and wondrous the interior was. The luxury was unprecedented and the attention to detail magnificent. With a dramatic about face we made our way into Zane's abode.

Zane lived in the basement room of a row house. The water was turned off, as was the gas. The electric bill had been paid though and 80's new wave music rang out endlessly in the night. A queen size mattress lay on the floor and most of the other furnishings consisted of milk crates. Cassettes, records, CDs, DVDs and VHS tapes filled the room creating a vast collection. Walls were strewn with 80's music posters and drawings Zane had done.

Zane was my personal conquest. After having met him some three or more years earlier I had been fascinated with him and his lifestyle. Zane exuded sex and personified happiness. His smile could bring joy and his eyes reveal wickedness. I was sitting on his bed unlacing my boots.

What followed was a night of wild sexual discovery; not love making but pure carnal indulgence. I was without hesitation and absent of guilt. The night seemed endless, and as the sun rose, only then did we pass into gratified sleep.

I slept but an hour before quietly getting dressed and lacing up my boots. I snuck out of the house and towards the bus stop as I had to get home to go to another engagement.

I stood on the corner awaiting a 71 toward town. My makeup, still thick, was smeared some. I was clad in a leopard print mini skirt and knee high, high heeled black boots. I wore a black bra with red lace and a fishnet shirt. I was accessorized with a chainmail belt, a studded belt, a spiked collar, spiked wrist bands and a giant skull earing. I stepped on the bus triumphant;

there was no walk of shame. Still one could not help but think what the others on the bus must be thinking. I laughed to myself as I pondered it.

Arriving home, I went to the bathroom to strip down. The shower rained down upon me removing the smell of sex, sweat and cigarette smoke. Removing my war paint took some extra effort. In time I was clean and smelling of fresh lavender. Fully clad I prepared to make for my great aunt's birthday party.

Walking down the street, I pondered the duality that was my life. Not hours before I found myself a sinner in the throws with Zane, and now I appeared a saint on the way to a lady's tea. I arrived at the party clad in a long dress of lilac colored lace. A wide brimmed black hat adorned my head, the like of which Audrey Hepburn might wear. My lace gloved hands held a fan, around my neck a string of pearls and on my face a lovely smile.

I felt home amongst family and friends. Conversations were engaging and interesting. I love tea and sipped upon a bold Earl Gray. I sat on a porch swing next to my baby cousin and as we swung I drank in the sunshine and celebrated the day. I felt so content.

Having had so little sleep, I returned home, and naked slipped between my covers. The sweet summer air passing through open windows, I breathed deep. As I drifted off, the contrast that was my being came to the front of my mind. I smiled and passed to dream.

Bryluen

"Damn." It's a common phrase. So common I barely notice it, anymore. My focus is too busy bouncing between the screen in front of me and the handwritten page beside my laptop. The TV drones in the background, set to Investigation Discover. They're playing a Homicide Hunter marathon, and I like the way Joe Kenda approaches crime solving.

I can't remember if liver temperature is impacted by ambient temperature within the first two hours of death. I reach for one of a teetering stack of pathology books piled around me, muttering to myself as I search out a detail currently escaping me. My brain doesn't always work like I want it to, these days. My recall isn't as instantaneous as it once was. It's frustrating, but I'm learning to cope with the effects of medication and illness. It only rarely slows me down when I'm working on a new book, anyway.

My killer's eluding me. I hate it when they do that. It's not the way I drafted the outline, but then again, characters rarely behave the way I assume they're going to. I've learned to adapt. I push aside my annoyance, and let them guide me toward where they want to go. "Whatever did this, it hardly left much in the way of flesh on the feet. Almost as if it started there, and worked its way up."

Hmm... That's more like it. I can work with that. Now I'm back into my book, and even the TV is a distant drone as I lose myself in the scene coming to life in my head as I type from the draft into the computer.

"No, I don't think your friend is capable of that. I've never seen trauma that presents quite this way, before. It's not even ritualistic. It's almost like something was ... eating the feet, and then just scraped the rest of the flesh and organs from the body."

Jonathan frowned. "How do you know that?"

"Are you going to be done soon?" The voice is an unwelcome intrusion, phrased in a tone that says what I'm doing is a waste of time, and an annoyance. My Significant Other has entered the room. Now, he stares at me with that haven't you wasted enough time? Look and repeats, "Are you going to be done, soon? You need to make dinner."

Resentment flashes through me. He's an adult. He could make his own dinner. We've been down this road so many times, I've grown exhausted with even bothering to comment. It only results in more screaming and attitude from him, and I'm just not in the mood, right now. Carefully, I lever myself out of my chair, making sure my feet are steady beneath me, before I make my way into the kitchen. "What do you want?"

"I don't care."

It's a common dance. And it has the same ending. I make what I think he wants. He turns his nose up at it and says "Never mind." He'll stomp around the house for a while, then instruct me that I'm to make him such-and-such, once I've had a cry with my head muffled under pillows, and then gone back to working. I sigh. I wish this game could be over. I don't want to play it, anymore. I don't want to play any of the games people insist on, anymore. Just leave me with my books. That's all I really want.

Jo

I returned to campus at the end of August, the day the dorms opened. I told Migdalia I was changing my major from special education to English. My mother was as an aide in a class for children with disabilities, and I needed to cleave my path from hers, but there was more to it than that. Literature had buffered my incessant despair, expanding my vision beyond the gelded frame of my life and presenting me with a prism of possibility. Imagined realities lifted the veil of my own experience from my eyes, so that it was no longer draped like a death shroud over the only view I'd had of the world. Characters such as Maya Angelou's young self in I Know Why The Cage Bird Sings were my lodestars, pinpricks of light in a dark consciousness. I recalled for Migdalia with unusual clarity the jolt of electricity that ran up my spine when I entered the magnetic field of soul recognition in Harriet Tubman's famous quote, "I had reasoned out there

was one of two things I had a right to: liberty or death. If I could not have one, I would take the other, for no man should take me alive."

Systematic subjugation had co-opted me nearly to the core; that which began as Self became a tower of cards, blown down by every wind. Within the slow burn of helpless rage that rape and torment engendered was an ember of self-determination fanned to flame by the breath of an idea: I will not let you do this to me! I glued a copy of Tubman's quote to the top of my dresser. It felt like sedition. When Todd Anderson stood on his desk to salute his renegade teacher with the words, "O Captain, My Captain!" in the movie Dead Poets Society, I cried in one of the theater's bathroom stalls for an hour, Rosa pacing and praying on the other side of the door. I couldn't explain my keening sorrow, the yearning this scene evoked in me. I was leaving the half-life I had led, a frightened, sad, fractured, subdued young woman with only imagination, the grittiest form of hope, to bolster and guide me. Without it, I would have had no desk to stand on, and no inkling that I could stand at all.

Felix

I have always been interested in acting. As a shy 8 or 9 yr old I started taking acting classes with a vibrant and charismatic teacher named Katie. Katie had red long hair and she had a vivacious smile and big expressive blue eyes. Her grin literally went from ear to ear and she was always fluttering around giving advice to her young students like an active hummingbird. Her coaching made me feel that she cared as long as I tried my best. Every muscle in her body seemed to be "on" during class. Her positive energy infected me to try as hard as I could. After a few week of taking classes, I started to love to act! I would swing my arms and swivel my pelvis while I commanded the stage. It was the first time I had control over my body.

Little did I know I would be cast as the lead in her original community play. The play was called "A Day in the Life of Mr. Bean." This was a completely made up character. I was cast as Mr. Bean. Although I don't remember the exact plot I remember blurting out funny lines like "what a great day to be me!" My character got along with everyone in the play.

In one scene I was slouched over a tan wooden table pretending to sleep. I wore a brimmed hat that was tan as well as Gails and a blue button down shirt. There were other actors having a conversation in front of me during this particular scene. I kept falling out of my seat which wasn't in the script but made the crowd bust out in thunderous laughter. I was improvising because I had a feeling it would add to the scene. My hat kept falling to the floor after i flopped to the ground. I kept falling to the ground and receiving thunderous laughter from the audience. My improv made the scene pop more! This taught me that comedy often is about the little things that can enhance the overall scene. The crowd was laughing with me and not at me which really was an amazing feeling! For much of my early life my disabilities had generated people saying things lime "retard" and "weirdo" which left me feeling shame and sadness. I remember receiving a standing ovation at the end and smiling ear to ear! My early theatrical experience helped to see my body in a more positive way than I had before.

Allister

As I run in the cold air of a Midwestern January, I examine the community, that being not just the cityscape, but the culture and people, in the things I am seeing. I see the towering skyscrapers, some which are new, some which have been there for some time. I am just visiting this place, but I observe the people milling toward their insurance offices and Fortune 500 companies, but also going to the restaurants and milling slightly in the park despite the cold air.

Accelerating my stride, I also remember running in another time and place, a smaller town, where I actually still live. I run in this community, too. It is the community, which brought me into being as a man, my old elementary school still stands, a bit more wounded for the wear, but still has the iconic marble towers and its glass doors.

The community hospital is still there and its size and influence has expanded. Medical services helped me fulfill my true potential. If I go a few blocks up the street, I would arrive first at my old middle school, now an office building, and a few blocks later would arrive at the church, which taught me about faith and community. A few blocks over would be the public library, where I would encounter books. If I had gone a different direction, I would be close to the public park, where I spent active time in nature along the winding human constructed creek. The path, winding with the shape of the creek, would come to the comprehensive college, formerly liberal arts college, whose campus I basically grew up on having been a faculty child. My run has gone on long enough, though. The air is brisk and it is quite a ways over there. I explore the neighborhood, but in this situation, I find I must choose my options.

This is the community in which I first derived my values: faith, justice, a love of learning and knowledge, love of physical activity and nature, and developed a sense of belonging, even of power. With knowledge and conditioning, there was not much I could not do; in this community.

As I wind down my memories, I come in from the cold Midwest winter, I take out my laptop. I reflect on what has brought me into being. I open a document and begin to write, to teach, to utilize my words. I can utilize these words as my power, my way to utilize the direction of my life toward an effective purpose. I begin to type feeling the touch of the keys and transferring the power in my body toward my brain to let my thoughts flow again over the screen.

Stephanie

My heart raced. My palms were sweaty against the steering wheel as I tried to drive my car down the thruway. For the past couple of weeks I had been talking on-line to a guy named Dave on an internet dating site, and unlike the other guys I had met or spoken with, this guy had potential. He was funny, kind and when I said I had a disability, and I understood that that could be a deal breaker, he responded with the fact that he didn't have a car or a license and he too understood that could be a deal breaker.

As I continued to head east to Canal City, a city I had only heard of and never been, I started to get worried. What if he didn't like me? What if I didn't like him? What if there was no chemistry there? I did what I have done by whole life; rely on the advice and expertise of a good friend. I called my then college apartment mate. Our conversation went a little like this:

Her: Stephanie, what's wrong?

Me: What if it doesn't go well? I'm freaking out. He seems like such a great person and this could ruin everything. I could ruin everything. Also, why am I so nervous? I've never been nervous before.

Her: Stephanie calm down. It will be fine. You're nervous because you like him and you want it to go well. And if you want it to go well, it will. Just be yourself.

Well, she was right. I never liked to recognize when she was right, but in this case, she was. I was nervous because nobody had ever been so okay with liking me for who I am. Granted, Dave had never met me in person, but I just had that feeling.

We got off the phone shortly before the Canal City exit and for the next few minutes I just took some long, deep breaths. I thought about all the possible outcomes. We could hate each other and never see each other again, and that was okay. He could like me and I could not like

him, and that was okay. I could like him and he could not like me, and, I suppose, that was okay.
Or, we could hit it off and both like each other, and that would be ok.

Well, five years later, I call Dave my husband and that is great!

Tim

Days raced towards, then passed the longest of 2005, consciousness failed me. No
active/cemented memories created; just vague impressions of the world outside, me. Irritating
noises, smells, voices – some vaguely familiar – brought the world closer; then faded into a dull
background, with heat flashes, alternated by chills, pain, confusion dominated. Where am I?
What happened? Why can't I move? Oh! But, I did move one day! Moved so quick and fast,
none could catch me; except the cold, hard hospital floor recently caressed by a mop laced with
an ammonia-based disinfectant. Squish! Smack! Thud! Splat! Ouch! No permanent physical
injury or marks derived, but inward scarring, for sure! What did I do wrong to deserve being
thrown down, then tied up? And, there I lay for weeks, tied up! Makes me want to cry, and I
think I will...!

Cold winter's night in late-January 2006; collapsed in bed at the end of a long day.
Glanced right; caught a stranger's face in a mirror. Who is that guy? Looks vaguely familiar,
but…?? Within and for minutes, entire body shaking, tears flowing. Difficult to catch my breath!
It's not to wonder! Been only eight month since calamity, five and a half months since surfacing,
three months since returning to work fulltime, two weeks since university part time. Wow! I am
back! Who is that guy?? Where is he going? Why does it feel like I am floating above a
bottomless chasm hoping to swallow me whole? Perhaps, my tears will permit me to land softly
and float, gently, yet firmly to the surface, safe! Makes me want to cry, and I think I will...!

Surrounded by family and friends at concert in Chicago's Grant Park on a late-summer 2008, lovely, perfect night. Wow! Gehry's work, mesmerizing: seems to float in the air; indeed my mind did perceive it so! There's a body on the grass viewed from on high. Whom is that man sobbing and why is he shaking? Why is he so upset? The man believes life is too much! Graduate school/assistantship beginning in just two days! How will I make it through? I feel in my bones it's the right thing to do to recover, but damn, I am scared as hell! Man on the grass looks up and senses a familiar presence. Hey you, up there? Can you hear me? It's me, and you are me!? It is not wonderful, breath taking to be alive! We will make it through! Makes me want to cry, and I think I will...!

Gail

One day as I was working on my dissertation, my partner called and said, "did you remember we are having people over for dinner tonite? We have no food. Can you go the meat market and get chicken breasts?" Damn, and I'd been writing well. I quickly threw on one of her tops, buttoned it up and raced to the well known store with the wonderful food.

Shit. Long line but lo, they waited on me first. I got the 4 breasts, grabbed the grocery bag and clutched the bag to my chest. Something felt wrong. I looked down and oh, shit my top button had come undone. I had somehow gone to the famous market topless and was clutching the breasts to my bare breasts.

I guess that is why I was first in line. I was proud of my 37 year-old breasts--if I do say so myself, they were pert and happy things.

But the punch line. The next day, as we were driving by the meat market, they had closed. No previous warning signs that they were going to close, they just closed. Was it my bare breasts that had closed the meat market? Everyone was saddened by the loss of the meat market,

most especially me. I did not leave my heart in San Francisco but I left two great breasts there but still I carry them proudly ...but covered.

Appendix B

Research Recruitment Text for Email and Social Media

CALL FOR PARTICIPANTS

This advertisement is for research purposes:

Native intersections: How structures of socioeconomic status and disability enable agentive

identity processes

Do you identify as a person with a disability?

Have you ever wanted to write/otherwise document a memoir or have you started one and have

yet to finish it?

This research conducted by a person with disabilities investigates disability, socioeconomic

status, and how you shaped your identity by generating portions of memoir and through

interviews.

Aside from collaborating to create this research text, you will get assistance:

• Organizing and expressing your experiences

• Documenting and revising your work

• Making creative and purposeful authorial decisions

• Continued support, feedback, and advisement for additional writing of your memoir for 6

  months after the completion of the research.

Participation requires a significant time commitment, though you will have flexibility about

when and where we collaborate. Participation is limited to people ages 18 years or older.

If you have any questions or would like to schedule a preliminary interview to discuss

participation please contact: Steve Singer at sjsinger@syr.edu (preferred) or (315)350-3803

Appendix C

Consent to Participate

SYRACUSE UNIVERSITY

CULTURAL FOUNDATIONS OF EDUCATION

SCHOOL OF EDUCATION

230 HUNTINGTON HALL

SYRACUSE, NY 13244

(315)443-4752

Native intersections: How structures of socioeconomic status and disability enable agentive identity processes

My name is Steve Singer, and I am a Doctoral Candidate at Syracuse University. I am inviting you to participate in a research study. Involvement in the study is voluntary, so you may choose to participate or not. This sheet will explain the study to you and please feel free to ask questions about the research if you have any. I will be happy to explain anything in detail if you wish.

I am interested in learning more about the relationship between disability and social class and their effect on the decisions you have made in your life that have created your identity. You will be asked to: 1) Participate in a series of interviews to document your life history. 2) Together, we will decide on certain significant moments in that history and you will write or otherwise document (e.g. audio record, paint, take photographs of non-human subjects, or video record) those in detail outside of the interview times. This will include approximately five to

eight written pieces, each about one to two pages long 3) Continue to participate in interviews to discuss the written portions and revise those portions if you wish.

It is difficult to predict how much time will be required to document this substantial amount of experience. Participants should assume that total interview time will exceed 20 hours total and that the writing or alternative response format may require a similar 20 hours of independent work. All information will be kept confidential. I will change all identifying information such as names, specific locations, and places of employment. Participants must similarly, to the extent possible, remove identifying information from their written accounts. Only I will have access to confidential information. Data that has already had personally identifiable information removed/changed may be shared with the advising Syracuse University faculty member Alan Foley for purposes of analysis or advising.

Your study data will be kept as confidential as possible, with the exception of certain information I must report for legal or ethical reasons. If our interviews or shadowing exercises reveal indications that either you or people with whom you interact are presently in danger (e.g. abuse or neglect), the researcher must report this information to the Syracuse Police Department. This does not apply to historical information.

I will use an audio recording device to unless your disability necessitates an alternative recording device for out interviews, which will always only be you, myself, and any support staff (e.g. personal assistants or ASL interpreters). All recordings, regardless of type, will only be used for data analysis and only I will have access to them. The recordings will be maintained until six months after the completion of the recording and then erased.

While there are research objectives in this work, its other purpose is to help participants reflect, organize, document, and revise their own memoirs. After the research is complete, the

researcher encourages participants to continue working with him, further developing their memoirs. He offers this assistance for a period of six months. This feedback and assistance will not be used for his own research unless both parties agree and new consent is given. This research fulfills the dissertation requirement for the researcher's university program

The benefit of this research is that you will be helping me to understand how people with disabilities form their identities, particularly how that process is influenced by socioeconomic factors. This information should help us to gain a more holistic understanding of the lives of people rather than focusing only on impairments. By taking part in the research you may experience the following benefits: a substantial body of self-authored work, a cathartic research relationship that may help you better meditate on your life, and a better understanding of other people who have forged their identities under multiple social forces.

The risks to you of participating in this study are: experiencing emotional distress due to the personal nature of this work and the potential consequences of people you know identifying you if they read the text. These risks will be minimized by obscuring personally identifiable information and ongoing assessment of participant fatigue and distress. If you feel distressed, you may seek counseling at your own expense at a provider of your choice or at the following:

Catholic Charities of Onondaga County (for uninsured or underinsured persons) 1654 West Onondaga Street Syracuse, NY 13204 and

Psychological Healthcare 600 E. Genesee Street Syracuse, NY 13202.

If you do not want to take part, you have the right to refuse to take part, without penalty. If you decide to take part and later no longer wish to continue, you have the right to withdraw

from the study at any time, without penalty.

If you have any questions, concerns, complaints about the research, contact the researcher, Steve Singer at sjsinger@syr.edu or (315)350-3803. You can also contact the research advisor Alan Foley at afoley@syr.edu or (315)-443-5087. If you have any questions about your rights as a research participant, you have questions, concerns, or complaints that you wish to address to someone other than the investigator or if you cannot reach the investigator contact the Syracuse University Institutional Review Board at 315-443-3013.

All my questions have been answered, I am 18 years of age or older, and I wish to participate in this research study. I have received a copy of this consent form.

___ I agree to be audio recorded

___ I do not agree to be audio recorded.

If audio recording and/or writing your memoir are not appropriate for your access needs, please discuss these needs with the researcher and enter them below

___ I agree to be video recorded

___ I do not agree to be video recorded

___I permit the researcher to use my visual art: painting, drawing, or photographs in this research

___I do not permit the researcher to use my visual art: painting, drawing, or photographs in this research

___I agree (additional alternative format discussed)_____

___I do not agree (additional alternative format discussed)_____

_____ _____

Signature of participant   Date

_____

Printed name of participant

_____ _____

Signature of researcher   Date

_____

Printed name of researcher

Appendix D

Demographic Survey

Name:_____

Age:_____

Disability information:

1. Please list your disability or disabilities

2. Have you had these disabilities your entire life? If no, at what ages did you acquire them? If more appropriate, briefly describe how the disability(s) have changed over the years.

Education:

3. What is the highest level of education you have completed?

4. What is the highest level of education your parents or the adults who you lived with when you were under the age of 18 attained?

Employment and income:

5. Are you employed? If yes, doing what? If no, how do you support yourself? What is your monthly or yearly income?

6. Describe other work you have done in the past.

7. What kind of work did your parents or other adults with whom you lived do when you were

growing up? Can you estimate their yearly income?

8. Do you have health insurance? What is the source?

9. Do you own a home, vehicle, and/or other assets?

Social activities:

10. Are you involved with any clubs or organizations?

11. Do you hold any kind of position in any clubs/organizations or civil offices?

12. Please describe relationship status: single, married, dating, widowed, interested in dating, not interested in dating, etc.

Supplemental Questions:

1. What is your gender identification? If this gender identification differs from the one assigned to you at birth, please describe.

2. What is your racial identification?

3. Do you identify with a certain ethnicity? If yes, please briefly describe the nature of that identification.

4. Do you practice a religion? If yes, what religion and did you practice it growing up?

5. Please briefly describe your sexual orientation.

References

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- Introduction to American Sign Language 101

Teaching Assistant, Syracuse University, NY

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Syracuse University Parent Advocacy Center

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- IEP consultation, Resource development, parent outreach, and research

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Level I Pennsylvania: Family and Consumer Sciences Teacher K-12

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PUBLICATIONS_____

Singer, S., Vroman (2018). A new model of educating Deaf students in D. Ford (Ed.) Key Words in Radical Education.

Singer, S. (2018). The shifting meaning of disability in romantic relationships. *The Italian Journal of Disability Studies.*

Singer, S. (2017). Twenty years claiming my Self aloud. In D. Rhyskamp (Ed.) *Spoon Knife II: Test chamber.* Autonomous Press.

Singer, S. (2016). Transforming transformative disability experiential learning. *Issues in Teacher Education 26(2)*

Singer, S. (2015). Come and go what may. *Salt Hill Journal. (34)*

CONFERENCE PRESENTATIONS_____

Singer, S. (2018). *Doing research with students using their second language*. Methodological paper

presented at Qualitative Methods conference, Banff, Alberta, Canada

Singer, S. (2018). *Claiming culturally Deaf identities in adulthood.* Research finding presented at Eastern Sociological Society conference, Baltimore, MD.

Singer, S. (2017). *From life skills to FACS for all.* Workshop given at Pennsylvania Association of Family and Consumer Sciences Conference, State College, PA

Singer, S, & Vroman, K (2017*). Emancipatory research methodologies: Fulfilling their promises?* Methodological paper presentation at Ethnographic and Qualitative Research Conference, Las Vegas, NV

Singer, S. (2016). The Shifting Meaning of Disability in Romantic Relationships. Research Findings present at Ethnographic and Qualitative Research Conference, Las Vegas, NV

Singer, S. (2015). *Feeling the Margins.* Invited Paper Presentation at Writing In-Between, Living In-Between, Syracuse, NY.

Singer, S., Fialka-Feldman, M. (2014). *Recognizing Value in Diverse Scholarly Writing: Questioning the Status Quo.* Paper Presentation. Equity and Social Justice, Syracuse, NY.

Singer, S., Stinson, M., Foster, S. (2014). *Finding Strategies and Technologies to Facilitate Cooperative Learning in Groups with Deaf/Hard of Hearing and Hearing Students.* Research findings presented at Eastern Sociological Society, Baltimore, MD.

Ingraham, C., Dacher, J., Singer, S (2014). *Minding the Gap: The Textually Mediated Experience of Institutional Accessibility--Building an Institutional Ethnographic Research Model.* Paper Presentation. Eastern Sociological Society, Baltimore, MD.

Singer, S (2014). *Social Issues around Cochlear Implants*. Panel Discussant. Eastern Sociological Society, Baltimore, MD.

Singer, S (2013). *A Self-Determination Model of Academic Accommodations.* Paper Presentation at

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Singer, S. (2013). *The Representation of Normative Societal Concepts in American Sign Language*. Paper Presentation at Society for Disability Studies Conference, Orlando, Florida & Critical Junctures, Atlanta, GA

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INVITED TALKS

Singer, S (2018). *Exploring Deafhood.* Towson University

Singer, S (2017). *From medical to mine: Claiming identity.* Trenton, NJ

Singer, S (2016). *ASL for secondary education*. Hamilton, NJ

Singer, S (2016). *Developing an ASL curriculum for elementary school programs*. Hamilton, NJ

Singer, S (2016). *Disability Monologue*. Lecture. Ewing, NJ.

Singer, S. (2015). *Processing Acts of Criptology*. Workshop. Cripping the Comic Con, Syracuse, NY.

Singer, S. (2015). *A Place at the Table.* Lecture Series. Syracuse, NY

Singer, S. (2011).*The Diverse Deaf Consumer.* Presentation. Registered Interpreters for the Deaf Northeast Regional Conference, Rochester, NY.

JOURNAL POSITIONS

Issues in Teacher Education, Reviewer 2014-Present

Critical Education, Reviewer 2013-Present

The SoJo Journal: Educational Foundations and Social Justice Education, Reviewer 2013-Present

GRANTS/AWARDS

Petroff, J., Panscofar, N., Vroman, K., Singer, S. (unfunded). *The New Jersey Wellness MAPS*

Project. U.S. Department of Health and Human Services Administration for Community

Living, National Institute on Disability, Independent Living, and Rehabilitation Research:

HHS-2017-ACL-NIDILRR-IFDV-019

TCNJ Support of Scholarly Activity Grant 2017-2019

This two year competitive grant provides course load reduction for two years. Faculty who

are funded are expected to produce scholarly outcomes beyond those expected of typical

faculty.

TCNJ Professional Development Grant 2016-2017 and 2017-2018

Grant to investigate and implement better methods to teach ASL at The College of New Jersey.

2016. Grant funded to develop training for itinerant teaching of the Deaf for the Education of

the Deaf and Hard-of-Hearing graduate program 2017.

Syracuse University Graduate School Fellowship

August 2012-2016

Hermera Foundation Reflection Fellowship

Incorporation of meditative philosophies and practices in the educational setting, November,

2015

Syracuse University Faculty Excellence Award

Award granted for pedagogical practices, 2015

Joan N. Burstyn Grant for Collaborative Research in Education

Minding the Gap: The Textually Mediated Experience of Institutional Accessibility

Grant written collaboratively March, 2014

Rochester Institute of Technology College Delegate and Commencement Presenter

May 2012

Rochester Institute of Technology Outstanding Graduate Scholar Award

May 2012

Indiana University of Pennsylvania Outstanding Achievement Commencement Presenter

May 2010

SERVICE_____

American Sign Language Honors Society Board Member

Fall 2017 - Present

Honors and Scholars Programming Council

Fall 2016-Present

Deaf and Hearing Connection Advisor

Fall 2016-Present

ASL Honors Society Chapter Head

Fall 2016-Present

TCNJ Outdoors Club Advisor

Fall 2016-Present

New Jersey Consortium of DeafBlind

Fall 2016-Present

Special Education Language and Literacy Diversity Task Force

Spring 2017-present.

Special Education Language and Literacy Council for Accreditation for Educator Preparation.

Spring 2017- present

Honors and Scholars Program Committee

Fall 2016-Spring 2017

PROFESSIONAL ASSOCIATIONS

American Sign Language Teachers Association

American Sign Language Honors Society

American Association of Family and Consumer Sciences

Pennsylvania Association of Family and Consumer Sciences

Society for Disabilities Studies