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"Ya I have a disability, but that's only one part of me": Formative Experiences of Young Women with Physical Disabilities

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"Ya I have a disability, but that's only one part of me":

Formative Experiences of Young Women with Physical Disabilities

by

Viki Peer

A thesis submitted in partial fulfillment
of the requirements for the degree of
Master of Arts
Department of Women's and Gender Studies
College of Arts and Sciences
University of South Florida

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Keywords: disability, gender, experiences, autonomy, microaggressions, community

Dedication

In loving memory of Annie Hopkins, Monika Butkute, and Samantha Marcus.

My life is brighter because of our time together.

Acknowledgements

Conducting my first major research project has been as challenging as it has been rewarding, and lucky for me, I had lots of support along the way. To my thesis chair, Dr. Diane Price Herndl, thank you for patiently helping me organize my thoughts and navigate the uncharted territory of interviewing my friends. To my committee members, Dr. Sara Green and Dr. Michelle Hughes Miller, thank you for your support and insight from the inception of this project.

To my parents, you are the best. Thank you for always being in my corner, for giving me siblings to grow up with, for teaching me how to be kind, and for letting me volunteer at camp when I was 16. I love you. To my favorite aunt and uncle, I wish every kid in the world could feel as special as you have always made me feel.

To the love of my life, Chris, thank you for moving across the country with me and for being willing to do it all again this summer so that I can become Dr. P. I appreciate every bit of you, especially the bit that reads drafts of my work at 2am and walks Nash and Zoe when I'm too sleepy.

Most importantly, thank you to each of the participants of this study, without whom this project would not have been possible – literally. Thank you for taking time out of your busy lives to share your stories with me and for being my friends. I 3E Love each of you!

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Abstract

Amidst our ableist social world, there are people with disabilities who are living the lives they want to be living and are, so-to-speak, "doing their own thing." This project focuses on what a few young adult women attribute as having helped them get to where they are today. There were two overarching open-ended research questions guided this project: (1) what opportunities and experiences have influenced the four women with physical and mobility disabilities in terms of getting to where they are today? And (2) how have these opportunities and experiences helped and/or challenged them along their journeys? The study analyzes responses from semistructured interviews with four young women with physical disabilities. Participants' responses suggest that growing up in supportive environments (family, friends, other people with disabilities) that foster a sense of disability pride helped participants adopt similar perspectives on disability. I argue that participants learned to understand disability as a valued form of social diversity in large part from their parents and from experiences that allowed them to interact with other young people with disabilities. Additionally, strategic positivity and persistence are two ways that help participants cope with the day-to-day ableism and anti-disability microaggressions that they experience.

keywords: disability, gender, experiences, autonomy, community, microaggression

Introduction

While people with disabilities[1] are significantly and negatively affected by our ableist society, many people with disabilities are living the lives they want to be living despite living in a world that has been strategically set up in ways that make it difficult, and sometimes, impossible, for them to do so. We live in a Western, industrialized, neo-liberal, capitalist society in which the legal, political, economic, and social disenfranchisement of people with disabilities is both historical and systematic (White, Simpson, Gonda, Ravesloot, & Coble, 2010) and women with disabilities in particular are disproportionately unemployed, underemployed, and underpaid (Priestley, 2013). While the proliferation of disability advocacy organizations, monumental anti-discrimination legislation, various social movements (e.g. 3E Love[2]), and significant disability rights activism have helped reduce the stigma commonly associated with the presence of disability, ableist ideologies continue to dominate our social world. If we understand disability as a social phenomenon, then we must take into account the other intersecting social variables (e.g. familial socio-economic status, racial/ethnic background, geographical location, educational attainment) that shape the ways in which individuals might experience this social phenomenon.

The women interviewed for this project are women with physical disabilities who are college-educated, married, dating, living alone, living with roommate(s), living with family, licensed drivers, and full-/part-time workers. This project focuses on what these women attribute

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[1] This project focuses on people with visibly apparent physical and mobility disabilities.
[2] For more information on 3E Love, visit www.3elove.com.

as having helped them get to where they are today. The overarching open-ended research questions that guided this exploratory research project were: first, what opportunities and experiences have influenced the four women with physical and mobility disabilities in terms of getting to where they are today? And second, how have these opportunities and experiences helped and/or challenged them along their journeys? Based on their responses, I argue that participants learned to understand disability as a valued form of social diversity in large part from their parents and from experience that allowed them to interact with other young people with disabilities. This suggests that young people with disabilities need to have opportunities that encourage them to cultivate understandings of disability that celebrate diversity and foster a sense of disability pride. Additionally, learning strategic positivity and persistence can help participants deal with the day-to-day anti-disability microaggressions[3] that they experience.

This project is rooted in the notion that the interview participants are living the lives they want to be living. It is hard to put this notion into words because I reject understandings of disability that are akin to "inspiration porn"[4] and the "supercrip,"[5] and am hesitant to use adjectives that are particularly value-latent (e.g. "happy" or "good" or "successful") to describe these women. Using these terms carries an implication that people who do not meet these subjective criteria for these adjectives are somehow living "unhappy" or "bad" or "unsuccessful" lives. Words like "thriving" and "flourishing," which might seem like a more neutral word, are often understood as somehow being in opposition to the presence of disability (Berube, n.d.).

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[3] Microaggressions are "everyday verbal, nonverbal, and environmental slights, snubs, or insults, whether intentional or unintentional, that communicate hostile, derogatory, or negative messages to target persons based solely upon their marginalized group membership" (Sue, 2010, p. 3).

[4] An image of a person with a disability doing something ordinary accompanied with a caption that promotes the idea that the person in the image "overcame" their situation and serves to objectify and sensationalize people with disabilities (Young, 2012).

[5] This concept of the "supercrip" marginalizes people with disabilities by perpetuating the idea that disability is something to be overcome via hard work, determination and a positive personal attitude (Haller & Ralph, 2006; Quinlan & Bates, 2008).

Amidst this complicated terminology, I hope to present their lives and experiences in an honest and cohesive manner so that readers have the opportunity to think that the participants are doing difficult and interesting things with their lives. In order to do so, readers must remain wary of some common disability-related pitfalls: 1) conceptualizing the presence of disability as tragic and/or deserving of pity and 2) being quick to reduce people with disabilities to objects and then sensationalize and any and all of their accomplishments (i.e. inspiration porn).

Terms

While there are some terms used to describe people with disabilities that are fairly accepted in disability communities, no term is without its limitations (Linton, 1998, 2006). For example, Gibson (2014) argues that the phrase "special needs" ignores key contextual factors, like the social, legal, economic, and environmental barriers addressed in this project. Since naming can be used as a mechanism of power (Gomez, 2012), some people in various disability communities advocate for "people first" language such as "people with disabilities" instead of "disabled people" (Cosier & Ferguson, 2012). Others advocate for "disabled people" as a way to emphasize that disablement is a social and collective process rather than a fixed identity (Titchkosky, 2006) or as a linguistic choice that indicates having pride in difference (Linton, 1998). Although I am acutely aware of this disjuncture and do not think there is a clear answer to the "people with disabilities" v. "disabled people" debate, I use "people with disabilities" because the participants all prefer it.

Additionally, while the term "disability" can refer to a wide variety of physical and cognitive arrangements (Strimple, 2013), it can also refer to the various ways in which people with perceived impairments are socially marginalized and economically disenfranchised (Priestley, 2013). Although I use "disability" as a proxy, I agree that, "the term 'disabled' cannot

easily be accepted as a self-evident phrase referring to a discrete group of particular people with similar essential qualities" (Kafer, 2003, p.78). While it might be useful in some circumstances to distinguish people with disabilities who live with chronic illness from those who do not, it is also important to note that many people who have physical impairments have health problems, that many chronic illnesses can cause disabilities, and that people with disabilities or impairments do not necessarily live with illness(es) (Filax & Taylor, 2014). So, even though the term "disability" is an unstable category, I use it because it is an identity that many people, including my participants, claim with pride (Baker, 2011).

Background Information

In the United States, as in many other countries, there are five traditional social "markers" or "milestones" of adulthood (completing education, securing employment and financial stability, leaving home, getting married, and having children) that have commonly been used in the assessment of young adults (Silva, 2012), all of which imply normalized notions of independence. These five milestones often remain important even though these markers prioritize individualistic notions of independence and do not acknowledge the many factors that affect young people. Similarly, they do not address the cultural significance that is placed on acquiring the skills necessary to build social capital, form close relationships, and reach their goals. For example, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) asserted that for many people with disabilities, having opportunities to be actively involved in decision-making processes and being able access to various physical, social, and economic environments are often more important for people with disabilities (UNCRPD, 2008). Similarly, the independence related to the adulthood marker of "leaving home" is not necessarily

about whether or not an individual lives alone but rather to what degree individuals with disabilities have decision-making capabilities in regards to where they live and what they do.

Much of the research that has been done regarding young people with disabilities focuses on structural opportunities (e.g. legal policies that secure them the right to attend publicly-funded schools and anti-discriminatory employment legislation). In their 2013 literature review of youth with disabilities and the various factors that influence the expectations and attainment of independence, Stokes, Turnbull, and Wyn call for researchers to pay more attention to the important factors that affect the opportunities that young people with disabilities have. The purpose of this study is to add to this research by focusing not on the larger factors that affect various opportunity structures but rather on the more intimate, experiential factors (such as mother-daughter relationships, summer camps, and microaggressions[6]) that are, as the participant in the pilot study for this project insisted, also very important. While it is important to understand that disability is a social phenomenon, not an individual problem, studying personal experiences allows us to gain a more nuanced understanding of how disability operates at the individual level. It is my hope that, through collaborative, qualitative research with people with disabilities, this paper highlights what four women with physical disabilities attribute as having been influential in their lives and how their experiences suggest that we reframe disability as being a type social difference rather than a personal problem.

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[6] Microaggressions are "everyday verbal, nonverbal, and environmental slights, snubs, or insults, whether intentional or unintentional, that communicate hostile, derogatory, or negative messages to target persons based solely upon their marginalized group membership" (Sue, 2010, p. 3).

Literature Review

This chapter provides an overview of the important disability-related concepts in which this project is situated. First, I offer information about the traditional social markers of adulthood as they relate to people with disabilities. In the second section, I provide a brief history of disability-related legal and political landscapes. The last section includes previous research that has been done regarding the importance of social support and a community of peers.

Traditional Social Markers of Adulthood

In the 1980s, the timing of major life events became salient in the understanding of this transition (Goldscheider & Waite, 1986; Hogan, 1981; Marini, 1985), but much of the focus was on structural factors, rather than individual aspects (Tisdall, 2001). Currently in the United States, five traditional social markers of adulthood (completing education, securing employment and financial stability, leaving home [i.e. living independently], getting married, and having children) are used in the assessment of young adults (Arnett, 2004; Silva, 2012), regardless of disability status. People with disabilities often have fewer opportunities to be involved in their communities (Chenoweth & Stehlik, 2004) and even people with disabilities who are living what might be considered "independent" lives (according to neoliberal frameworks of autonomy and independence) often still feel isolated from their communities (Taylor, 2000).

For earlier generations of young people in America, marriage and parenthood were often the salient markers of adulthood (Ben-Amos, 1994; Modell, 1989) however, for current generations of young people in America, securing a full-time job and independent residence are

often the most salient markers of adulthood. Research on young people (Arnett 1998, 2004) suggests that young people often do not gauge adulthood based on these social markers but instead on individualistic characteristics such as making decisions for oneself, earning enough money to support oneself, and accepting responsibility for one's actions. Within this individualistic neoliberal framework, adulthood, as defined by characteristics of autonomy (e.g. the opportunity to make decisions for oneself), is understood similarly among young people with and without disabilities, and the historical and continued disenfranchisement of people with disabilities is ignored.

Many factors affect if, when, and how young people reach these milestones of adulthood and Dutch scholars Aart C. Liefbroer and Laurent Toulemon argue that it is important to study various demographic markers in young adulthood (Liefbroer & Toulemon, 2010). For example, while the typical age range during which most people reach these markers of adulthood is 20-29 (Arnett, 2001), people with disabilities, if they reach them at all, often reach these adulthood milestones later in life (Janus, 2009; Leiter, 2012). The significant changes in economic and labor market opportunity structures, and unprecedented changes in the gendered patterns of the American workforce, has made this transition increasingly more complex and difficult for young adults (Settersten, Ottusch, & Schneider, 2015; Stokes & Wyn, 2007; Waters, Carr, & Kefalas, 2011). Similarly, an individual's family background, resources, and racial, ethnic, and gendered diversities affect their opportunities and experiences within the broader social world (Holdaway, 2011). These varying contexts in which many young people transition into adulthood are changing in ways that affect if, when, and how they reach adulthood milestones in different ways:

1. the level of education required for many occupations is increasing, prolonging the amount of time that many young people spend pursuing their education;

2. full-time, salaried employment opportunities are scarce;

3. record-high costs of higher education, resulting in record-high amounts of student debt, make it difficult for young people to become financially stable and sufficient;

4. and although it is becoming more socially acceptable for young people to live independently before marriage, many young people are delaying and, in some cases, opting out of marriage and parenting as a result of their bleak financial situations (Settersten, & Ottusch, & Schneider, 2015).

Although reaching these social markers of adulthood is context-specific, they are still widely considered to be important indicators in the process of measuring success among young adults.

Transition to adulthood for people with disabilities.

Individualism and individualistic models of adulthood that are supported through the dominant American majority culture affect how young people, with and without disabilities, understand various milestones of adulthood and thus, their strategies to reach those milestones (Arnett 1997, 2001). However, the experience of navigating various pathways in the transition into adulthood is not universal. For example, research has shown that working-class and low socio-economic status (SES) circumstances (Benson & Furstenburg, 2007; Osgood, Ruth, Eccles, Jacobs, & Barber, 2005), religion (Nelson, 2003), and disability (Leiter, 2012) are linked with young people having notably different experiences with this transition. Although disability and illness are socially constructed and maintained (Conrad & Barker, 2010; Oliver, 1996, Shakespeare, 1994), they often have very substantial effects on if, when, and how a person reaches various adulthood milestones.

In their 2008 study of how people with disabilities understand community participation, Hammel, Magasi, Heinemann, Whiteneck, Bogner, & Rodriguez found that autonomous participation, experiences to build community with others, and opportunities for meaningful reciprocity were the salient features of community participation according to people with disabilities themselves (Hammel et. al, 2008). In their research report on young people with disabilities, Stokes, Turnbull, and Wyn (2013) draw attention to the lack of literature focused on the personal and social factors that affect young people with disabilities' transitions into adulthood and highlight the need for increased opportunities young people with disabilities need to develop social networks. Since strong social networks and the opportunities to become meaningfully involved in the community are important parts of this transition, their report highlights the lack of opportunities for youth with disabilities to develop these social systems of support. My project aims to address this dearth of academic scholarship by adding the lived experiences of young women with physical disabilities to the literature. In the next section, I provide information on how important the success of social movements and the passage of federal acts have created the particular legal and political landscapes in which people with disabilities navigate their lives.

Legal and Political Landscapes

The Civil Rights Act of 1964 prohibited discrimination on the basis of race, color, religion, sex, or national origin, but it was not until section 504 of the Rehabilitation Act of 1973 that it became illegal to discriminate on the basis of disability status. Before the Rehabilitation Act of 1973 was passed, disability rights activists in the Independent Living Movement (ILM), who were fighting for their civil rights to be legally legitimized, were laying the foundation by highlighting how it is social practices and environmental barriers that affect a person's ability to

be independent, not an individual person's medical condition. According to Chava Willig Levy's insightful monograph on the history of the ILM (1998), the Rehabilitation Act of 1978 had more substantive effects than the previous Rehabilitation Act of 1973 because Title VII of the 1978 Act enacted a national program for independent living wherein people with disabilities would be substantially involved in decision making processes. Echoing this sentiment, for Charlie Carr (n.d.) and disability rights activists across the country, one of the most important philosophical tenets of the ILM was the notion of choice and the importance of people with disabilities having control over themselves and having opportunities to be able to make decisions for themselves.

The disability-related legislative breakthroughs that occurred during the latter half of the twentieth century ultimately led to the Americans with Disabilities Act of 1990 (ADA). The ADA provides civil rights to people with disabilities and is considered, "an 'equal opportunity' law for people with disabilities (U.S. Department of Justice, n.d.). It is now more than twenty-five years since the passage of the ADA, and generally speaking[7], people with disabilities now have many important legal rights and protections. That said, negative social attitudes towards people with disabilities and constraining environmental barriers continue to stigmatize people with disabilities (Smart, 2004). In the section that follows, I explain the significance of microaggressions as manifestations of negative social attitudes that stigmatize people with disabilities.

Supportive Parents and Creating Community

While the legal and political gains of the twentieth century have undoubtedly determined the degree to which young people with disabilities can access the social world, there are certainly other factors that have the potential to affect how a person with a disability experiences their life.

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[7] It is worth noting, however, that over the last few years, the Supreme Court has curtailed the extent of the reach of the ADA. For more information see Goren, 2016.

For example, in his critique of rehabilitation facilities for people with disabilities, Condeluci (1999) argues that shifting the focusing onto creating strong relationships is one of the most important changes we can make to help people with disabilities become more successful. For people with disabilities, finding and creating community amongst other people with disabilities (e.g. specialized summer camps and online forums) can be important strategies to help young people with disabilities build the practical skills and social systems of support that will help them succeed in their communities. Social interaction and close relationships, which are important for people with and without disabilities (Cummins & Lau, 2003), can be encouraged by supportive parents and can be experienced in online forums and specialized summer camp programs.

Supportive parents.

Through encouragement, support, provision of opportunities, and skilled negotiations with various professionals, parents and family members often play instrumental roles in a young person with a disability's understandings and expectations of their future (Stokes, Turnbull, & Wyn, 2013). These instrumental roles that parents and family members can play are so important that Joseph P. Shapiro (1994) claims they are the most crucial factor in the success of the young person with a disability. In their study of youth with spina bifida, Zuckerman, Devine, and Holmbeck (2011) found that intrinsic motivation is important for youth with spina bifida and that parental support can play an instrumental role in overall youth success. Furthermore, children with disabilities whose parents encourage them from a young age to adopt a positive understanding of their disability identity are more likely to be personally satisfied with their lives (Siebers, 2008).

Creating community.

Summer camps, particularly those aimed towards youth with disabilities, foster environments for participants to have fun and engage with peers in recreational, and therefore, nonclinical, settings (Thurber & Malinowski, 1999). Summer camps can provide fun and safe environments in which participants have opportunities to meet new people and try new things (McCarthy, 2015). In their study of Canadian youth with disabilities, Goodwin & Staples (2005) found three themes that emerged from the experiences of youth with disabilities who attended summer camp: development of a sense of community, stronger sense of independence, and increased opportunities to engage in various activities. Summer camp can be an experience wherein people with disabilities learn to articulate and effectively communicate their needs (if any) to others and create social systems of support amongst people with and without disabilities. This ties to having supportive parents because it is often parents who seek out these recreational summer camp opportunities and encourage their children to partake.

Other opportunities to form communities with people who share similar life circumstances are online forums. Reinke & Solheim (2015) found that parents of children with autism spectrum disorder find informational and emotional support through online communities. In their 2014 study of online forums for parents of children with type 1 diabetes, Balkhi, Reid, McNamara, and Geffken (2014) explain that there is minimal empirical data on the effectiveness of online forums for special populations. While many studies about the importance of online communities have focused on parents of children with disabilities and/or chronic illnesses, there have been fewer studies that focus on people with disabilities and/or illnesses themselves. One notable study that centers on people with disabilities themselves is about women with disabilities

and the instrumental role that a support group played in strengthening their sense of belonging

(Mejias & Gill, 2014). In this study, Mejias & Gill found that through this support group,

participants shared information, helped each other build skills, and empowered each other. Being

a member of a community of people with similar life circumstances (e.g. a particular chronic

illness) can be useful not only for mutual support but also to learn from each other by sharing

and receiving information from other members of the forum.

Theoretical Framework

While multiple frameworks for understanding disability exist, the social model of disability is the perspective that informs this project. Disability studies scholars who advocate for social construction approaches to understanding disability (e.g. Oliver, 1996; Shakespeare, 1994; Shakespeare & Watson, 1997) stress that disability is not determined solely by an individual person's illness[8] and/or impairment but instead is produced through the physical environments and social and cultural attitudes that do not accommodate them. Adopting the social model of disability allows this project to focus primarily on participants' personal experiences and social interactions rather than their individual illnesses[9] and/or impairments. More broadly, this project is aligned with the celebration agenda of disability rights activism (Baker, 2011): the idea that disability is a valid and valued type of social diversity. In this project, the particular social locations that result in participants' experiential knowledge are appreciated and respected.

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[8] For more information on the social construction of illness see Brown, 1995 and Conrad & Barker, 2010.
[9] All participants in this study live with various forms of Muscular Dystrophy, a chronic, progressive, and terminal disease that causes physical and mobility disabilities.

Methods

In the interviews conducted for this project, participants offered their perspectives on what has led them to become the people they are today. This chapter outlines and explains the methodological approaches I used in this project. In the first area of this chapter, I identify the theoretical approaches and feminist considerations that justify the rigor of this project. Next, I discuss the various inclusion and exclusion factors for the participants. The third area of this chapter is where I offer information on the various research methods that I used to collect information in this study. Lastly, the area of this chapter about data analysis explains how I analyzed information and other various considerations taken into account regarding the interpretation of the participants' responses.

Theoretical Approaches and Feminist Considerations

Inductive research methods, such as grounded theory (Glaser & Strauss, 1967) and phenomenology (Schutz, 1967), offer methodological strategies that allow participants the opportunities to highlight what they attribute as having been influential in their lives. Interpretive analyses aim to represent the lived experiences of people or a group of people (Denzin, 1989) by describing their social locations, feelings, and reflections (Charmaz, 1996) and meaningfully engaging with the cultures and communities represented in the data (Chilisa, 2012). According to Harding (1987), distinct methodological features of research that have important epistemological

implications are what characterize feminist research. Additionally, feminist epistemology and grounded theory can be used to mutually inform the research process because they both lobby for the understanding of research as a process, the importance of context, and recognition of "multiple explanations of reality" (Wuest, 1995, p. 127). When feminist research perspectives and indigenous research methods are applied to grounded theory and phenomenology, the entire research process can be transformed into a feminist-based project that uses personal experience as a base for knowledge production and allows for the data to drive the findings and any subsequent theories.

Dwyer & Buckle (2009) argue that diligent reflexivity during the research process, meaningful acknowledgement of the researcher's relationships with participants, genuine interest in the experiences of participants, and the commitment to the fair and appropriate representation of their experiences can reduce the influence of the researcher's insider or outsider status on the research process. For this project, I collaborated with people with various "types" of disabilities as well as the participants (who are friends of mine) in attempts to cultivate a research project that acknowledges my relationships with people in disability communities while remaining wary of the exploitative risks posed when a researcher is not considered to be a member of the participants' community. This approach allowed me to select a topic that is relevant to the participants while acknowledging the identity I hold as a person without "the traits we think of as disability" (Garland-Thompson, 2005, p. 1558). The collaborative approach to this project is important because close researcher/participant relationships allowed me to read participants in more nuanced ways and thus, allow for more ethical research (Ellis, forthcoming). Continuous reflexivity supports the construction of a more relevant and honest account of the social world (Harding, 1986).

Broadly defined, a general feminist perspective would have us understand the world in a way that encourages diversity and a fairer world for all people (Adichie, 2014). Disability issues have notoriously been left out of feminist theory and research, and many feminist scholars remain uninformed about disability perspectives (Garland-Thompson, 2002). Adopting a feminist disability perspective allows this project to recognize the social barriers (such as microaggressions), celebrate disability as an appreciated way of being in the world, and challenge normative understandings of the body. Through careful consideration of and collaboration with the participants, along with continued feminist reflexivity, my aim has been to use feminist research tactics to make this project as methodologically strong as it is relevant to the participants.

Pilot Study

In preparation for this project, I conducted a pilot study and interviewed a friend of mine, Joey,[10] who, like the participants interviewed for this project, is a woman with a physical and mobility disability. I asked Joey, who is in her mid-30s, to reflect on various coming-of-age experiences she had, how she understands the concept of independence, and how she has come to understand it in such a way. She navigates her life in an ableist social world that is not designed for people with disabilities to be independent, autonomous, and successful at reaching their goals. And yet, she, like the participants interviewed for this project, describes herself as independent, autonomous, and successful at reaching her goals. I wanted to know which experiences and opportunities she attributes as having been most influential in helping her achieve her goals.

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[10] Pseudonym

The practice of interviewing a friend prior to this study eased some of my methodological concerns (e.g. how would my friendship with the participant affect the research?) and also challenged my original focus: independence. While notions of independence and autonomy are commonly promoted as unproblematic and universal goals (Fine & Glendinning, 2005), the elements of dependency that are often associated with people with disabilities are "shaped by a variety of economic, political, and social forces" (Oliver, 1989, p. 17). Joey highlighted the importance of feeling supported by her family and friends, connecting with other people with disabilities, and learning how to deal with ableist attitudes and complicated social services offices. Joey also explained that everyone comes from different backgrounds and has different goals for their future, and that what is important is that we, people with and without disabilities, do not create a hierarchy of these goals. For her, success means financial stability, residential independence, and a positive sense of self-worth, but for someone else, their version of success and what it means to be independent will likely be very different from hers. Drawing from this pilot study, I decided to shift the focus for this project away from notions of success and independence and instead focus on experiences and opportunities that have influenced participants' goals and helped them on journeys towards achieving those goals.

Participants

For this project, all participants were between the ages of twenty-three and thirty-one years old because although the period during which most people reach milestones of adulthood is twenty to twenty-nine years old (Arnett, 2001), people with disabilities often reach these adulthood milestones a few years later than their peers without disabilities (Leiter, 2012). Additionally, since all participants were very young in age (ranging from unborn to five years old) when the Americans with Disabilities Act passed in 1990, they grew up in an era of

American history in which many beneficial legal policies and social programs were available. It is also important to note that the participants navigate their lives in Western social climates and political contexts (e.g. women's rights to vote, own property, and hold credit) that both allow, and to some degree, expect, women to be independent and otherwise successful (Traister, 2016).

This study included four participants, each of whom self-identifies as a woman who has a physical and/or mobility disability and requires assistance with their activities of daily living[11] (ADLs). Since a major component of this project is for participants to reflect on their experiences from childhood, adolescence, and young adulthood, it was important that all participants also identify as having grown up with physical and/or mobility disabilities. All participants were born with a form of muscular dystrophy (MD), diagnosed within the few years of age, and have been acquiring their physical and mobility disabilities over time. Although the participants might be included in the category that Wendell (2013) names "healthy disabled" (meaning that although they may sporadically experience fluctuations in their health, they consider themselves to be healthy, not sick). Participants might also be included in the category of people with chronic illnesses, a category that is not easily defined or understood. While it is relevant to note that all participants frequently, if not always, experience the inability to pass as nondisabled (Humphrey, 2000), the specifics of their various medicalized conditions did not affect my analysis so I do not provide many specific details about the participants' diagnoses. Since all participants use power wheelchairs for mobility, their experiences with various architectural and environmental barriers are coupled with social marginalization they experience, which is often a result of dominant interpretations of their apparent impairment(s).

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[11] There are six basic activities of daily living (ADLs): eating, bathing, toileting, dressing, transferring, and continence.

This project, with a total of four participants, does not represent a scientific sample. At the dozens of summer camps where I have volunteered each summer for the last twelve years, I have developed an extended group of friends who have physical and mobility disabilities. The participants I chose to interview for this project are all friends that I have made at these summer camps. While their racial, ethnic, religious, national, nor SES-based identities factored into the inclusion criteria, each participant presents a number of different intersecting identities that both allowed and required an intersectional analysis. In their discussion of the importance interrogating intersectionality (Crenshaw, 1989) in feminist research, Dill and Kohlman (2012) warn researchers of exploring differences without any genuine or comprehensive analysis, a methodological faux pas that they refer to as "weak intersectionality" (p. 169). Heeding their warning, this project was designed with careful consideration to allow for strong engagement with and analysis of the intersecting identities and social locations of the participants. In my interpretation of their responses, I have tried to represent the array of similarities *and* differences among participants, as authentically as I can.

Procedure

Semistructured interviews with open-ended questions as the interview guide (listed below) allowed the participants the opportunity to address the same topics and ensured that each participant had the same capacity to focus on the various topics (Green, 2013). At the beginning of each interview, participants were asked a series of demographic questions. During these dialogic and interactive interviews, I worked to a conversational atmosphere in order to facilitate candid responses (Ellis, Kiesinger, & Tillman-Healy, 1997). Although compassionate interviewing practices (Ellis & Patti, 2014) may seem more relevant when topics are explicitly sensitive (e.g. death, loss, trauma), they were applicable for this project because I asked

participants to explain and reflect on experiences on topics have the potential to be emotionally charged (e.g. family dynamics, struggles, and sense of self).

The participants chose the dates and times for their interviews, all of which were conducted via online video messaging. Since the goal of these life history interviews was to have participants talk about their experiences of living with a disability, there were minimal potential risks or benefits to the participants. All participants openly agreed to the verbal consent form[12], which allowed me to use the results of their interviews as data for this MA thesis and in future academic presentations. This study, #Pro00025293, has been approved by the USF Internal Review Board.

Table 1: Participant Demographics

Pseudonym[13]	Demographics
Jamila	A White Arab-American 23 year old woman who lives in a large urban setting in the Midwest, has a college degree, works full-time for a national nonprofit organization, and lives in an apartment with a roommate.
Lana	A White American 31 year old woman who lives in a semi-rural setting outside of a small city in the Midwest, has a college degree, works part-time for a local nonprofit organization, and lives in a house with her partner.
Cat	An Asian-American 24 year old woman who lives in a suburban setting in the Midwest, has a college degree, and works as a freelance writer while working on her own projects, and lives at home with her mom.
Hanna	A White American 24 year old woman who lives in a large urban setting in the Midwest, has a college degree, and works full-time for a large retail corporation, and lives in an apartment by herself.

* While college experience was not a criterion for inclusion, it is important to note that all participants graduated from large, residential universities.

Data Analysis

Analysis and interpretation of qualitative interview responses must recognize the language and discourses that are available to participants (DeVault & Gross, 2012) and such

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[12] See Appendix C

[13] I worked with participants to select a pseudonym for themselves and have altered any other identifying information in order to protect their identities.

recognition is particularly relevant for this project because the participants' use of various terms that have specific academic connotations (e.g. "disabled" and "independence") needed to be carefully examined to avoid conflation and misrepresentation. Participants' discursive constructions of their identities and their experiences are the results of a variety of factors (Benwell & Stokoe, 2006) (such as age, geographical location, and primary language) and not all people have access to specific communities of practices and shared knowledges (e.g. exposure to disability-related academic literature, experience with disability activism and advocacy groups). If these responses were to be analyzed using only academic understandings of terms and concepts, the semantics of their language and discourse, as presented in their responses, could be misinterpreted. One of the most important responsibilities has been to ensure that participants' descriptions of their experiences are interpreted in an authentic manner, to the best of my ability.

In order to organize and interpret the information, responses were analyzed using open coding strategies (Glaser & Strauss, 1967) and thematic coding strategies (Bowen, 2006; Gilgun, 2007). The codes and themes that emerged from the data analysis process (e.g. camp, caregiver struggles, microaggression, persistence, parental support, personal drive, community), and relevant quotations from the interviews, are presented in the next chapter.

Results

In the early stages of this project, I searched for a concise way to say that the participants are doing the things they want to be doing, in the ways that they want to be doing those things, and that they are satisfied with how they are living their lives. I read existing academic literature and had conversations with friends and colleagues about this linguistic gap, and the terms that came up did not seem quite right. Adjectives like "successful," "independent," and "happy" are value-laden and have strong subjective connotations. Additionally, given that all participants in this study live with progressive muscle-wasting diseases, it seems odd to use adjectives like "thriving," "strong," and "flourishing," terms that are often used within medicalized frameworks of illness and disability. I decided to use the interviews as an opportunity to ask participants for help finding new language but this, too, came up with nothing new, and I believe that it is because I am looking for a word or phrase that does not yet exist. In short, I use "it" in the section headings of this chapter as a proxy for the idea that the participants in this study are living the lives that they want to be living and doing so in the ways that work best for them.

The goal of this project has been to better understand what helped these young women with physical disabilities become who they are and lead the lives they are currently leading. As such, this section is presented in a loosely chronological manner and is organized into five major areas: believing I could do it, seeing others do it, getting help doing it, challenges doing it, and

helping others do it. In each of these five major areas, I include relevant themes that emerged from the coding process. While I do not mean to suggest that the responses that each of the participants necessarily have implications for the other participants, I do hope to highlight commonalities in their responses. In this chapter, I will refer to the literature addressed in the literature review as it is relevant to their responses and will provide an in-depth discussion of the significance of their responses in the following chapter.

Believing I Could Do It

Overwhelmingly, participants expressed the importance of experiences that helped them figure out what kind of people they wanted to become and what kind of goals they wanted to set for themselves. They also explained how important it was that they believed they could achieve their goals and cited the various experiences they think were most influential. Not being treated differently by their parents, having a supportive mom, and understanding that "it" is different for different people were all cited by participants as having been important in their coming-of-age processes and believing in themselves.

   Not being treated differently by parents.

Hanna, Jamila, and Lana all talked about how their parents did not treat them differently on account of their disability. For Hanna and Jamila, this is in reference to not being treated differently than their siblings. For Lana, this is in reference to not being treated differently than she imagines other parents would treat a child with a disability and chronic illness. Overwhelmingly, their responses demonstrate how their parents did not make them feel different or bad about themselves and their disabilities.

Hanna, who grew up with sisters who are close in age, explained how her parents treated her growing up and says that her parents' normative standards helped her feel capable of reaching her goals:

> My parents first and foremost didn't raise me any differently from my sisters, you know, they really had the same expectations for me as they did for my sister and that really helped. They never raised me like I was a different kind of kid so I think that was a very big thing. Ya I have a disability, but that's only one part of me.

Hanna grew up with parents who did not treat her disability as an undesirable or individualized trait and, as an adult, she recognizes the positive effects that had on her in terms of what she thought was possible for her future. In regards to how her mom disciplined her and her siblings, Jamila, who grew up with one brother who has the same disability as her and another brother who does not have a disability, offers this example of how she was not treated differently because of her disability:

> She never treated me different [laughs]… my mom did *not* [emphasis added] care; she wasn't going to give me a little slap on the hand just because I was disabled.
>
> She beat me just the same as my able-bodied brother…she treated us all the same.

Of course, their medical diagnoses and physical disabilities meant that Jamila and Hanna needed their parents to do things for them that were not necessary for their siblings. For example, their parents needed take them to frequent medical appointments, make various architectural changes to their homes (e.g. add wheelchair ramps, widen door frames, replace bathtub with roll-in shower), and provide physical care, much of which came from their moms, in ways that their siblings did not need. What Jamila and Hanna's responses suggest is that although their parents

undoubtedly did have to treat them differently because of their disability, their parents did not make them *feel* different, or bad, on account of their disability.

Later in our conversation about her decision to go away to college, Jamila talked about how her parents *did* treat her differently than one of her brothers, who also lives with a neuromuscular disease and uses a power wheelchair for mobility. She explains that this differential treatment was on account of her parents' conservative cultural and religious beliefs and says,

My parents were so against [me going away to college] but it was mainly not even because I was disabled but because I was a girl. My brother almost went [away to college] and my mom was all about it and was like going to help him go and take him there and everything, but when I said I wanted to go away to college she said she would basically disown me and my dad was like, 'no, you're a girl you can't do that.'

In this example, Jamila's parents, who ultimately came to terms with her decision to leave home and attend a large residential university, treated her differently on account of her *gender*, not her disability. Although her parents' patriarchal beliefs led to differential treatment between Jamila and her brothers, these beliefs did not prevent her parents from treating the presence of disability as a valued form of social diversity.

Lana, who did not grow up with siblings, explains how her parents did not treat her differently on account of her physical disability despite the fact that she spent much of her childhood in and out of hospitals:

I don't feel like I was treated as though I had a disability, you know? Like, in comparison to other people [with disabilities] who were treated a little bit more

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delicately when they were young. I feel like they treated me as though I was

another kid, I just got sick a little easier.

Throughout our conversation, Lana repeatedly referenced how the sense of pride that she grew up having for her disability identity has influenced her work and volunteerism with local disability-serving organizations. Despite her frequent hospital stays as a child, Lana's parents treated her muscular dystrophy as being one part of her life, a part did not automatically prevail over the other parts of her life. I believe that having parents who did not treat her negatively because of her disability helped foster Lana's sense of disability pride.

While their physical disabilities certainly gave their parents more or different parenting responsibilities, Hanna, Lana, and Jamila's parents did not stigmatize their disabilities. This is not to suggest that their parents treated their disability as an unimportant part of their life, only that they did not treat it as a bad part. Moreover, their parents did not make them *feel* bad or different about their disabilities and their responses suggest that growing up in an environment that fosters a positive disability identity, wherein disability is a valued type a social diversity, helped the participants adopt this understanding of disability for themselves.

Strong mama.

While participants highlighted the influence of growing up with parents who did not treat their disabilities as a negative part of their lives, and thus, did not make them feel like they were somehow radically different because of their disabilities, they did not shy away from acknowledging the significant responsibilities placed primarily on their mothers.

Cat's mom raised Cat and her siblings on her own for a significant portion of Cat's childhood. During our conversation, Cat talked about the close connection that she and her family feel for each other and that Cat attributes the supportive family dynamic she experienced

as a kid to her mom. Cat, who recently moved back into her mom's house after graduating

college, credits her mom and her family's caring dynamic for helping her believe from a young

age that she is loved and supported, which has helped her through some tough situations. When

Lana and I talked about her childhood family dynamics, she acknowledged the powerful role that

her mom played in helping her cultivate a determined and resilient personality, two traits that

Lana says can be very helpful for people with disabilities living in an ableist world. She said,

"My mom did not work until I was 12 so she was a big part of my life. Like, she was always

there. My mom is a very, very strong and motivated woman so I think I got a lot of that from

her."

In a few different parts of our conversation, Jamila noted the different ways that her mom

helped her learn to advocate for herself. She said,

> My mom was actually like our biggest advocate. She made sure we got the best
>
> resources and the best wheelchairs and the best like doctors and I mean she
>
> always took us to like 7 million doctor appointments and stuff like that.…when I
>
> was growing up, she actually encouraged me to take public transportation. I was
>
> scared to go on my own and she was like 'why, they're accessible just go'…
>
> normal parents would be like, 'no you're disabled like don't take the bus or
>
> whatever like it's not safe' but my mom was always just like disabled or not,
>
> that's not an excuse.

Whether helping Jamila with the majority of her personal care, ensuring that Jamila (and her

brother) had good medical resources, encouraging her to learn how to use public transportation,

or showing her how to advocate for herself, Jamila's mom played a key role in Jamila's belief

that she could do "it." Many adults with disabilities believe that when parents coddle their

children with disabilities, they negatively affect their children's attempts to live autonomously (Green, 2015). So, we can understand the encouragement that Jamila's mother offered her, in terms of learning to take public transportation on her own, as having had a positive effect on Jamila's progress towards autonomy.

While their mothers experienced the brunt of the responsibility regarding their daily needs, and surely experienced various social and institutional obstacles related to the participants' physical disabilities, participants credit their mothers for not stigmatizing their disability. Instead, their mothers taught them the importance of motivation, persistence, and self-advocacy.

Understanding that "it" is different for different people.

While there are dominant normative standards of what it means to be an adult, to be happy, and to be successful or independent, participants readily acknowledged the importance of having flexible standards that accommodate for the diversity of people's individual motivations, desires, abilities, realities, etc. For example, Lana explained that it's hard to say what is the most helpful for people with disabilities as a group and said, "Everyone is different. I think it has to be up to the individual and what they want." When Hanna talked about her own goals, she was quick to add a caveat and said, "You also have those people who still live at home which is totally fine it's just definitely not what I wanted." Here, Hanna makes it clear that her version of what it means to be an independent adult will not be the same as everyone else's version and that is not only to be expected but also perfectly acceptable. Along similar lines, Cat also brought up the importance of respecting different goals for different people and said:

> My definition of successful is wining an Emmy, like that's the long term life
>
> goal…but that's just me. I don't think that it's cut and dry because people should

have the opportunity to be successful however they want um but I think they

should also be able to make the decision to say 'eh, I don't want to do that.'

While each participant explained that individual life goals are inevitably going to vary from

person to person, participants also referenced some similar goals that people, with and without

disabilities, often share (e.g. financial stability, autonomy).

Jamila cites her family's conservative religious culture as having played a leading role in

the goals she had for herself and explains how going to a summer camp designed for kids with

physical and mobility disabilities offered her alternative ways of understanding what goals she

could set for herself. She said:

> Going to camp helped me, like, that one week in the year I would find myself and
>
> be like, 'okay I'm not like this, I'm not conservative and I'm not like this little
>
> you know, goody two shoes girls, prim and proper and that's not me and that's
>
> okay.'.... It was through camp and the people I met at camp that helped me
>
> become this person I am and it also like allowed me to think and like figure out
>
> what I want. It [camp] has allowed me to not only compare different social
>
> aspects of society but also um helped me become whoever I wanted to be.

While Jamila did not talk about the variation of people's individual goals as explicitly as Lana,

Hanna, and Cat did, her comments about how her own goals changed echo similar sentiments.

These responses suggest an understanding of what might be called adulthood, success, or

independence that is fluid and multidimensional. Participants rejected pitting one person's goals

and aspirations against anyone else's. While normative standards certainly inform how we all

develop personal goals and social circumstances influence the degree to which we are able to

achieve those goals, participants explained that there is no "one size fits all," which is yet another reason finding language for "it" is difficult.

Seeing Others Do It

In reflecting on their childhoods, having systems of support reinforced that disability is a valued form of social diversity. As Cat said, "Being around other kids like me changed the way I saw myself." According to the participants in this study, it's important for people with disabilities and chronic illnesses to have opportunities to meet, as Cat put it, people like them.

Camp.

Recreational activities, like summer camp programs, that cater to specific populations are one way that kids with disabilities and chronic illnesses can meet other kids with disabilities and chronic illnesses. All of the participants in this study attended summer camps for children with disabilities when they were young and all participants talked about what they got out of their summer camp experiences. Lana explained that, "Connecting with other people who were like me was I think probably the biggest thing because before camp, I'd never really met anyone with [my diagnosis]." Cat said that, "I went to a school district in which I was the only person who used a wheelchair…and then I went to camp and I was like oh wow a lot of these people have the same issues and the same frustrations and experiences that I do." A pervasive theme in the responses from all four participants was the importance of having been introduced to other people with disabilities and witnessing firsthand a broad array of options for people with disabilities. Jamila went so far as to say that, "I wouldn't be anywhere without people that I met at camp."

Hanna and Lana both spoke specifically about the same person they met at camp when they were young. Lana said, "When I was a kid and I went to summer camp, I met people like

for instance, Joey, who was you know older than me but was going to college and doing her own thing and I was like whoa I *can* [emphasis added] do that." Similarly, Hanna said, "Joey…that girl was like my role model for a while because she had the life that I wanted, living on her own and having her own care workers and doing her own thing and having a full-time job. She showed me that I could do it too." According to participants, exposure to other people, whose physical and mobility circumstances were similar to their own, played a large role in shaping the realm of what they thought was possible for themselves.

Since we know that summer camp programs can offer young people with disabilities the opportunity to socialize with other young people with disabilities (Goodwin & Staples, 2005; Thurber & Malinowski, 1999) and that young people with disabilities often have limited opportunities to socialize with their peers with disabilities (Priestley, 2013), it was not surprising that participants stressed the important role that attending summer camp played not only in the development and affirmation of their disability pride but also the formation of their future goals. Just as growing up in supportive environments, and understanding that what "it" means for one person might not mean the same to another person, helped participants develop a sense of disability pride, getting to interact with other people with disabilities helped encourage participants to understand disability as an appreciated way of being. While participants emphasized the influence of having parents who helped them foster a sense of disability pride and create flexible goals for themselves, having opportunities for other people with disabilities affirm these beliefs was also important.

Getting Help Doing It

To varying degrees, participants were quick to highlight that they have not gotten to where they are without help. An important caveat: while this section focuses on the supportive

environments that participants have experienced, this is not to suggest that the "imperialist white-supremacist capitalist patriarchy" (hooks, 2004, p. 58) and ableism that plague our social world have not posed serious challenges throughout their lives. A combination of (1) learning from other people who have similar life circumstances, (2) having helpful and supportive friends, (3) working hard to strategically keep a positive attitude, and (4) various racial and economic privileges remain persistent have played, and continue to play, significant roles in their lives.

Learning from others.

A common thread throughout many of the participants' responses is not only the importance but also the necessity of learning from other people. Lana said, "The nice thing about camp is you have people from all different walks of life…[there are] people that are living differently than you that have different aspects and different ideas and they have their own experiences that they can give you and help you with." While participants all talked about how helpful their childhood camp experiences had been, Lana was the only participant to reference camp has having been an experience conducive for soliciting help from her peers.

Whether at summer camp or somewhere else, Lana explained that access to a community of peers is important: "It's helpful to learn from other people with similar experiences, it's helpful to learn what they've done…I mean, a community of people that are similar to you is definitely one of the most helpful things." Cat also stressed the importance of learning from other people with disabilities and said that "Learning a lot from people before us and how they dealt with um different problems and different experiences" has been very helpful as she has transitioned in and out of college. Jamila, Lana, and Hanna are all members of an online community of people with muscular dystrophy and Hanna emphasized the very real effects of

having a community of people to learn from. She offered an example of another way that she

continues to learn from other people:

> I wouldn't have known about the surgery that I just had unless I was part of the
>
> [private group for people with muscular dystrophy] on Facebook like you know
>
> what I mean, you just have to learn from your peers that are going through it
>
> maybe sooner than you are and like can help you kind of navigate the MD [i.e.
>
> muscular dystrophy] world a little bit better.

Lana talked about the difficulties of trying to navigate various agencies in order to

acquire, secure, and maintain her government benefits. Although there are many different

services that she is eligible for, since the offices that manage these services (Department of

Human Services, Social Security, etc) operate independently from each other, recipients like

Lana are often left to navigate the complex limitations and restrictions of these services by

themselves. She said "I think the hardest part is just not knowing what is available out there.

Like, for a long time I didn't even know that I could work and like still have Medicaid like that's

wrong, like why is that information not readily available?" This illustrates one of the ways that

not having easy access to information negatively affects people with disabilities and their

families. When people with disabilities can create and/or join communities of other people with

disabilities, they are able to ask questions, share information, and offer support to one another.

Lana learned how to be employed without compromising her Medicaid benefits by consulting

with other people with disabilities who are employed and receive similar benefits. Opportunities

to learn from other people with similar lived experiences is an incredible resource for young

people with disabilities who are trying to learn how to navigate various social service offices.

Helpful friends.

In addition to learning from their peers, participants rely on helpful friends. When Hanna told me about a recent trip she took to visit a friend, she described how she and her friends got creative in order to make sure she was able to go on the trip without having to figure out how to get her power chair in and out of her friend's house and said:

> [It] was super fun… I took a manual wheelchair instead of my power chair
> because um Becca's house isn't super accessible so I was like, 'well why don't I
> just bring my manual chair and then you guys can just like carry me around places
> and like put me in the chair?' So um, that actually worked really, really well.

Jamila also told me about situations in which she has relied on helpful friends. In our conversation about her negative experiences with a caregiving agency she used when she first went away to college. Jamila explained what she would have to do when the agency's nurses would call off from their shift last minute and said, "They would call off last minute sometimes and there was nothing I could do and so I would just be like 'hey, Mika, no nurses are coming can you come put me to bed?' I mean, if it weren't for Mika um coming over last minute on those nights, like I would have slept in my chair." Having a helpful friend like Mika, who was able to help Jamila when her agency would [illegally] leave her without a caregiver, was what Jamila had to rely on in order to shower, change clothes, and sleep in her own bed.

Lana talked about the importance of having helpful friends in a broader context, particularly for the situations when services and resources don't quite cover it. She said:

> I wouldn't be where I [am] today if I didn't have people who were willing to
> spend time to help me and not get reimbursed by it or it's like having that safety
> net of friends or family who are available to support you…I think we rely a lot on

the kindness of other people who are willing to you know help us make our way

in the world.

From the friends who helped Hanna get in and out of Becca's house and Jamila's friend, Mika, who used to help Jamila get into bed when the nurses would cancel last minute, to the friends who hang out with Lana and do not have any obligations to help her with random tasks she may need help with, participants recognize the practical importance of having helpful friends. In all three examples, the participants point out that is it the inaccessible buildings and care giving agencies, not their individual disabilities, which make them rely on helpful friends. In other words, participants demonstrate a keen awareness of the social and environmental barriers that create the situations in which they have to rely on their friends to be helpful.

Keeping a positive attitude and being persistent.

While Hanna, Lana, Cat, and Jamila all talked about the help they have gotten (and continue to get) from their peers and from their friends, they also addressed the role they themselves play in getting the help they need and the practical importance of motivation, keeping a positive attitude, and being persistent. Unfortunately, people with disabilities are often used on social media platforms and by charitable not-for-profit organizations as sources of inspiration, a concept commonly referred to as the "supercrip." Although all participants openly contested the idea that all people with disabilities should be expected to "overcome" their situation or that their ordinary accomplishments should be considered inspirational, they acknowledged the day-to-day practicality of keeping a positive attitude and being persistent. These seemingly individualized characteristics do not exist solely on an individual level but rather these characteristics function as practical strategies that are being used within larger social structures.

While talking about her recent professional milestones, Cat said, "the work that I've done and the things that I've done…. really had to do with the fact that I'm determined…and really driven." Along the same lines, while talking about her current work/home life, Lana said, "I always kind of had it in my mind that that's what I was going to do like I wasn't going to stay home with my parents living in a small town. I wanted to do more…the motivation to be my own person was kinda huge." Hanna also made reference to the importance of being motivated when she said,

> I think you need to have that drive and that fight in you um to want equal equality
>
> for yourself. I know a lot of issues I'm seeing with the kids who want to be
>
> [equal] but…don't really feel that they should be equal…and they just don't have
>
> that like fight in them but I think that fight has been taken out of them by years of
>
> being told that they won't have a similar life to their peers.

Although the end of this passage ("similar life to their peers") might seem to suggest that Hanna is using normative standards to measure equality for people with disabilities, more importantly, she is highlighting the importance of the strong support systems that enable young people with disabilities to develop the persistence needed to combat the ableism of our social world. She articulates a sense of frustration with adults who do not foster a sense of disability pride in their children and thus, halts young people with disabilities' sense of motivation and persistence, whether they're motivations are normative or otherwise. While people without disabilities or illnesses often emphasize individualized expectations of being willing to fight, Hanna challenges this line of thinking by suggesting that what is important is the conditions that have enabled them to be persistent. When young people with disabilities are not surrounded by adults who help

foster a positive disability identity, they may never develop the positivity and persistence that participants claim are key.

Participants also attributed persistence as an important part of getting to where they want to be. Jamila explains that she is still very persistent,

One of the most important is persistence; that's a good adjective for me. I'm very persistent. Like, if I want something to be done, it will get done. Like, no matter what, I will talk about it for weeks and it will be annoying like I get annoying until something happens. I will just talk and talk and talk about that one thing until it gets done the way I want it to be done and so I think persistence is important. I mean, that's how I got to college and that's how I started living, you know, in the city. I just kept saying I'm going to live in the city, I'm going to live in the city, I'm going to live in the city, and now I'm here.

Jamila's decisions to go away to college and her post-graduation move to the city live with a friend were both directly related to her relentless persistence. Hanna also talked about the importance of being persistent, particularly in reference to getting information from peers, and said,

I always felt like my life is like trying to get a job, it's who you know and who you can ask, who you can talk to and then just continuing to grow that network and continuing to ask the people around you like how they did it and it doesn't matter if you asked them 14 million times, like I probably ask Joey the same questions a hundred times but like until you get it until you get the right stuff, you gotta use the people around you.

During our conversation about the importance of persistence, Lana made sure to stress the importance of motivation and persistence when advocating for herself. She said, "You have to be pretty motivated. Like making phone calls and being kind of pushy, you don't have to be mean but you have to be kind of pushy about the things you need and standing up for yourself." Critical of the supercrip and inspiration porn, participants each explained various situations in which they feel that it is to their benefit to stay motivated and be persistent, all while trying to keep a positive attitude.

Privilege.

The interview guide included a question that allowed space in the conversation for participants to address the topic of privilege and how various social and/or institutional privileges might have affected the experiences they have had. I asked participants about other parts of their identities and/or life circumstances that they think might have affected how they have been able to navigate the world, in terms of their disability status or otherwise. As an emerging feminist disability studies scholar, the notions of privilege and disprivilege are certainly at the forefront of my mind, but I wanted the conversations to be driven by the participants as much as possible so I did not place more emphasis on this topic than I did any of the other topics we discussed. Although Lana was the only participant to address how various privileges have shaped her experiences, this does not mean that other participants are not aware of their economic and educational privileges. Since I did not press issues of intersectionality or privilege, it would not be fair to assume that participants do not recognize social and structural inequalities simply because they did not address them in their interview.

In my interview with Lana, she talked about how supportive her parents have always been of the goals she sets for herself. She also recognized that their financial situation played an

important role in the degree to which they were able to support her in terms of going away to school and having wheelchair accessible vans. She said, "I would say that um I lucked out having parents who aren't poor um they're I wouldn't say they're rich but they have been able to help me financially if I need it." What Lana called "luck," I believe can also be called "privilege." She acknowledged that the economic status of one's parents affects how much they are able to financially accommodate for the various financial hardships that families of children with disabilities often face.

Challenges Doing It

Since it is well known that people with physical and mobility disabilities often encounter negative social attitudes and environmental barriers, this project was designed to highlight the different experiences that have helped participants navigate such barriers. However, during the interviews, our discussions included various issues that participants are still dealing with in their everyday lives. The issues brought up in our discussions fall into the categories of caregiver hassles and microaggressions.

Caregiver hassles.

All four participants receive government funding that allows them to employ people to help them with their ADLs. Depending on what agency is being used, these employees might be called "personal assistants," "personal care workers," "caregivers," or "nurses." A common theme that surfaced throughout these conversations was how these agencies often prioritize business over humanity.

Lana explained that a recent situation she has been dealing with is that her agency limits the number of hours an employee can work to forty hours per week. The State does not provide Lana, and many other people with disabilities, with enough funding to cover the actual amount

of caregiving services that she needs to live the life she wants to live. In other words, the agency no longer provides her with the funding necessary for her to do "it." Since Lana's partner is her full-time caregiver, it has limited the number of hours per week for which her partner can receive financial compensation. For years, her partner been providing care for Lana far beyond the number of hours for which she receives funding because she needs more than forty hours per week to live the life she wants to live and he has done so out of love and frankly, necessity. Now, her partner is only allowed to receive compensation for a fraction of the time he helps her. Lana explained, "They say it's to prevent caregiver burnout but really, no, it's cuz they want to save money." She went on to stress the importance of, "Navigating through the relationship aspect of things, like things working for you or like people working for you… and that even has to do with like your social workers and the nurse and stuff. You kind of have to develop a personal relationship to them so they know that you're a person and not just another number, you know?" Her situation highlights the sense of humanity and dignity that is often lost in the bureaucratic shuffle when people with disabilities are understood more as cases than as clients, or even, as people.

When Jamila first went away to college, she used an agency that has a database of employees who provide care for their clients, as opposed to agencies that have clients hire their own caregivers, like the agency Lana uses, for example. During the interview, Jamila explained that although she is currently happy with her caregiver situation, she vividly remembers how hard it was for her to deal with various agencies. For example, she said, "There were some nights where the agency would actually text me, like the boss would text me and be like. 'no one can come tonight.' That's all she would say like, and what was supposed to happen is if no one could come then she's supposed to come. I didn't know that until later." Here, she points out the

compromising situation that her caregiving agency put her in on more than one occasion. As a first-time college student, living away from home for the first time, not having reliable caregivers caused her a lot of stress, not to mention the physical discomfort that stems from having to sleep in her wheelchair after getting a text from her agency telling her that no one would be coming to help get her into bed that night. This is another example of an agency not prioritizing a person's humanity. She went on to say, "I wish that would happen to me now only because I have such like a larger voice now that I didn't really speak up before…I didn't really speak up a lot I just kind of like took whatever came my way and now I'd be like no that's fucked up like this is your job fuck you I'm suing your ass. Like, I have the loudest voice now." Now, Jamila speaks up and advocates for herself when she feels like she is not being treated fairly.

When Hanna relocated for a new job, she knew that finding enough reliable caregivers and getting them all on a steady schedule would be a challenge, but it turned out to be more difficult than she had anticipated. She said, "The big thing was like finding people to take me to the bathroom during the day at work because I live about 45 minutes away from where I work…it's been hard to find personal care workers during the say so that's why I got this supra pubic catheter [SPC] surgery um to hopefully alleviate finding people to take me during the day and being able to be as independent as I want, to not be having to do pee math and having to pee and no one being able to take you is kind of the worst feeling on the planet." Here, Hanna's comments on the physical discomfort that results from not having caregivers when she wants/needs them, much like Jamila's memories of the physical discomfort she felt when her agency would cancel on her via text message. Hanna's recent caregiver struggles brought her to the decision to get an SPC and as a result, she has been less reliant on caregivers throughout her

work day which has allowed her to focus more on her work rather than how soon someone was going to come help her go to the bathroom, something that previously caused her a lot of stress[14].

Microaggresssions.

Amidst our conversations, participants brought up recent situations in which they have experienced microaggressions. For the purposes of understanding the microaggressive interactions that participants experience, we can define microaggressions as being small, everyday interactions that serve to remind participants that people attach negative stereotypes to participants' apparent physical and mobility disabilities. This understanding of microaggressions helps situate the uncomfortable, and often hurtful, interactions that participants cited as being relatively common in their daily lives.

As previously mentioned, Hanna had surgery the day before our conversation. During the interview, she told me that, "The anesthesiologist yesterday asked me, she's like, 'oh okay you're in a wheelchair' and she's like, 'ok are you a paraplegic or a quadriplegic?' and I was like, 'c – none of the above' like why would you assume such a silly thing? Like, as a doctor you'd think like, it says SMA on my chart…I was like, 'my muscles don't work.'" In this situation, Hanna did not experience some explicit form of discrimination nor did she experience an environmental barrier. Instead, she experienced a medical professional making [incorrect] assumptions about the cause of her mobility disability. As Hanna points out, medically, this doctor had access to Hanna's medical chart and therefore should have known her diagnosis, but she also should have been more conscious of the harmful implications of assuming that Hanna would appreciate pre-surgery conversation centered on her physical disability.

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[14] It is important to note that Hanna's caregiver struggles, which result from a sociopolitical environment that does not value disability issues, were so enduring that she was willing to undergo a relatively invasive surgical procedure as a way to maintain bodily autonomy.

Hanna also talked about a recent trip she and some friends took to Seattle. She explains that when she was at her local airport, the Transportation Security Administration (TSA) agents had clearly not been trained on how to accommodate travelers with physical and/or mobility disabilities. She explains, "We missed our first flight…and it was because security needed to pat me down because I can't go through you know, the metal detector, and it took forever to find someone to pat me down." Again, this was not an overt act of discrimination nor was she unable to physically access the airport, security checkpoint, or the plane. Instead, it was a microaggression in which Hanna was reminded that TSA agents do not have customers like Hanna in mind when they train their new agents and/or schedule their employees on a given shift.

Although the previous two microaggressions were caused by people in positions of power (doctor and TSA agents), the microaggressions that Cat talked about were caused by a stranger at a dog park and a barista at Starbucks. She explained:

> For example, I went to the dog park the other day with my dog and some lady
> came up to me and said, 'oh my god like it's so good for you that you're out like
> I'm so proud of you' and I was like my dog is taking a shit right now. I mean,
> you're really that proud of me?

Here, not only is this lady a complete stranger to Cat but she feels compelled to tell Cat that she is proud of her for being out in public, as if to imply that people like Cat are not expected to be out in public. In this situation, Cat was reminded that people do not expect her to be out and about in her community; they do not expect her to own her own pet and take care of it. The other recent microaggression that Cat talked about happened in a local Starbucks. During the conversation we had after she shared her dog park experience she said:

And the narrative of course is that disability is like the worst thing ever and so

there are any stigmas and stereotypes that people attach to disability that I don't

even think they're aware of so um for example, the other day I was sitting at a

Starbucks and to make a long story short, everyone was given these surveys that

they had to fill out um just for like statistic reasons and whatever up and then the

person didn't hand me one and I understood that okay like, you didn't hand me

one because you think that like I'm mentally incompetent and unable to fill out a

survey.

In the dog park and at Starbucks, not unlike some of the similar microaggressions that Jamila and

Hanna shared, Cat did not experience overt discrimination on account of her physical disability.

Instead, these experiences demonstrate small, daily reminders to her that other people attach

some serious stereotypes to her visible physical disability.

Helping Others Do It

During the interviews, I asked participants to talk about what has helped them on their

journeys thus far, but I also wanted to make sure that participants had the opportunity to talk

about the many different ways that they themselves work to help other people on their journeys,

too. Since I have a friendship with all participants, I know they "give back" so to speak, and I

wanted to ensure that this project did not gloss over their advocacy and volunteer work. Hanna,

who serves on the board of directors for a local not-for-profit that serves adults with disabilities

and frequently speaks at public forums for young people with her diagnosis, says, "When I was

in college um I ran a student organization … that was really to reach the campus and community

area just about disability in general about people with disabilities and basically trying to break

down that stereotype and stigma."

During our interview, Cat explained that the architectural set up of the many of her college classrooms forced all wheelchair users into the back of the room, all concentrated in one area. Cat is using her experiences and social connections to diversify her church's architectural layout of accessible seating in order to increase the physical integration of people with disabilities. She explained:

> So the other thing that I've been doing has been working with um a local church about disability awareness…we're basically just trying to promote change, a social change but also like literal change. Like, we're trying to get a proposal on the floor to change the seating arrangement in the auditorium so that handicapped seating isn't just shoved in the back so that we can try to get it more dispersed through the auditorium.

Cat has experienced architectural segregation first hand in college and is now spearheading her church's effort to add more wheelchair accessible seating options and be more conscious of members with disabilities.

Jamila, who has her own online blog where she writes about her experiences, ranging from her adventures using Tinder to body image and self-esteem, said that she likes blogging because she knows that she's gotten a lot of useful insight from various online sources so she hopes her blog can be that resource for other people, too. She also currently serves on the board of directors and heads up a planning committee for a local not-for-profit that serves adults with disabilities. Earlier in our interview, Jamila talked about how formative her experiences at summer camp had been for her and when asked about her current involvement with various disability-serving organizations she said, "I like being on the board and on different committees because camp is so important to me." These sentiments of reciprocity regarding these particular

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organizations align with the work that Cat and Hanna are doing in order to support people with disabilities and the organizations who serve them.

Based on their own experiences, both positive and negative, each of the participants is working to ensure and/or enhance various experiences that people with disabilities have. Their sentiments about the work they are doing do not align with charity or medical models of disability but rather with the celebration agenda of the disability rights movement (Baker, 2011) wherein disability is understood as a valid and valued form of social diversity. Whether they are advocating for better physical integration of people with disabilities in physical public spaces (i.e. Cat's church), collaborating with others to educate young people about different disabilities (i.e. Hanna's college club), or sharing their experiences online and serving in leadership positions (Jamila's blog and board of directors position), they are work to support experiences and opportunities that allow for the acceptance of people with disabilities in a way that celebrates people with disabilities rather than pitying them.

In this chapter, I presented the information from the interviews that I believe best helps address the research questions that guided this exploratory research project by including responses that demonstrate the opportunities and experiences that have influenced the four women with physical and mobility disabilities in terms of getting to where they are today, and how these opportunities and experiences helped and/or challenged them along their journeys. In the next chapter, I connect their responses to larger issues and explain the significance of some of the major themes that emerged in the interviews in order to support my overall claim that when young people with disabilities have experiences that encourage them to understand their disability as a valued form of social diversity, they are better prepared to become adults who strategically use positivity and persistence to deal with the daily challenges they face.

Discussion

A social model of disability (Oliver, 1996; Shakespeare, 1994; Shakespeare & Watson, 1997) emphasizes that the disability is socially produced through various macro- and micro-level interactions. In fact, the cultural model of disability allows us to celebrate disability as a form a valued social diversity (Baker, 2011; Linton, 1998). Overwhelmingly throughout the interviews, the participants placed emphasis on the social interactions that have shaped their understandings of themselves and of their lives. As displayed in the previous section, participants highlighted five overarching concepts associated with their experiences growing up and becoming young adults: 1) supportive environments and believing in themselves, 2) having examples of people with disabilities living how they wanted to live, 3) receiving help and staying positive, 4) daily hassles caused by people and organizations, and 5) their commitment to advocacy and volunteer work that aligns with the cultural model of disability. Their responses suggest that supportive environments (families, friends, other people with disabilities) and a positive and persistent attitude have had the greatest influence on them transitioning from childhood into young adulthood. In this chapter, I connect themes from the participants' responses to existing academic research to extend the central arguments of this project. The second chapter focused on critical literature about individuals with disabilities; it was only after my conversations with participants did I make connections to literature on parents of children with disabilities and literature on microaggressions. In order to ground my findings in existing academic work, I use

the next few paragraphs in this chapter to provide information on microaggressions and mothering children with disabilities.

During our interviews, each participant mentioned that they had not been asked about their experiences in the ways that I was framing them in my questions. In each interview, I heard comments about how people without disabilities usually want to know about the discrimination they have faced or about the struggles of living with a physical disability. Hanna, Jamila, and Cat each said they were excited to talk with me about their experiences with disability in ways that do not bring their hardships to the forefront of the conversation. As they talked through different aspects of their childhoods and reflected on what was helpful to them, it was heart-warming to hear them talk so fondly about certain memories from their childhoods and it was fun to laugh with them as they described various awkward situations they have found themselves in. That said, it was frustrating to hear about the microaggressions that they face. Since I am friends with each of the participants, I know they experience explicit and implicit discrimination because I have heard them talk about it, I have read their blog posts about it, and in some cases, I have been there when it has happened. While I did not think that the interviews would produce such rich data about the disability microaggressions that they have faced and continue to face, it was my responsibility to confront this major theme, even though I was not expecting it.

The term "microaggression" has been used most often in the context of race. In their 1978 study of racism against black people in TV commercials, Pierce, Pierce-Gonzalez, & Willis explained that microaggressions are seemingly subtle insults and the people who experience them often pay high emotional tolls (Pierce, Pierce-Gonzalez, & Willis, 1978). A few years later, in 1986, Gaertner & Dovidio suggested that, in the context of racial minorities, prejudice and discrimination were becoming subtler and more furtive (Gaertner & Dovidio, 1986). More

recently, researchers Sue, Capodilupo, Torino, Bucceri, Holder, Nadal, & Esquilin (2007) added nuance to the concept of microaggressions by specifying three different types of microaggressions: microassaults, microinsults, and microinvalidations. Microassaults occur when a person does or says harmful things to a person with a marginalized identity, even though they know the negative implications of their words or actions. Microinsults occur when a person unknowingly uses rude and insensitive verbal or behavioral cues that devalue a person's marginalized identity. Microinvalidations occur when a person unknowingly employs comments or behaviors that deny and demean the feelings and/or experiences of a person with a marginalized identity. These three types of microaggressions were originally conceptualized in regards to racial microaggressions, but they can be extended to include disability-related microaggressions.

I am by no means the first person to apply the concept of microaggressions to another historically disenfranchised group of people, such as people with disabilities. Over the last few decades, more researchers have studied these stigmatizing interactions and have found that concept of microaggressions is also useful when extended to other marginalized groups. For example, Keller and Galgay's (2010) study about how people with disabilities experience microaggression supports the previous assertions that microaggressions have negative consequences for the people who experience them (e.g. internalized oppression, emotional stress, frustration, and embarrassment). Another example of microaggressions being studied in disability populations is Davila's (2015) study of Latina/o students in special education classes. Davila explores how these students experience the subtle, cumulative, and identity-based insults from their teachers, and, based on the results, created three categories for the microaggressions the students experienced: low expectation, disregard, and bully. Whether their teachers made

assumptions about what these students were not able to do (low expectation), did not take the students' concerns seriously (disregard), or flat out harassed the students, these students were experiencing what Davila terms "disability microaggressions." Similar to racial microaggressions, these disability microaggressions are usually unconscious to the person committing them (the teachers) but cause unnecessary stress to those who experience them (the students). As the participants in this study suggested, having networks of social support, a community of peers who have similar experiences, can be a helpful for members of marginalized groups and the microaggressions they experience.

Since participants cited their parents (and specifically, their mothers) as having played formative roles in their childhood and adolescence, it would be remiss not to engage with literature focused on mothering children with disabilities. While it is relatively agreed upon that mothers are held disproportionately responsible for childcare, what about mothers of children with disabilities, whose needs extend beyond those of children without disabilities? While it common for first-time parents to be nervous, mothers of children with disabilities often lack previous experience and preparation to care for a child with a disability (Green, 2001) and end up having to do things they are not comfortable doing (Green, 2004). Caring for a child with a disability often means facing obstacles such as lack of necessary support services (financial and social), stigma from others, and heightened care giving responsibilities (Seligman & Darling, 1997). We know that mothers are often assessed via the success of the children (Hays, 1996) and that there are some people who consider children with disabilities to be tragedies (Thompson, 2000), it should come as little surprise that mothers of children with disabilities often experience distress, guilt, and inadequacy (Green, 2003; Heiman, 2002). While there certainly many reasons that mothers of children with disabilities experience these hardships, it is crucial to recognize

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that it is the lack of necessary services and community support systems that cause feelings of guilt, inadequacy, and exhaustion, not the presence of disability (Saxton, 2013). Caring for people with disabilities is often very meaningful and rewarding (Green, 2007; Saxton, 2013) but social, financial, and environmental obstacles often obscure these positive elements of caring for a person with a disability.

While there are a numerous books about parenting a child with a disability (e.g. Capper, 1996; Cook, 1992; Thompson, 2000), new parents of children with disabilities will be hard-pressed to find a self-help style book that helps them adopt a positive understanding of disability, one that recognizes the social circumstances that produce disability. Take, for example, the first sentence of the book by Charlotte E. Thompson, *Raising a handicapped child* (2000). It reads, "As the parent of a child with a disability, you have already survived the terrible blow of being told your child is not normal" (Thompson, 2000, p. 3). Given the heavy responsibilities that accompany raising a child with a disability, and the insufficient resources available to parents of children with disabilities, it seems that a how-to book, like Thompson's, might offer practical strategies. In this project, I asked young adult women to reflect on their lives and tell what they found most helpful and overwhelmingly, their responses indicate that having parents who embraced their disability status and supported their goals is what was most helpful. While the results of this study cannot be generalized, participants' responses certainly expressed the importance of having parents who did not view their disability as a "terrible blow," as Thompson (2000) put it, but rather, as merely another part of their life, one that is not inherently bad. As referenced in the title of this paper, participants emphasized the importance of parenting styles that celebrate disability.

Whether in terms of having parents who did not make them feel different or less than, being introduced to other people with disabilities at a young age, or having opportunities to build and/or join communities where they can learn from each other and support each other, participants attributed micro-level social interactions as having been salient factors in growing up and transitioning into adulthood while living with a physical disability. Although Lana acknowledged how her family's financial stability and racial privilege account for their ability to support her in various ways, she was the only participant to situate her experiences within a broader context. As mentioned previously, the participants all grew up in particular legal and political contexts (e.g. after section 504 of the Rehabilitation Act of 1973 and the ADA of 1990 were enacted) that have created the parameters within which they have had the experiences they shared with me during our interviews. Given the scope of this project, I did not ask participants about these macro-level forces or historical legal landmarks. Instead, I asked them about their own personal experiences and did so in a way that, as in Lana's interview, allowed for them to make connections between institutional and/or ideological frameworks for disability and their own lived experiences.

Additionally, whether in terms of seeking out information from others, advocating for themselves, or keeping a positive attitude and staying persistent, there was a particularly individualistic quality to their responses about important ways they cope with ableism and the day-to-day anti-disability microaggressions that they experience. This is interesting to me because I think it is important to address that these four women play an active role in their lives and exercise agency in strategic ways in order to accommodate ableist environments and disability microaggressions. Each of the participants talked about the practicality associated with their tactics in terms of acquiring resources, accessing and building communities of support, and

managing the emotional tolls of disability microaggressions. As mentioned earlier, participants openly rejected notions of inspiration porn and readily acknowledged the importance of respecting the idea that different people have different goals for themselves. Attributing positivity and persistence to their successes is not to suggest that they have "overcome" their disability or that they are somehow not negatively affected by ableism and anti-disability sentiments. Rather, it highlights some of the practical strategies they use in their everyday lives to deal with the ableism and anti-disability sentiments they encounter.

Conclusion

The purpose of this study has been to better understand the experiences that shape the ways in which the participants have experienced and continue to experience the social phenomenon of disability. This study was designed to lean more about what opportunities and experiences have influenced the participants in terms of getting to where they are today. After conducting semistructured interviews with four young adult women with physical and mobility disabilities, it is clear that growing up with supportive parents and having opportunities to build/join communities of their peers has been very influential in their lives. Additionally, strategic positivity and persistence help participants cope with the day-to-day ableism and anti-disability microaggressions that they experience. Much like the disabilities that they live with, the experiences they attribute as most important, both positive and negative, are socially produced. Growing up with supportive families (Shapiro, 1994; Stokes, Turnbull, & Wyn, 2013; Zuckerman, Devine, & Holmbeck, 2011), having opportunities to form community amongst peers (Goodwin & Staples, 2005; Mejias & Gill, 2014) in order to learn from and get support from, and strategic positivity and persistence have been crucial in getting participants to where they are in their lives today. More people need to adopt the social and cultural models of disability to reduce the stigma that tends to surround the presence of disability, particularly for this project, apparent physical disabilities. The disability microaggressions they experience are a harsh reminder that people without disabilities need become more familiar with microaggressions and the harm they can cause for people with disabilities (Lu, 2014).

Although I worked to ensure the relevance and rigor of this project, there were some major limitations. First, a sample size of four participants is small and therefore, cannot be generalized. Second, since the method of data collection for this project was life history interviews, the participants did not have the opportunity to share their experiences in the same way that they would have been able to if the method of data collection had been, for example, surveys, Additionally, the interview guide that I created, as open ended as it was, undoubtedly steered the conversations in particular directions. This leads me to the third limitation: time. Time constraints only allowed for one interview with each participant. Had there been more time, I would have been able to conduct multiple interviews with each participant. This would have allowed for more in-depth discussions because after the first interview, I would have been able to use each subsequent interview to focus on the specific topics addressed in the previous interview(s). Fourth, while I believe that my close rapport with each participant helped facilitate an honest and comfortable environment in which they were able to talk openly about their experiences, my positions as a friend, researcher, and person without a physical disability, likely caused them to censor some of their responses, particularly when talking about our mutual friends. Finally, and most importantly, this is a project about women with physical and mobility disabilities that was carried out by a researcher who does not have an ascribed or avowed disability identity. Although I worked hard to remain reflexive about my relationship with the participants and ensure fair and appropriate representation of their experiences, my social location as a person who does not live with "the traits we think of as disability" (Garland-Thompson, 2005, p. 1558) undoubtedly influenced the research process.

In the 2014 book about the life of Jon Feucht, a man who lives with cerebral palsy, Feucht, one of the book's co-authors, reflected on the process of writing the book and the effects

it had on his life both personally and professionally (Berger, Feucht, & Flad, 2014). For example, writing the book helped him appreciate his parents in new and meaningful ways. He also explains that hearing his mother say that he was a "lovable child" in an interview touched him in a way that motivated him to pursue a doctoral degree. Drawing on Feucht's reflections, I believe that interviewing the parents of this study's participants about their experiences of raising a child with a disability might elicit responses that would be heartwarming and even affirming for the participants to hear. Similarly, if the parents of this study's participants were to read their children's responses about the long-term positive effects that their parenting attitudes and actions had on their children's lives, I believe that it would be moving, and maybe even validating. For mothers (and, more broadly, parents) who are currently experiencing the burdens and stigma that often accompany raising children with disabilities (Green, 2003, 2007), hearing adults with disabilities reflect on their parents' positive contributions during their childhoods could prove to be encouraging.

Based on the results of this study, more research needs to be done on the experiences that young people with physical disabilities attribute as having been most helpful to them so that we can better support the policies, programs, institutions, organizations, and ideologies that allow for those formative experiences. Since this study focused on four women who, as children and adolescents, all attended summer camps for youth with physical disabilities, and who, as young adults, all attended large residential universities, a study including participants with different gender identities and/or presentation would allow for more analysis of the influence of gender on these experiences. Likewise, what about young people with physical disabilities who did not have summer camp opportunities or residential college experiences? Including participants who were not able to attend summer camp and/or go away to college would prompt information about

different formative experiences and opportunities. The more research we have on young people with disabilities and their formative experiences, the better we will be able to understand what experiences, opportunities, and environments are the most helpful and relevant for young people with disabilities, which will allow us to create and foster the experiences and opportunities that are most helpful for these young people. The more we can substantiate my claim that children with disabilities need to have a variety of formative experiences that promote a positive understanding of disability, the more we will be able to endorse the people, place, and ideologies that advance this positive understanding of disability.

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Appendix A:

IRB Approval

USF
UNIVERSITY OF SOUTH FLORIDA

RESEARCH INTEGRITY AND COMPLIANCE
Institutional Review Boards, FWA No. 00001669
12901 Bruce B. Downs Blvd., MDC035 • Tampa, FL 33612-4799
(813) 974-5638 • FAX (813) 974-7091

10/14/2016

Victoria Peer
Women's & Gender Studies
3609 Data Drive #301
Tampa, FL 33613

RE: **Expedited Approval for Initial Review**
IRB#: Pro00025293
Title: Experiences that affect overall levels of satisfaction among women with physical disabilities

Study Approval Period: 10/13/2016 to 10/13/2017

Dear Dr. Peer:

On 10/13/2016, the Institutional Review Board (IRB) reviewed and **APPROVED** the above application and all documents contained within, including those outlined below.

Approved Item(s):
Protocol Document(s):
Study Protocol

Consent/Assent Document(s)*:
Verbal Consent Form   **granted a waiver

*Please use only the official IRB stamped informed consent/assent document(s) found under the "Attachments" tab. Please note, these consent/assent document(s) are only valid during the approval period indicated at the top of the form(s). **Waivers are not stamped.

It was the determination of the IRB that your study qualified for expedited review which includes activities that (1) present no more than minimal risk to human subjects, and (2) involve only procedures listed in one or more of the categories outlined below. The IRB may review research through the expedited review procedure authorized by 45CFR46.110 and 21 CFR 56.110. The research proposed in this study is categorized under the following expedited review

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category:

(6) Collection of data from voice, video, digital, or image recordings made for research purposes.

(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Your study qualifies for a waiver of the requirements for the documentation of informed consent as outlined in the federal regulations at 45CFR46.117(c) which states that an IRB may waive the requirement for the investigator to obtain a signed consent form for some or all subjects if it finds either: (1) That the only record linking the subject and the research would be the consent document and the principal risk would be potential harm resulting from a breach of confidentiality. Each subject will be asked whether the subject wants documentation linking the subject with the research, and the subject's wishes will govern; or (2) That the research presents no more than minimal risk of harm to subjects and involves no procedures for which written consent is normally required outside of the research context.

As the principal investigator of this study, it is your responsibility to conduct this study in accordance with IRB policies and procedures and as approved by the IRB. Any changes to the approved research must be submitted to the IRB for review and approval via an amendment. Additionally, all unanticipated problems must be reported to the USF IRB within five (5) calendar days.

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-5638.

Sincerely,

Kristen Salomon, Ph.D., Vice Chairperson
USF Institutional Review Board

Appendix B:

Interview Guide

Demographics:
Pseudonym?
Age?
Racial and/or ethnic background?
Citizenship status?
Sexuality?
Religion?
Location growing up?
Location now?
Summer camp experience (type of camp and years attended)?

Question Guide:
1) What's been going on in your life for the last few months?
    A. Can you describe something good and something not-so-good?

2) Before we get too far into of my questions, how would you describe your life to someone who doesn't know you?
    A. "Where are you today?"
    B. What adjectives come to mind?
       • happy? socially active? thriving? What do you think of those?

3) What do you think helped you get to where you are today?
    A. Tell me about your parent(s) and family.
       • Supportive/unsupportive? How?
    B. How and why did you first get involved in going to summer camp?
       • Other recreational/social experiences?
       • Anything that would be hard to learn/experience in other spaces?
    C. Tell me about your college experience.
       • Specific benefits/challenges? Were they out-of-classroom? Were they institutional?

4) Everyone has multiple, intersecting social locations/identities and everyone has challenges. Are there any specific challenges you've faced that you think were easier/harder/more complicated for you because of your various social locations/identities that you'd like to share?
    A. How did you deal with them?
    B. Gender/physical disability/age/location/socio-economic status/racial/ethnic background?

5) What is your relationship with the people/organizations who have helped you?
   A. Healthy caregiving relationships? Participation in organizations?
   - side note: What have you done to fulfill your goals and/or get the resources you need[ed]?

6) The literature suggests that a major goal for people with disabilities should be to become "thriving adults who are meaningfully integrated into their communities" – what does that mean to you?
   - what do you think of this as a goal?
   - what does "thriving" and "meaningfully integrated" mean?
   - what skills, experience, and/or opportunities would help you or someone else reach this goal?

7) Is there information I should know? Other questions I should have asked that you'd like to talk about before we end our conversation today?